PROFILE OF 38 OREGON TUBERCULOSIS RELAPSE PATIENTS IN 1963

by

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INTRODUCTION

Introduction to the Problem

The National Tuberculosis Association Committee for the Guidance of the Tuberculosis Program, in a report for the United States Public Health Service, emphasized that one of the basic aspects of a tuberculosis eradication program in the United States is a lifetime followup of all former patients, whether their disease is active or inactive.(30) This 1960 statement of concern was further supported by the December, 1963 Report to the Surgeon General of the Public Health Service by A Task Force on Tuberculosis Control(32) that gives second priority to the inactive cases of tuberculosis. The "Task Force believes that 'most relapses in patients who have received drug therapy occur during the first 5 years after the disease has become inactive'." Further, Dr. Sidney J. Shipman, testifying on behalf of the National Tuberculosis Association before the U.S. House of Representatives' appropriations subcommittee on health, education, and welfare-labor said, "We now know that tuberculosis patients should be medically supervised for the rest of their lives, yet no health department covering a population of any considerable size can seriously consider such a task. Indeed, many large cities are hard put to follow patients

after their discharge once turns inactive." (24)

These former patients, then, are an important source of new cases and therefore a high priority group for case-finding programs. In the above reports the fact that very little is being done to provide lifetime followup is stressed. However, these reports remind that needed patient followup of this kind involves new methods of record keeping, additional personnel, and new techniques to motivate patients to cooperate in the programs. (30) (32)

No single numerical figure adequately indicates the size of today's tuberculosis problem. The measure commonly in current use is the number of new active cases of tuberculosis reported each year. In 1962 there were 53,315 new cases of tuberculosis in the United States. This figure does not include the estimated 10,000 relapses which should be added to the total annual incidence. (32)

A realistic measure of the persons now directly affected by tuberculosis includes 110,000 known active cases on tuberculosis registers, an estimated 250,000 inactive cases whose disease was active less than five years ago, and 250,000 newly reported cases for a total of 610,000 persons in the United States.

In Oregon it is estimated that some 322,000 citizens have live tubercle bacilli in their bodies, bacilli which can cause active disease at any time. (8) Of those potential cases, there was a total of 1,510 cases of tuberculosis on the active registry of the Tuberculosis Control Section of the Oregon State Board of Health in 1963. (8) For the same 12-month period, ending December 31, 1963, 82 cases returned to the active registry and 38 cases returned for clinical

reasons.

Statement of the Problem

The seriousness of the problem of reactivating tuberculosis patients is of obvious concern to medical personnel throughout the nation. Dr. Edward Blomquist, in his report to Tuberculosis Control Officers and Sanatorium Directors given in May, 1963, said, "I do not think we are going to get rid of tuberculosis very soon. The peculiarity of the disease is such that even if we could stop all new infections right now we would still have potential cases for the future among the large number of personnel who have already been infected." (4) According to the Task Force Report, (32)

> Most infections, whether they cause overt disease or not, are short lived in the human host, either disappearing completely or causing changes in the body that result in lasting immunity. Unlike these, tuberculosis infection, even when it does not develop into disease directly, remains dormant through a lifetime; in some persons, at some time during their lives, it is stirred into activity by stress. Infection does result in a certain amount of specific acquired resistance against subsequent exposure to the bacillus, but in this country today the advantage of this specific acquired resistance is more than offset by the risk of dormant infection breaking down into disease.

The fact that medical science has found a way to control the disease by chemotherapy, chemoprophylaxis, the tuberculin test, the chest X-ray, epidemiological investigation and statistical analysis (32) is further substantiated by Dr. Blomquist's statement, "...the dramatic effectiveness of present drug therapy which makes possible recovery for more than 95 per cent of all patients with active disease who receive appropriate drug therapy

from the time of diagnosis. Even for patients with far-advanced cavitary disease, recovery is possible for at least 90 per cent." (4)

That most tuberculosis patients are in a sense recovering from the disease is a direct result of these advances in medical science and is a complicating factor for, according to the 1963 Task Force Report, "...having active tuberculosis and recovering from it increases rather than lessens the likelihood of having the disease again...a person who has had tuberculosis is far more likely to have it again than one who has never had it." (32)

This research was planned to determine the major characteristics in the profile of 38 tuberculosis patients who reactivated in 1963 and who were returned to the active registry in Oregon; further it was deemed important to find the reasons the patients gave for reactivating in order to help in the future planning for the care of the tuberculosis patient and ultimately to help the patient adjust more successfully to life with inactive tuberculosis.

Limitations

The study was limited to the selected group of 38 patients in Oregon with inactive tuberculosis who reactivated in 1963. These patients had tuberculosis, were determined inactive and discharged from the active registry of the Tuberculosis Control Section of the Oregon State Board of Health after two years of inactivity. These same patients relapsed in 1963 and were returned to the active registry. The problem was also limited to information that could be obtained from the registry card and

from the data patients were willing to provide during the course of the personal interview.

Assumptions

For the purpose of this study it was assumed that:

1) The registry of the Oregon State Board of Health Tuberculosis Control Section consisted of an accurate record of the patients who reactivated during 1963;
2) The data collecting tool was adequate for the study;
3) The selected group of patients would be willing and able to answer accurately the questions in the interview; and
4) The information obtained by the interview had merit in ascertaining some of the reasons for reactivating.

Importance of the Problem

Having active tuberculosis and recovering from it increases rather than decreases the likelihood of having the disease again. The estimated 10,000 persons who have had tuberculosis and have had a relapse of the disease in 1963 are the means by which tuberculosis is perpetuated. (32)

Traditionally, the public health nurses have been responsible for the care and supervision of the tuberculosis patients and their families in their homes prior to, during and following

hospitalization. Followup, the most difficult part of this assignment, is the key in the inactive patient. It has to be done meticulously, for all patients and for longer periods of time if tuberculosis is to be eradicated. As patients reactivate, this information must become known at once to local health officials and before patients have opportunity to spread the disease to family, friends, and colleagues.

Procedure for the Study

This study began by obtaining the list of the 38 patients, their names and addresses, who reactivated and were returned to the 1963 active registry of the Tuberculosis Control Section, Oregon State Board of Health. Dr. Ambrose Churchill, Director of the Tuberculosis Control Section, gave the investigator permission to obtain this list and to acquire all necessary data from the registry cards. Subsequently Dr. Churchill was asked to validate the findings.

In selecting the tool it was decided it would be necessary to visit each of the patients individually asking questions based on the Interview Guide (page 82) which was approved in advance by Dr. Churchill, by twelve Registered Nurses, and the writer's adviser. In addition, data were obtained from the Oregon State Tuberculosis Hospital, Salem, Oregon; the Veterans Administration Hospital, Portland, Oregon; Portland, Oregon, Health Department; Multnomah County, Oregon, Health Department; the Julius L. Meier Tuberculosis Clinic, Portland, Oregon; and from interviews with public health nurses supervising the patients.

The data collecting tool consisted of the following information about each patient:

1) Name and address

2) Age, sex, race, marital status

3) Employment record

4) Medical history

   a) Year and age of first report of tuberculosis
   b) Years between inactive status and reactivation in 1963
   c) Diagnosis: first to inactive status and then 1963 reactivation
   d) Medications
      1) Name of drug
      2) Dates given
      3) Dosage

5) Followup care after discharge from the registry

   a) Continuity, type, and extent
   b) Number of outpatient clinic or personal physician visits
   c) Number of public health nurse contacts, either in person or by telephone

6) Personal interview with the patient and, if necessary the public health nurse

   Since the personal interview was designed to gather expressions of attitudes and statements of opinion about their reactivating, patients were asked questions summarized here and detailed in the Interview Guide on Page 82 .

   a) What do you think caused you to become ill again?

   b) What was your condition immediately before reactivating including mental attitude, eating and sleeping habits, feelings of fatigue, emotional crises?

   c) What are the attitudes of family and friends toward your disease?

   d) Is there any history of tuberculosis in your family?

e) Have you had other diseases, complications, or trauma?

f) What was your attitude about having to face tuberculosis again?

g) Who was most helpful in explaining your disease, the medications and tests? Why and how was it helpful?

h) How well do you think you understand your disease?

i) Is there other information that might have prepared you better for life as a recovered patient?

j) Could anything have been done to prevent your relapse, in your opinion?

k) How did tuberculosis affect or drastically change your attitude about the kind of work you should do?

   1) Give details of the kind of work you did before you contracted the disease.
   2) Could you support your family on your salary or was it necessary (in the case of married male patients) for your wife to work?

l) What were your home conditions?

   1) Where did you live?
   2) How many were in your household?

m) Did you ever take any anti-tuberculosis drugs, and if so, what, when, and what was the dosage?

n) Did you have regular visits from a nurse during the time you were inactive and were these visits satisfactory?

o) How frequently were you examined by a physician?

In addition, patients were asked for any personal information listed above not available on the hospital, outpatient clinic and public health nurses' records. In those cases where it was impossible to obtain satisfactory interviews with patients, the public health nurse was interviewed wherever possible.

Following the personal interviews, the findings of this investigation were compiled and compared to other current studies.

Goals

The primary goal of this study is to provide information which may be of value in improving not only the quality of the care of the tuberculosis patient to prevent relapse but also to give precise information essential for evaluating the present situation. Further, it is hoped this study will help in the future planning for the efficient medical and public health supervision of the patient with inactive tuberculosis. Thus, although widespread generalizations cannot be made on the basis of a sample obtained in this study, it can be assumed that there is sufficient generality in the findings to apply outside the immediate group of the study.

It is hoped that this study might give some information that will encourage increased appropriations to be used to raise the level of tuberculosis control activities so that modern knowledge of the disease can be applied to its fullest potential.

CHAPTER II

REVIEW OF LITERATURE AND RELATED STUDIES

Many patients are never really cured of pulmonary tuberculosis. It becomes increasingly evident that there is substantial basis for the assertion by the Committee for the Guidance of the Tuberculosis Program of the National Tuberculosis Committee that one of the keys to the eradication of tuberculosis in the United States is lifetime followup of all former patients. It is also apparent that not enough is being done for these patients, even though the evidence, widely known and well-documented, clearly shows the tendency of the disease to lie dormant and recur in previously affected patients. (9) While available figures do not show the extent of the problem, the concern shown by some authors should serve as a clue to its seriousness. The majority of tuberculosis cases under supervision in thousands of public and private clinics throughout the country are inactive tuberculosis patients. In the battle to eliminate tuberculosis, attention has been focused on the patient with the disease in its active state and efforts have been directed toward bringing his tuberculosis to sustained inactivity. Because most programs are oriented toward this patient, it was difficult to find specifically designed programs or studies for persons with inactive tuberculosis.

However, there is some evidence, although limited, that the

problem of relapsing pulmonary tuberculosis is becoming one of concern. Results of the Los Angeles Veterans Administration Outpatient Survey (37) indicate patients with inactive tuberculosis need to be told more fully and more definitely about the proper regimen for inactive tuberculosis. Further, more attention needs to be given to their other medical or psycho-social problems; they need help in tolerating and handling stress in their lives; they need to be encouraged and motivated to accept responsibility for parts of their surveillance; and finally, they need to be instructed on how to do this most appropriately.

Fuchs and Hesse (10) in an unpublished report, raise the question of how to deal with the patient who no longer needs to take drugs, pointing out that no answer to the question of whether or not he is indeed a patient at all, appears in the literature. These authors encountered two extremes: first, the public health departments that have put the names of their patients into their inactive files shortly after termination of drug treatment; second, some physicians who see their patients once a month for years after the last dose of INH. Further, Fuchs and Hesse found that followup examinations themselves vary from a mere fluroscopy of the chest to a work-up consisting of posterior-anterior and lateral chest films as well as sedimentation rate, complete blood count, and urinalysis. They also report that with such widely divergent practices it seems timely to inquire into principles and techniques for standards on which tuberculosis programs in the drug era should be based. They emphasize that the patient

whose tuberculosis is most likely to reactivate needs more follow-up care than the patient who is expected to be safe from re-activation.

While some studies have been done on the reactive tuberculosis patient, these reports emphasize primarily the medical field of treatment. Representative of this type of study done in the last 15 to 20 years is Albert R. Allen's Why Do Tuberculosis Patients Reactivate? (1) The author presumes that a certain percentage of tuberculosis patients reactivate regardless of the type of treatment and the extent of disease. The latter is the major factor because the more extensive the disease, the greater the probability there is for virulent, viable tubercle bacilli in the tissue.

There is little information on the "typical" patient, but Steininger and Howard (31) report the usual retreatment patient in their study was unskilled, alcoholic, with far-advanced fibro-cavitary disease of two years' duration. This would imply that their patients, at least, would be difficult to find for the all-important followup.

One key to the problem of encouraging patients to take part in followup programs is anxiety. Calder, and others, in The Patient Looks at Tuberculosis, (6) a presentation of the results of an extensive survey on how tuberculosis patients feel about their disease, report that despite the extensive educational campaigns acquainting the public with the facts of tuberculosis, and despite the anti-tuberculosis drugs, most patient's biggest fear was re-currence of his disease after discharge. Many patients were

psychological stresses for a person and his family. For reasons that may lie in his personality, and attitudes in his economic situation, in his experiences with sickness, hospitals, and doctors, a person may have problems in deciding to put himself under the care of a physician. He may not be able to admit being sick, or to face up to the implications of his illness. He may find the conditions of clinic attendance, of tests and examinations, frustrating and he may reject the whole business of the care he needs. (21)

New hope for the discharged tuberculosis patient may be found in an observation by Allen (1) who writes, "The old ideas that physical exertion, pregnancy, etc. are the causes of reactivation are not true." Most of his patients returned immediately to moderately heavy or heavy work, yet those doing the lightest work, retired people, had the highest reactivation rate, 14 per cent.

It is important to consider the factors contributing to the incidence of recurrent tuberculosis in former patients. The women in Allen's (1) study had the lowest reactivation rate because they came to the hospital for treatment earlier in the course of their disease, accepted surgery more readily than men, and few left against medical advice. Apparently pregnancy is no factor in reactivation since 18 of the women in Allen's study had 26 pregnancies with no relapse.

Selye (25) emphasized that a person with inactive tuberculosis may become active again if under intense strain, be that stress due

to emotional upset, to malnutrition, to an incidental infection of an altogether different germ, or to anything else. Supporting this contention is Warthin's study, Reactivation of Pulmonary Tuberculosis in Relation to Subtotal Gastrectomy for Peptic Ulcer, (35) of 356 patients with peptic ulcer treated by gastrectomy, in which two per cent of the patients developed active pulmonary tuberculosis. However, healed tuberculosis was usually present before operation and weight loss preceded the onset of pulmonary symptoms some months later.

Some patient's permanent recovery is jeopardized by their choice of unsuitable occupation; recovery is also threatened by distu bances arising from home situations. Certain personality disorders such as drug addiction or alcoholism handicap the patient in attempts to follow an inactive regimen. (29)

In Sembera's report, (26) factors which are likely to promote recurrence are reported and include intensive contact after discharge; insufficient diet, sleep, and comfort; psychic trauma, worry, anxiety, feeling of insecurity; overdone sport; diabetes; ulcer disease; and unsuitable work. A group of mental patients with inactive tuberculosis were studied by Katz, and others, (12) to determine the frequency of reactivation, with particular attention to its relationship with exposure to infectious tuberculosis. For the group as a whole, the average annual reactivation rate was two per cent. Reactivation was more frequent among males and among patients less than 45 years of age. Exposure of patients

with inactive disease to cases of infectious tuberculosis apparently increases the probability of reactivation.

Recurrence of tuberculosis was further noted by Kaulessar [14] in 51 of 1,508 patients in whom resection for pulmonary tuberculosis was done. Before 1953, 7.6 per cent recurrences were seen; after 1953 only 1.5 per cent; in the last four years no recurrences were seen. Most recurrences were seen within two years after surgery. According to Mamolat and Rosenberg, [16] relapses were more common after lobectomy (6.5 per cent), pneumonectomy (three per cent), segmentectomy (one per cent), promoted by inadequate anti-bacterial treatment in preparation for the operation and by the resistance of the drugs. In this study, 1,063 patients were followed for periods ranging from six months to seven years.

Wernli-Hissing [38] concludes:

> Reactivation of quiescent pulmonary tuberculosis seems to occur not solely by virtue of an alteration of immunity, but definite anatomo-pathological conditions must be fulfilled. Pagel and Whelinger, and after them the American authors Baum and Amberson, drew attention to the influence of non-tuberculosis pulmonary infections (lobar pneumonia, broncho-pneumonia, pulmonary abscess, purulent pneumonia and bronchiectosis) on a co-existing pulmonary tuberculosis. While in a certain number of cases this influence is nil, in others it is detrimental. The activating influence consists in a tissue-destroying process of the walled-in tuberculosis focus by the secondary infection, followed by dissemination of liberated bacilli.

There seems to be no safe period for tuberculosis patients, although Rasmussen and Wenge [22] confirm the assumption that the

frequency of relapse in pulmonary tuberculosis decreases with increasing duration of the inactive phase of the disease. It is emphasized however, that relapse may occur up to 20 years after the disease has become inactive. There were 1,329 patients in this study with 693 relapses; 48.3 per cent of the relapses were between three and four years after becoming inactive; 24.2 per cent between five and six years; 17.4 per cent between the seventh and ninth years; 7.9 per cent between the tenth and fourteenth years and two per cent after 15 years. The largest number occurred in patients between the ages of 35 and 44.

Bøyum (5) says during the ten-year period, 1946 to 1956, 439 tuberculosis patients out of 1,712 studied, reactivated. There was a constant move toward higher age among the relapses and a greater tendency to relapse among men than women. Most relapses, 36 per cent, occurred in the age group of 30 to 39 years, usually after the patients had started to work again with poor financial conditions and physical strain increasing the relapse tendency. Persons with permanent collapse relapsed less frequently than did those with temporary collapse or conservative therapy. Nearly three-fourths of the relapses occurred within five years after completion of treatment. All relapses after resectional surgery occurred within one year with over four-fifths of relapses after thoracoplasty occurring within five years.

A statistical analysis by Oyama (19) of 1,259 patients followed from 11 months to six years after discharge shows that 28.5 per cent

of the group relapsed. There is a definite difference in the relapse rate between males and females. In the youngest and oldest groups there was no great sex difference but at the other ages relapses occurred approximately twice as often in men as in women. In age groups of 30 to 69 years, relapse occurred twice as frequently in patients with far-advanced pulmonary tuberculosis (34.4 per cent) than in those with minimal lesions (17.4 per cent). Relapse rates were apparently unrelated to the duration of the disease.

From these studies the great need for increased supervision of the inactive tuberculosis patient is apparent. Jean South, in her paper Nursing Responsibilities in TB Eradication, (27) states:

> All patients and contacts will need public health nursing care and supervision for a much longer time than was thought necessary in past decades. It has been found that patients receiving drug therapy or prophylactic treatment that are visited regularly by public health nurses are more likely to take their drugs regularly and without interruption than those without their service. All patients should continue under medical supervision for life.

Miss South further delineates the role of the nurse in these programs when she reports:

> I was impressed with the preliminary summary report of the findings of a Non-Hospitalized TB Patient Study conducted recently by a state TB association. Questions were raised that will need to be answered by others than nurses but some relate specifically to nursing. For example, 26 per cent of the patients had had no public health nursing follow-up in the past six months.
>
> It is important that nurses understand that a patient's

> overt behavior may be due to any number of problems of which he may or may not be aware. He needs help and as a helping profession, we must be able to look beyond the diagnosis of TB and try to identify other problems that each patient may have and in which he needs help either to face them realistically or which can be resolved through our ministrations or through referral to others who have competencies in special areas of health and welfare that we do not possess. The question in this same Study asking the patient, 'How do you feel about public health nurse visits?' gives us all pause because the same response and feelings might also be elicited by patients in hospitals, clinics and elsewhere. Responses to this question reveal that 100 out of 212 patients gave positive answers. Twenty-six were classified as neutral, and 35 or one out of every four and one-half patients replied negatively to the question. Some of the replies were as follows:
>
> 'Public health nurse too pushy'
> 'Treats patient like a criminal'
> 'Makes conversation only'
> 'Public health nurse's orders different from physician's'
> 'Public health nurse does not understand TB'
> 'Public health nurse does not understand follow-up'
> 'Public health nurse is not informed about tests'

The author further emphasizes, "We must each take these comments very seriously...it is imperative that we try to improve our service through knowledge of TB and TB nursing, its scope in relation to concomitant problems faced by these patients and families and, above all, to improve our interviewing skills so that we will give the quality of service that our patients and families so richly deserve."

Further confirming the value of prolonged observation of inactive cases are Comstock's (9) findings. Although the risk of reactivation may decrease with the passage of time after the initial report, it remains sufficiently great to warrant super-

vision for at least ten years after a lesion is recognized. In this study, the risk was greater for persons with advanced tuberculosis, and greater among the young than the old. Females had only slightly lower reactivation rates than males.

The use of drug therapy in recent years may provide a solution to the currently high rates of reactivation of tuberculosis patients. Mitchell's [17] study is important to use as a baseline to measure the advantage of drug therapy and the relation of drugs to reversible collapse therapy and surgery. In a period of from 15 to 25 years, 1,504 consecutive admissions were followed. Relapse occurred in 28 per cent of the moderate and far-advanced cases during the 20 years, mostly within the first five years after discharge. When relapse occurred, it was not affected by the original extent of the disease after that disease became arrested. Relapse of minimal disease was almost the same: 27 per cent.

Humphrey and Tachen report in Results of Outpatient Anti-Tuberculosis Chemotherapy After Discharge from the Hospital [11] that relapse and mortality were higher in patients who had interrupted their treatment and that the prognosis of even irregularly discharged patients was good if they continued chemotherapy faithfully. In another study by Alling and Bosworth, [2] both the relapse rates and the remission rates observed among three groups of persons tended to decrease as the length of time in the arrested or inactive state of tuberculosis increased.

Allen [1] also reported that minimal tuberculosis responds well to drugs only, with no reactivations. In moderately and far-advanced disease those patients with resection of caseous areas have fewer relapses than those who received drugs only.

In Low's [15] study there were 838 cases. In 1946, 1947, and 1948, 425 patients were discharged who had received no chemotherapy; 413 patients discharged in 1953, 1954, and 1955 did receive chemotherapy. "For the non-chemotherapy group, the cumulative relapse rate over an eleven-year follow-up period was 31.5 per cent. For the six-week-to-six-month group, the rate over a nine-year follow-up period was 21.8 per cent. For the streptomycin-PAS group, the rate over a five-year follow-up period was 12.5 per cent, and for the multiple-drug (including isoniazid) group, the rate over a four-year follow-up period was 8.8 per cent." This drop was brought about by treatment which is considered to be inadequate today.

Katz, and others, [12] studied 513 patients to find out the effect of isoniazid in preventing reactivation. While 266 served as controls, 247 patients received 300 mg. INH daily. In a two-year period there were twice as many reactivations among the controls, but the authors do not consider it practical to use isoniazid on a large scale to prevent reactivation among persons who have not received prior anti-tuberculosis treatment.

A review of the literature so far indicates the great amount of work to be done with inactive tuberculosis patients and the

general lack of definitive information on the subject. Further, it implies that tuberculosis patients should no longer be considered "patients" for the length of their hospitalization only, but for their lifetimes. Finally, although new methods of treatment are being evolved, none so far has eliminated the necessity of continued patient contact.

Specifically, the review shows too many patients are never cured of tuberculosis and these patients who may reactivate up to 20 years following first inactivity constitute a major problem in any broad tuberculosis eradication program. Patients who formerly would have died with tuberculosis are now being returned to an inactive state by the relatively recent developments in medical science both in the fields of surgery and drug therapy. The growth of this problem has been so rapid there are no figures that yet show its extent.

While most studies of tuberculosis patients deal with their active state, there is evidence of an increasing concern for the relapsing patient. Further, there is a trend toward considering the whole patient and his total needs including his other medical and psycho-social problems. The major recommendation in all reports is that extended followup of all patients following hospital release is essential.

A second prevalent recommendation is one for improved communication with the patient and the public on the part of health personnel for too many patients still feel a stigma attached to

tuberculosis. This program of better communication would also make extended followup programs much more successful most authors agree.

There is a need to reevaluate some current ideas about tuberculosis. Formerly it was thought that physical exertion and pregnancy were a cause for reactivation but studies found to the contrary, that patients doing moderately heavy work did not reactivate at the same rate as those doing the lightest work. However, a new look needs to be taken at stress, other disease, insufficient diet, contact with tuberculosis after discharge as some of the sources for reactivation.

A third major point emphasized was the need for better informed nursing personnel giving better service to those patients and families affected by tuberculosis.

Finally, the importance of drug therapy was emphasized but use of drugs does not yet prevent reactivation although it does seem to reduce the reactivation rate.

CHAPTER III

REPORT OF THE STUDY

Introduction

While no single figure adequately indicates the magnitude of the tuberculosis problem in the United States, authorities estimate that about 10,000 patients with recurrent tuberculosis should be added to the 1962 figure of 52,315 new cases making a total of one-sixth of the cases that year "relapses". While not of the same proportion in Oregon, the problem of tuberculosis control is still serious with 1,510 total cases registered during 1963 with the Tuberculosis Control Section, Oregon State Board of Health, and 38 cases returned for clinical reasons. In addition, the 322,000 Oregonians living with live tubercle bacilli which can cause active disease at any time, constitute a major problem for the health professions of the state.

It is with these figures in mind that the study was begun of the 38 patients in the state who reactivated during 1963. It was felt that in talking personally with the patients, as well as referring to their medical records, perhaps patterns of behavior, attitude, education, and post-hospital care could be found that would help in the future planning for new tuberculosis patients and those with the disease in an inactive state.

The general public including, surprisingly, families of tuberculosis patients, is unaware of the size of the problem. It considers tuberculosis a "dead" disease, that is, one that is decreasing in incidence, and further, one from which patients recover completely. Because of these facts it is hoped that this survey will also provide information for expanded educational programs that can be carried on by nursing personnel.

Procedure of the Study

This study was designed for the purpose of determining the reasons given by patients for their reactivation during 1963.

The method selected for the study of reactivated tuberculosis patients was a survey of the patients by use of the personal interview technique based on a detailed "interview guide". Two sources of primary data were needed. Background for the interview was provided by the Tuberculosis Register card from the Tuberculosis Control Section of the Oregon State Board of Health; the patient folder from each county public health department; and the patient hospital and clinic record. The interviewer was thus provided with personal and medical data upon which to base the questions during the contact. The Interview Guide was developed as a second major source of data for the study. Although the personal interview can sometimes be a limiting factor in itself, it was felt that with patients involved, this technique would be far more successful in eliciting responses than, for example, the

mailed questionnaire.

The tool was evolved with the assistance and guidance of 12 experienced professional nurses. A copy of the Interview Guide is included as Appendix A and a detailed description of its development begins on page 6.

Names and addresses of patients to be interviewed were provided by the Tuberculosis Control Section of the Oregon State Board of Health and verified through city and county public health departments, public health nurses, and telephone directories.

Of the 38 men and women with recurrent tuberculosis in 1963, 33 or 86.8 per cent were eventually interviewed during the course of the study.

The Tuberculosis Registry card was the first approach to the problem. It was felt that the economic and social backgrounds of these 38 patients, 37 Caucasian and 1 Oriental, to be interviewed was as important to the study as their area of residence.

Of the patients interviewed, 24 lived in the greater metropolitan area of Portland with 15 in the city, seven in Multnomah county and two in neighboring Clackamas county. Clatsop county accounted for four patients and Marion county, three (including two who were patients at the Oregon State Hospital, Salem). Table I and Table II show the detailed breakdown of the area of residence of the patients contacted.

TABLE I

PLACE OF RESIDENCE IN 1964
IN THE GREATER METROPOLITAN AREA
OF PORTLAND, OREGON, OF 24 PATIENTS WITH
RECURRENT TUBERCULOSIS

Place of Residence in the Greater Metropolitan Area of Portland, Oregon	Number of Patients
Within Portland city limits	
Southwest	6
Southeast	4
Northwest	4
North	1
Within Multnomah county, but outside Portland city limits	
Northeast	3
Southeast	3
Gresham	1
Within Clackamas county	
Southeast	1
Southwest	1
Total	24

TABLE II

COUNTIES OF OREGON OTHER THAN MULTNOMAH AND CLACKAMAS IN WHICH 14 PATIENTS WITH RECURRENT TUBERCULOSIS IN 1963 RESIDED IN 1964

County of Oregon	Number of Patients
Clatsop	4
Marion	3
Douglas	1
Hood River	1
Lane	1
Linn	1
Union	1
Wallowa	1
Wasco	1
Total	14

In order to form an accurate profile of reactivating tuberculosis patients in Oregon for comparison with similar studies, additional personal information was obtained, including age, marital status and time of relapse.

Studies by Rasmussen and Wenge [22] indicate that the largest number of relapses occur in patients between the ages of 35 and 44 while Bøyum [5] found that 36 per cent of the relapses fell into the 30 to 39 year age group. Oyama [19] found a definite difference in the relapse rate between males and females with little sex differences in the youngest and oldest groups, but at other

ages relapses occurred approximately twice as often in men as women.

The Oregon survey shows little correlation between the patients in the 1964 study and those of Rasmussen and Wenge and of Bøyum. Further, a higher percentage of men, nearly three to one, relapsed in the middle age groups in Oregon than Oyama reports.

TABLE III

AGE AND SEX DISTRIBUTION
OF 38 PATIENTS WITH RECURRENT TUBERCULOSIS IN 1963
IN THE OREGON SURVEY GROUP

Age Group	Male Patients	Female Patients	Total
20-29 years...	0	1	1
30-39 years...	0	0	0
40-49 years...	4	4	8
50-59 years...	12	2	14
60-69 years...	9	0	9
70-79 years...	4	1	5
80-89 years...	1	0	1
Totals.....	30	8	38

Allen's [1] thesis was that women had the lowest reactivation rate because they returned to the hospital earlier and accepted suggestions more readily than men. The number of patients in the Oregon study was too small to be useful in making comparisons with

Allen's study, but the ratio of eight women to 30 men leads to the conjecture that Allen's hypothesis might be valid here, too.

Because Perlman [21] emphasizes the psychological stresses of tuberculosis patients and their families, it was felt to be important to this study to determine the marital status of the interview group. According to the Tuberculosis Registry cards, 17 of the selected patients, or 44.9 per cent, were married; ten, or 26.3 per cent, were single; six, or 15.7 per cent, were divorced or separated; four, or 10.5 per cent, widowed; and the marriage of one patient had been annulled.

According to studies by Rasmussen and Wenge [22], while there is no really safe period for tuberculosis patients, 48.5 per cent of 693 relapsed cases in the study relapsed between three and four years after becoming inactive. An additional 24.2 per cent reactivated between five and six years and 17.4 per cent between the seventh and ninth years; 7.9 per cent between the tenth and fourteenth years and two per cent after 15 years. In Bøyum's [5] survey, three-fourths of the relapses occurred within five years of completion of treatment.

The Oregon study shows the highest percentage of recurrence between the fifth and fourteenth years after completion of treatment with 63.3 per cent and only 2.6 per cent recurring from the first through fourth years.

TABLE IV

RELAPSE RATE FOLLOWING COMPLETION OF TREATMENT OF 38 PATIENTS WITH RECURRENT TUBERCULOSIS IN 1963 IN OREGON

Years Following Completion of Treatment	Number of Patients N = 38	Percentage of Total
0-4.....	1	2.6
5-9.....	15	39.4
10-15.....	9	23.9
16-19.....	6	15.7
20-29.....	6	15.7
30-39.....	1	2.6

It is also pertinent to note that of the survey group, 11 of the 38 had some form of pulmonary surgery before reactivation, not always in the inactive period.

The validity of Jean South's [27] statement, "All patients and contacts will need public health nursing care and supervision for much longer time than was thought necessary in past decades," is further substantiated in the Oregon study. While five patients, 13.1 per cent, reactivated during the first five years, 17, or 44.7 per cent, became active tuberculosis patients again between the fifth and tenth years. In addition, 12 patients or 31.5 per cent, joined the active rolls again between the tenth and fifteenth

years of inactivity with four patients, or 10.5 per cent becoming reactive between the fifteenth and twentieth years. These findings further support Comstock's [9] contention that prolonged observation of patients is essential.

TABLE V

RELATIONSHIP BETWEEN AGE AND LENGTH OF CURRENT TUBERCULOSIS INACTIVITY FOR THE 38 PATIENTS IN THE OREGON SURVEY GROUP

Age Group	Number of Patients (and Percentages) According To Years of Current Inactivity			
	0 - 4	5 - 9	10 - 14	15 - 19
20-29.....		1 (2.6)		
30-39.....		1 (2.6)		
40-49.....		3 (7.9)	3 (7.9)	1 (2.6)
50-59.....	3 (7.9)	6 (15.8)	2 (5.3)	3 (7.9)
60-69.....	2 (5.3)	6 (15.8)	1 (2.6)	
70-79.....			5 (13.1)	
80-89.....			1 (2.6)	
Number All Ages	5	17	12	4
Percentage All Ages	13.1	44.7	31.5	10.5

Mitchell's [17] study of 1,504 patients readmitted during a period of 15 - 25 years (of which 90 per cent were followed) shows

relapse occurring in 28 per cent of both the moderate and far-advanced cases and relapse of minimal disease at 27 per cent. According to this study most patients reactivated during the first five years after discharge.

In the study of Oregon patients it was found that on original diagnosis, 23.9 per cent of the patients had minimal tuberculosis; 55.2 per cent had moderately advanced and 15.7 per cent were far-advanced. In addition, 5.3 per cent of the patients were diagnosed as "nonpulmonary". Eleven patients' sputum was negative and 27 positive. On reactivation, 13.1 per cent of the patients who reactivated in 1963 in Oregon were diagnosed as minimal cases; 57.9 per cent as moderately advanced; and 26.3 were far-advanced. Miliary tuberculosis was diagnosed in 2.6 per cent of the cases. Fourteen patients showed negative sputum and 24 positive.

The information so far presented in this chapter was obtained from the Tuberculosis Register card before the patients were interviewed.

The Interview Guide was designed to obtain the patient's statements of attitudes, opinions, and knowledge of reasons why his tuberculosis became active in 1963. The items were grouped into six areas with additional probing questions under each category to encourage as complete responses as possible from the patients. The Interview Guide was reviewed by 12 experienced

registered nurses for its validity.

Permission was granted by Dr. Ambrose Churchill, director of the Tuberculosis Control Section, Oregon State Board of Health, for the personal interview of each patient in the survey group.

A letter was sent to each public health officer of each county where the patients lived asking for 1) an appointment; 2) permission to review the records; and 3) permission to interview the selected patients. An accompanying form letter from Dr. Churchill was enclosed. Copies of the two letters are found in Appendix B and C.

Public health department personnel were prompt and cooperative in replying to the letters and made appointments allowing several days for scheduling. The response most often came from the public health nurse and as a result subsequent correspondence was with her.

The Portland area patients were studied and interviewed first. The public health nursing departments of Clackamas and Multnomah counties and the city of Portland were contacted for appointments to review patients' folders and to obtain current addresses. It was found that one patient in the southeast area had been committed to the Oregon State Hospital, Salem, another was in the Oregon State Tuberculosis Hospital, Salem, and still another was a patient in the Portland Veterans' Administration Hospital. From the southwest area, one patient was in the Portland Veterans' Hospital and another from the northwest area also was a patient there. With

the exception of two patients interviewed at the Julius L. Meier Tuberculosis Outpatient Clinic, all other patients were interviewed in their places of residence. It was the plan to make no appointments with patients in advance and this was accomplished in the metropolitan area in every case but one which will be detailed later.

In the first screening of the Portland area, patients were interviewed in the designated geographical divisions. There were only seven of the first 17 patients not at home on the first visit. Four of these were interviewed on the second visit; one on the third and one on the fourth. It was impossible to contact one patient who moved frequently until he was hospitalized later in Multnomah Hospital.

From the information obtained from the Tuberculosis Control Section of the Oregon State Board of Health, it was learned that there were four patients in Clatsop county. Through correspondence with the public health department there, it was discovered that only one patient was a county resident currently. One had died; one was a patient in the Oregon State Hospital, Salem, and the other patient from Clatsop county was a patient at Columbia Park Hospital, The Dalles. During the course of the survey, all three were interviewed.

The patient in Douglas county was interviewed and only one of the two patients at the Oregon State Hospital could be interviewed. Another was interviewed at the Oregon State Tuberculosis Hospital,

Salem. Only two of the three patients from Marion county were living and both were interviewed; the patient from Linn county had died. A patient at the Veterans' Administration Hospital, Portland, the one patient from Lane county was interviewed there.

According to the medical records cause of death in the three cases cited above, who died before the interview could be obtained, was given as, cardiac failure due to tuberculosis and histoplasmosis; cerebral hemorrhage; and bronchopneumonia.

Another group of interviews consisted of the two patients residing in Hood River and Wasco counties. Although the patient in Columbia Park Hospital, The Dalles, was not able to be interviewed, the medical records were seen. Those patients living in Union and Wallowa counties were interviewed.

A public health nurse was present during four of these interviews. Although some interviews were by appointment, the majority were not and it was found the on-the-spot interviews were highly successful. There were no refusals since patients were given a concise, simple explanation of the purpose and objectives of the visit and emphasis was placed on the fact that while the information they provided would be used in this study, they as individuals, would remain anonymous.

The interviewer set the direction of the conversation but the patient was not discouraged from discussing unrelated subjects. Notes were taken during the interview.

A total of 33 personal interviews were conducted during the survey. Three patients had died before the interview could be arranged; another, a patient at the Oregon State Hospital, could not be interviewed; and another, with chronic brain syndrome, was contacted but would communicate only in Finnish.

This accounts for the 38 patients who had reactivated in Oregon in 1963.

During the two months of the survey, approximately 2,000 miles were traveled to complete the study. Details of the questions asked and responses given appear later in this chapter. The investigator recorded, below, brief observations of the patient, family, environment, or other factors which might be useful in understanding the situation, in addition.

Number 1: 44-year-old white male. Married.

Diagnosis: first - minimal (sputum positive); 1963 - moderate (sputum negative)

Age at first report: 31

Years from last activity: 9

> This is a family man who has probably never accepted the idea of having tuberculosis. He seems bitter with the world and would be a difficult patient in the hospital. He does not like nurses and remarked that doctors could spend more time with the patients. He needs some help and someone to talk with but doesn't seem to know how to go about it because of the resentment he evidences. He lives in an average neighborhood in a fairly nice appearing home and his family life seems normal and satisfactory.

Number 2: 38-year-old white female. Marriage annulled.

Diagnosis: first - moderate (sputum positive); 1963 - minimal (sputum negative)

Age at first report: 31

Years from last activity: 6

This patient was interviewed at the Oregon State Hospital, Salem. She is a delicate, pretty woman who gave pleasant, though guarded and shallow answers to the questions. Hostility is veiled behind her not unpleasant manner. She has a history of being aggressive, destructive, flying into rages, and even being assaultive. Her hair is not tidy and at times she seems out of touch with reality. The nurse stayed in the room at first, then left. Later the nurse reported the patient does not eat well, nor will she do odd jobs around the ward, although she seems to want to at first. The prognosis of her mental condition is poor.

Number 3: 52-year-old white male. Single.

Diagnosis: first - minimal (sputum positive); 1963 - moderate, active (sputum negative)

Age at first report: 45

Years from last activity: 5

This patient lives in Portland's Skid Road district and was difficult to contact. A message was left with him to telephone for an appointment which he did when the reason was explained. He did not keep the first appointment because he had an opportunity to pick berries. Another message was left for him and not answered. Finally the public health nurse contacted him and he did call for an appointment the same day. He talked with the interviewer in her car outside his hotel. He was very cooperative. A tall, thin, very nervous individual with worn but very clean clothes, this man relaxed during the interview. He enjoyed talking so much in fact, it was difficult to end the conversation.

Number 4: 53-year-old white male. Married.

Diagnosis: first - moderate (sputum positive); 1963 - far-advanced (sputum positive)

Age at first report: 39

Years from last activity: 9

The interview with this patient, who lives in below average circumstances, was conducted in the back yard of his home. His wife was asleep in a chair a few yards away. He is well-groomed and neat in appearance although he evidences a "don't care" attitude about himself and his future. He admits to not giving himself proper care and to keeping late hours. While he did not specifically indicate that drinking is a problem, he gave the interviewer the impression that it is.

Number 5: 66-year-old white male. Divorced.

Diagnosis: first - far-advanced (sputum positive); 1963 - moderate (sputum positive)

Age at first report: 57

Years from last activity: 7

This patient was interviewed at the Veterans' Hospital under good conditions. He answered many of the questions as if he had to. He does not admit he is an alcoholic who would rather drink than eat.

Number 6: 57-year-old white male. Single.

Diagnosis: first - minimal (sputum negative); 1963 - moderate (sputum positive)

Age at first report: 51

Years from last activity: 5

Natural suspicion and a hearing impairment made this

patient difficult to talk with at first. As he gained confidence he wanted to do all the talking. The interview took place at the Tuberculosis Clinic where he was reporting for a check-up. This man is small in stature and has a desire to work but is really not employable. It is assumed he picks berries in the summer for additional funds.

Number 7: 84-year-old white male. Single.

Diagnosis: first - moderate (sputum negative); 1963: moderate (sputum positive)

Age at first report: 68

Years from last activity: 11

This is a pleasant, lonesome old gentleman whose apartment is simple, in a low-income bracket, and clean. He is hard of hearing and sometimes it is difficult to understand him because of his Norwegian accent. This was the first interview and it was difficult for both the interviewer and interviewee. He seemed glad to have someone visit him because, he said, it is difficult for him to get around because of "the pain in my legs". He lives on the second floor of the building and does not seem to associate with his neighbors except to watch television occasionally. On the kitchen table there is a photograph of his "girl friend who died".

Number 8: 55-year-old white male. Divorced.

Diagnosis: first - moderate (sputum positive); 1963 - moderate (sputum positive)

Age at first report: 44

Years from last activity: 7

This patient was interviewed in the lobby of his hotel which is a cold, dirty, dismal place. He probably weighs no more than 130 pounds and is thin and sick looking, but with clean clothes. He said he does not leave the hotel often as it is difficult for him to

breathe and he is weak. He can get some meals at the hotel, he said.

Number 9: 68-year-old white male. Single.

Diagnosis: first - minimal (sputum positive); 1963 - moderate (sputum positive)

Age at first report: 63

Years from last activity: 4

The public health nurse was present for the interview with this pleasant, courteous gentleman who wanted to talk in his room since the lobby of the hotel was crowded. His room is fairly comfortable, but not really clean because he cannot do much for himself. He said the hotel personnel cleaned it but it must not be too often. He seems to be existing and waiting for something to happen. He is a responsible man who keeps his Clinic appointments, takes care of himself and, according to the public health nurse, does not drink.

Number 10: 51-year-old white male. Single.

Diagnosis: first - minimal (sputum positive); 1963 - moderate (sputum negative)

Age at first report: 45

Years from last activity: 4

This patient was interviewed at the Veterans' Hospital under good circumstances. He is clean and although not anxious to discuss his disease at first, did answer the questions as they were put to hom. He was slow to admit he is an alcoholic, but quick to report that the world owes him a living. He was discharged from the Army because he had tuberculosis.

Number 11: 66-year-old Oriental male. Single.

Diagnosis first - moderate (sputum positive); 1963 - moderate

(sputum positive)

Age at first report: 43

Years from last activity: 5

This man lives in one of the less desirable hotels on Second Avenue. Had the public health nurse not been present, the interview probably would not have been conducted. The patient was in bed, but finally came to the door and opened it about ten inches. The interview was conducted from a box in the hallway with other hotel tenants peeking out of their doors to see what was going on. It would have been difficult to enter this man's room since it was dirty, smelly, and only a pathway over clothes, papers, and cans to the bed was seen. With the window blind drawn, the room was almost dark. The manb clothes were soiled, his hair untidy and he was difficult to understand at times. The interview was made even more difficult to conduct by the fact that this man is hard of hearing.

Number 12: 45-year-old white male. Widowed.

Diagnosis: first - moderate (sputum negative); 1963 - far-advanced (sputum negative)

Age at first report: 34

Years since last activity: 6

It took all summer to find this patient. None of his addresses was valid. Finally, through the Welfare department, it was found that he was a patient in Multnomah Hospital. He was polite and cooperative during the interview. According to his history he is a true alcoholic who will say and do almost anything for a drink.

Number 13: 53-year-old white female. Married.

Diagnosis: first - moderate (sputum positive); 1963 - moderate (sputum positive)

Age at first report: 33

Years since last activity: 10

This is a nice appearing, 53-year-old housewife with two teen-age children and a lovely, "lived in" home. She does not take her followup X-rays seriously. Her family comes first with her and if there is ever a need for more money to keep her children in school this woman will probably take a full-time job and forget the care of herself.

Number 14: 50-year-old white male. Divorced.

Diagnosis: first - moderate (sputum positive); 1963 - moderate (sputum negative)

Age at first report: 41

Years since last activity: 7

This patient wanted to make an impression. He seems to feel sorry for himself. It is hard for him to remember many things that happened during the inactive period. It was necessary to go to four different addresses before finding his place of current residence and two more trips and a telephone call before finding him for the interview. The last trip was successful with the help of the apartment manager who said the patient had just left and pointed him out as he was walking up the street two blocks away. Because of his emphysema he walks slowly and was easy to overtake in the next four blocks. On returning to his apartment, it was found to be neat and comfortable. He is a lonesome man on welfare assistance and not able to work because of his physical disability.

Number 15: 65-year-old white male. Widowed.

Diagnosis: first - genitourinary tuberculosis; 1963 - moderate pulmonary (sputum positive)

Age at first report: 53

Years from last activity: 10

A patient at the Veterans' Hospital, this man is anxious

to give the impression it is his fault he has tuberculosis. He is pleasant and cooperative in answering questions. He said he expects Welfare and the Veterans' Administration to care for him for the remainder of his life. He seemed negative in some of his responses and his truthfulness is questionable. He gave the impression during the interview that he was hiding his true feelings.

Number 16: 65-year-old white male. Married.

Diagnosis: first - tuberculosis of the hip (sputum, drainage positive); 1963 - miliary pulmonary tuberculosis (sputum positive)

Age at first report: 23

Years since last "hip" activity: 8

This man and his wife live in a one bedroom house by a creek which they purchased for their retirement. They have no children but seem contented and happy. The patient has had several handicaps during his life but with the help of his wife has been able to deal with them effectively.

Number 17: 46-year-old white male. Single.

Diagnosis: first - moderate (sputum negative); 1963 - moderate (sputum positive)

Age at first report: 26

Years since last activity: 11

It was not possible to interview this patient, a patient at Columbia Park Hospital. All information came from medical records.

Number 18: 69-year-old white male. Married.

Diagnosis: first - minimal (sputum negative); 1963 - moderate (sputum negative)

Age at first report: 61

Years since last activity: 7

This is a well-nourished, talkative individual who believes he needs more money to live on. His home is neat and clean and comfortable. He has an attractive wife who remained in the kitchen during the interview. It is difficult for this man to breathe on exertion of any kind and easy to see why he is unable to do any kind of work. Although there was a Cadillac parked in front of the house, the home is in a low-average income district. The patient is a pleasant man who was under the impression the interviewer could get him more money.

Number 19: 54-year-old white male. Married.

Diagnosis: first - minimal (sputum negative); 1963 - minimal (sputum positive)

Age at first report: 50

Years since last activity: 3

This patient was seen in the company of the public health nurse. Although it was 11 a.m. the family was still in bed, but on our arrival were up and about in no time. They appeared to have slept in their clothes. Six friendly individuals invited us into their very close, dirty, messy quarters -- a cabin of three rooms, typical of those found in the orchard country for transient employees. The mother and father uncovered some worn chairs for us to sit on. The interview with the father of the family was conducted in a tiny room, 10 by 14 feet, with the wife, public health nurse, and children ranging in age from 1½ years to 10 years, looking on and sometimes taking part. It is presumed they were in bed to keep warm because there was no heat in the cabin and there were no windows. Light came from one tiny light bulb. The man was poorly clothed, dirty, ill, tired, and worried. Yet, and even under these circumstances, the family seemed happy.

Number 20: 52-year-old white female. Married.

Diagnosis: first - moderate (sputum positive); 1963 - minimal (sputum negative)

Age at first report: 26

Years since last activity: 19

The tiny, vivacious woman, not much over four feet tall, talked continuously, so much in fact it was difficult to conduct the interview. Although the public health nurse accompanied the interviewer to the patient's residence, she did not stay for the interview. For several years this patient asked not to be visited by the public health nurse. It was not until her relapse and a change in nursing personnel that she requested an occasional visit. She does her own housework, and has done so since 1953. Her children are now married and away from home. She never visits them because she is afraid of giving her grandchildren tuberculosis or of catching something from them. This patient needs much help in understanding tuberculosis.

Number 21: 44-year-old white female. Widowed.

Diagnosis: first - far-advanced (sputum positive); 1963 - far-advanced (sputum positive)

Age at first report: 20

Years since last activity: 10

This patient was interviewed at her place of employment, one of the State hospitals, where she works on a half-day basis. Although she was nervous at the beginning of the interview, she seems to be doing well. She, willingly, talked about her husband who died in 1962, but her grief is great. She looks tired and depressed and it seems difficult for her to breathe with her one lung. She is a nonaggressive individual who is neat looking. She enjoys photo-tinting, knitting, and reading, but is slow to make friends and seems to want to stay by herself much of the time. Other hospital personnel were most helpful when the interview was arranged and seem to be trying to help her adjust to her problems.

Number 22: 71-year-old white male. Single.

Diagnosis: first - moderate (sputum negative); 1963 - moderate (sputum positive)

Age at first report: 51

Years since last activity: 10

This patient died in February, 1964. All information came from the medical records.

Number 23: 65-year-old white male. Divorced.

Diagnosis: first - moderate (sputum positive); 1963 - far-advanced (sputum positive)

Age at first report: 57

Years since last activity: 7

This patient died in May, 1964. All information came from the medical records.

Number 24: 55-year-old white male. Married.

Diagnosis: first - moderate (sputum positive); 1963 - moderate (sputum positive)

Age at first report: 42

Years since last activity: 10

This patient lives in a rambling farm house with fairly good home conditions. These are clean, cooperative people. The family members were interested and present for the interview. Although they probably do not understand why this man needs more rest than they do, they are trying to provide proper living conditions. Late night noise and television seem to be a problem. This man will work if he can find a job that is not too hard since he does not like to accept welfare aid. He has only a seventh grade education but the public health nurse is seeking help for him since Vocational Rehabilitation

refuses to help him.

Number 25: 72-year-old white male. Married.

Diagnosis first - moderate (sputum positive); 1963 - moderate (sputum negative)

Age at first report: 46

Years since last activity: 11

This patient died in September, 1963. All information came from the medical records.

Number 26: 77-year-old white male. Divorced.

Diagnosis: first - far-advanced (sputum negative); 1963 - far-advanced (sputum positive)

Age at first report: 61

Years since last activity: 11

This patient was interviewed at the Oregon State Hospital. It was most unsatisfactory since the patient did not want to come. An attendant brought him. He was afraid, thin, and emaciated. He couldn't understand why he should be interviewed. All information came from the medical records.

Number 27: 49-year-old white female. Married.

Diagnosis: first - far-advanced (sputum negative); 1963 - moderate (sputum positive)

Age at first report: 22

Years since last activity: 19

In her home in the high hills surrounded by peach trees and overlooking the Columbia river, this patient painted murals on the walls of the front room. She talked a great

deal about many things including the new, brick house. Her husband listened from the kitchen and later came in to ask questions about tuberculosis.

Number 28: 67-year-old white male. Married.

Diagnosis: first - moderate (sputum positive); 1963 - far-

a advanced (sputum positive)

Age at first report: 58

Years since last activity: 5

Interviewed while a patient at the Oregon State Tuberculosis Hospital, this man was not feeling well at the time and was rather uncooperative. He was thin and sick-appearing and when he turned over in bed with his back to the interviewer, she left.

Number 29: 27-year-old white female. Married.

Diagnosis: first - moderate (sputum positive); 1963 - minimal

(sputum negative)

Age at first report: 20

Years since last activity: 7

This patient has a beautiful, modern, well-kept home. She is pleasant to talk with and has two lovely children. On the warm afternoon the interview took place she had been in the back yard with them. She was in college when her tuberculosis was discovered and spent six months in the hospital before resuming her college work. She seems to have been able to live a normal life but probably did not obtain the rest she needed during 1962. She seems to have gained much from her last hospital experience and says she will be more careful and have more check-ups in the future.

Number 30: 51-year-old white male. Single.

Diagnosis: first - far-advanced (sputum positive); 1963 - moderate

(sputum negative)

Age at first report: 25

Years since last activity: 3

This medium-size, pleasant man seemed nervous at the prospect of being interviewed. He lives in his own home which he helped build in an above average income district. He has had tuberculosis since he was 24 years of age, and has reactivated four times. He works under pressure at his job and although he says he dislikes it he has been there for 22 years. He said during the interview that he resents some of his duties; does more than one person should; didn't want to marry because of his tuberculosis; has always made good money; didn't want to accept responsibility; drinks heavily at times. He also indicated that he had met a girl during the October 12 storm he might have married but she broke it up. He now wants to meet someone else and get married.

Number 31: 41-year-old white male. Married.

Diagnosis: first - moderate (sputum positive); 1963 - moderate

(sputum positive)

Age at first report: 28

Years from last activity: 11

This patient was interviewed at the Veterans' Hospital under good circumstances. The man was willing to talk and answer questions. The doctor's note said this man has an inadequate and immature personality. The patient had been a prisoner of war for four years before contracting tuberculosis. A nice looking, six-footer, the man had obtained his high school diploma while he was in the hospital in 1951. He was divorced in 1957 and married again in 1962 to a waitress in a restaurant and tavern.

Number 32: 56-year-old white male. Married.

Diagnosis: first - minimal (sputum positive); 1963 - moderate

(sputum positive)

Age at first report: 45

Years since last activity: 8

This patient seems to have had tuberculosis since 1943 but it was not reported to the Tuberculosis Control Section until 1952. He had been treated mostly at home and not much history is available. He seems to be an independent individual who wants to take care of his own problems. He and his wife live in an average home with a nice, well-kept yard. This patient was not sympathetic to the interview and his confidence was not gained.

Number 33: 63-year-old white male. Single.

Diagnosis first - far-advanced (sputum positive); 1963 - far-advanced (sputum negative)

Age at first report: 55

Years since last activity: 4

This man was interviewed in a clean, comfortable nursing home. He was cooperative although he had a history of being withdrawn and would not talk unless he had to. He answered many of the questions with expletives scattered through his conversation. He is a bitter, lonely man who was a logger in his younger days. He was, then, a hard drinking, rugged individual who was discharged from the hospital in 1958 as permanently disabled. In spite of this dramatic change to his life, he is adjusting fairly well.

Number 34: 57-year-old white male. Widowed.

Diagnosis: first - far-advanced (sputum positive); 1963 - moderate (sputum negative)

Age at first report: 28

Years since last activity: 15

This patient was hard to find. At the address given first, the woman who answered the door (assumed to be the patient's wife and later found to be his sister-in-law) thought the interviewer wanted her husband since both men had been hospitalized at the same time. In unraveling the confusion, it was found that one was in the Oregon State Hospital while the other was in the tuberculosis hospital. With the correct address in hand at last, the interviewer found the patient in an adequate, four-room house which has a neat, but well-cared-for yard. The man, who lives alone, was dressed in faded but clean clothes. He was courteous and eager to discuss his disease. He was nervous, worried and has quite a limp. He commented on his family's mental problems and is concerned about losing his job with a bank as a janitor.

Number 35: 49-year-old white female. Married.

Diagnosis: first - moderate (sputum positive); 1963 - minimal (sputum negative)

Age at first report: 43

Years since last activity: 5

This patient gave the appearance of being a hard-working but insecure individual. She was dressed satisfactorily and was most willing to discuss all her problems. The interview took place in the Clinic where her husband brought her in a dejected-looking pickup truck. He works in a junk yard or junk parts place and both he and his clothes were dirty. He was unpleasant to his wife indicating the trip to the Clinic was taking far too much of his time.

Number 36: 72-year-old white male. Married.

Diagnosis: first - minimal (sputum positive); 1963 - far-advanced (sputum positive)

Age at first report: 51

Years since last activity: 11

This patient was interesting to interview. Both he and his wife had tuberculosis and were hospitalized at the same time in 1942. Their children had been placed in foster homes. Although traumatic to the parents, they seem to have adjusted and now have a somewhat normal life. A six-year-old boy was living with them at the time of the interview but his relationship was not explained. He was a well-mannered, well-nourished child who had his toys throughout the house. This was a pleasant interview conducted in a clean home with the well-lived-in look. The wife was most interested in the interview and would offer her thoughts frequently. Of particular interest was the comparison of today's methods of treatment with those of 1942 and their feelings that patients have too much freedom today.

Number 37: 77-year-old white female. Widowed.

Diagnosis: first - moderate (sputum positive); 1963 - far-advanced (sputum negative)

Age at first report: 47

Years since last activity: 13

This woman was found in her flower garden which she seems to enjoy. The garden and back yard were in top shape and this 77-year-old lady cares for it. She has a nice, warm face and wears a hearing aid. She seems well-adjusted to her way of life and although she is having more frequent check-ups at the Clinic, the tuberculosis does not bother her. She is well-nourished and seems to have few worries. Her children look after her needs but leave her to manage for herself as much as possible -- the way she wants it.

Number 38: 53-year-old white male. Divorced.

Diagnosis: first - moderate (sputum negative); 1963 - moderate (sputum positive)

Age at first report: 35

Years since last activity: 18

> This is a reliable citizen concerned about his own welfare. He is a social worker who lives in a high rent apartment building in a neat-appearing bachelor apartment. He is interested in guns and has several around. The patient was on a one-month leave from the hospital and was concerned if he would have to remain much longer. He dislikes all doctors and did not mention nurses.

One of the real values of describing the setting for the interview was to acquire a better understanding of the patient and his family. Thirteen were seen in hospitals or clinics (of these 13, it was not possible to interview two patients); 22 others were interviewed in or near their places of residence. Seven lived among conditions that could either be described as "low income" or worse: drab, noisy, dirty, overcrowded, poorly ventilated, and unheated. These people had been ill and some appeared far from well at the time of interview. Most were not gainfully employed to the extent of being free from financial concern. While some seemed to eke out an existence in various ways, none was totally free of the problem. All have had tuberculosis more than once. The unanswered question is, "How soon will they reactivate again?"

Of the 36 patients with recurrent tuberculosis in Oregon in 1963, 33 were interviewed in this survey in an effort to determine their attitudes and reactions toward the disease. To the author's knowledge, this is the first such study done where the emphasis is on the patient with inactive tuberculosis and this fact is

borne out by the Tuberculosis Outpatient Survey conducted by the Nursing Service, Veterans Administration Outpatient Clinic, Los Angeles and the Tuberculosis and Health Association of Los Angeles, in 1962.

Following are the detailed responses patients gave during the personal interviews:

1. What do you think caused you to become ill again?

Patients gave a number of responses to this question.

Alcohol	13	Emphysema	3
Improper care of self	13	Cough	2
Mental illness, emotional strain, or upset	7	Heart condition	2
Unknown	6	Hemmorhage	2
Improper diet	5	One lung	1
Overwork	5	Oregon weather	1
"A cold" 4-5 months prior to reactivation	4	Pneumonia	1
Poor living conditions	4	Severe arthritis	1
Reducing diet/weight loss	4	Silicosis	1
		Surgery for ulcers	1
		Surgery on lung	1

a. How did you feel?

To this question, seven patients answered good; nine, fair; four, poor. Further, eight explained they had no pep and five added they were nervous. In addition, 25 said they were irritable and eight responded they were not.

b. How was your appetite?

To answer this question, 11 respondents said good; 16 replied "good when not drinking"; one answered fair; and 16 said

poor.

c. What were your sleeping habits?

Good..... 19 Poor..... 14

1. Did you have adequate rest periods?

Yes..... 8 No..... 25

2. Was there too much noise?

Yes..... 10 No..... 23

d. Did you experience any feeling of fatigue prior to the onset of your reactivation?

Yes..... 27 No..... 6

e. Did you experience any crisis or emotional upset prior to the onset of your reactivation?

The responses were:

No crisis.....	9	Family problems.....	4
Job difficulties or stress.....	7	Worry, emotional stress (1960, 1962).....	4
Alcohol.....	6	Five children.....	1
Death of a loved one (1955, 1957, 1962).....	6	Pregnancy (1962).....	1
Unrelated illness or surgery (1960, 1962, 1963).....	6	Related illness or surgery.....	1
		Loneliness.....	1
		No answer.....	1

In their responses to this question, patients interviewed substantiated contentions of Perlman,[21] Selye,[25] and Sembera[26] that persons with inactive tuberculosis may become active again if under stress, be that psychic trauma, worry, anxiety, feeling of

insecurity or other emotional upset.

f. How do your wife and other members of your family feel about your illness?

Nineteen respondents indicated acceptance by their families; 12 had no families and two said their families could not accept the fact of their disease.

g. Have any other members of your family had tuberculosis?

Ten patients said yes; 23 answered no.

h. Did you contract other diseases, complications or trauma while in the inactive state? If so, what?

Patients listed a number of responses to this question.

Frequent upper respiratory infection	11	Bronchitis	1
Emphysema	11	Cerebrovascular accident	1
Pneumonia (1962)	9	Colostomy	1
Chronic alcoholism	7	Concussion	1
Ulcers	5	Deafness	1
Depression	4	Heart (1955)	1
Arthritis	3	Histoplasmosis	1
Sinusitis	3	Ischiorectal abscess	1
Asthma	2	Kidney infection	1
Eczema	2	Laennec's cirrhosis	1
Hernia	2	Mastectomy (1956)	1
Hypertension	2	Nervous breakdown	1
Myocardial Infarction	2	No motion in left knee	1
Nervous tension	2	Peripheral neuritis	1
Prostatectomy	2	Pregnancy	1
Thyroidectomy	2	Rheumatism	1
Ulcer surgery	2	Schizophrenia	1
Varicose veins	2	Severe diarrhea (1962)	1
Alcoholism	1	Silicosis	1
Anemia	1	Spastic paralysis	1
Brain hemmorhage	1	Syphilis	1
Broken legs	1	Therapeutic abortion	1

i. How did you feel about having to face tuberculosis again?

Didn't believe it.....	8	Upset.....	4
Discouraged.....	7	Rheumatism is worse.....	2
Resigned to never being well.....	5		

j. Who was most helpful to you in explaining your disease, medications, and tests?

The patients responded:

Physicians.....	15	Lectures in hospital....	3
Books.....	9	Patients.....	3
Public health nurses....	5	Myself.....	2
Health personnel - combination.....	4		

Nine patients specifically supported contentions by Jean South and Dr. Donovan Ward that both physicians and nurses must improve their communication with patients. In answering the question above, two patients said, "doctors didn't have time" while seven answered, "nurses didn't have time".

k. What was said and why was it helpful?

To this question, patients answered:

Was told nothing special.....	8
They gave no clear answer.....	6
They answered questions - only.....	4
Told how to protect others.....	3
Importance of X-rays.....	2
Live a normal life.....	2
Rest every day.....	2
Avoid alcohol.....	1
Take care of self.....	1
To cooperate.....	1
You have it and have to live with it.....	1

Although two patients answered this question with a shrug of

the shoulders, those who had adequate explanation and who understood it, appreciated it. That 14 of the patients felt they were told nothing special or were given no clear answers and another four patients felt information came only in response to their questions, again point up Miss South's and Dr. Ward's concern about diminishing communication between health personnel and patients.

l. What was done?

The responses were:

Doctors explained.....	8	Read books.....	3
Can't remember.....	5	Lectures.....	2
Movies.....	5	Nurses explained.....	1
No answer.....	5	Was told how to protect others.....	1
I asked questions.....	4		
Public health nurse explained.....	3		

In several cases, patients gave more than one answer to the question above.

m. How well do you think you understand your disease?

Nine patients responded "well enough"; 11 said "fairly well"; and 13 indicated they had "no understanding".

n. What additional information do you think might have prepared you to function better as a recovered patient?

Fourteen of the 33 patients responded that they either needed no additional information or that they were prepared. However the remainder of the patients gave a variety of answers, some outside the purview of the nurse. Some patients gave several responses.

Nothing	12
Needed more information on limitations of activity	5
Doctors need to sit down and discuss the future with patients	3
Adjustment after hospital release	2
Need more pension	2
Want to be left alone	2
Was prepared	2
Doctors need to tell patients the truth	1
Didn't need any help	1
Help to adjust to life's problems	1
How to be more active after leaving the hospital	1
More adequate job training	1
More visits from public health nurse	1
Resign yourself to having the disease	1

o. Do you think anything could have been done to prevent your relapse? If yes, what?

The patients responded as follows:

No	14
Yes, inadequate care of self	3
Yes, too much alcohol	3
Yes, too much worry	3
Don't know	2
Worked too hard	2
Avoid colds	1
Better adjustment to disease	1
Couldn't get job	1
Improper diet	1
More money to live on	1
More work	1
Needed help of Vocational Rehabilitation	1
Need more education about tuberculosis	1
No, because I wanted to drink	1
Pneumonia caused it	1

p. What is the most difficult problem a person with tuberculosis has to face?

Patients gave a number of responses to this question.

Public understanding (stigma)	14
Adjustment to a different life	5
Hospitalization	5
Separation from family	5
Trying to get a job afterward	4
Living alone	3
Confinement	2
Don't feel well anymore	2
Financial problems	2
Have to be careful	2
Isolation	2
Adjustment to hospital	1
Being a cripple is worse	1
Breathing	1
Can't be near children	1
Can't do work as before	1
Can't get insurance	1
Had to have a house on one floor	1
No visitors	1
Realization of seriousness of the disease	1
Staying in bed	1
Worry of recurrance	1
You're not normal like other people	1

Although patients in this survey gave many different answers to this question, the answers support Calden, and others, [6] in their findings that the stigma of tuberculosis is felt by the majority of patients in varying degrees. Public understanding was listed most often as the major problem facing tuberculosis patients.

2. How did tuberculosis affect or change completely your thinking about the kind of work you should do?

Both Sparer [29] and Sembera [26] warn that unsuitable occupation may be a contributing factor to the recurrence of tuberculosis. However in the Oregon study only four patients had to change occupations; two couldn't work steadily and 12 retained

their same jobs. Fifteen indicated they did not work.

a. Were you working while inactive?

Thirteen said they worked full-time; five indicated part-time employment and 15 said they did not work.

b. What was the nature of your work?

The patients interviewed gave the following answers:

Office work	4
Several jobs	2
Army engineers	1
Humane Society	1
Kitchen work and janitor	1
Laboratory technician	1
Machinist	1
Nurse aide	1
Orchard	1
Photo studio	1
Seasonal painter	1
Social worker	1
Telephone answering	1
Yard work/ pass hand bills	1

c. Was the work difficult?

Yes	10	No	8

d. Did you like your work?

Yes	12	No	6

e. Did you work indoors or out-of-doors?

Eleven answered indoors; two said out-of-doors, and five indicated both.

f. Did you work for yourself or a company? Under supervision?

Three patients indicated they were self-employed; three worked for a "company" and 13 said they worked under supervision.

g. Had you been on the job long?

To this question patients gave the following answers:

35 years	1	10 years	2
24 years	1	9 years	1
22 years	2	4 years	1
19 years	1	1 year	1

h. What were your working hours?

The patients answered:

8 hours a day	9	12 hours a day	3
Part-time (4-5 hours a day	4	10 hours a day	1
		Seasonal - part-time	1

i. Did you have vacation time, holidays and sick leave?

Ten patients indicated they had had vacation time and two said they did not; holidays off were given to 13 patients while they worked and four did not have this compensation; 13 had provision for sick leave in their jobs, five did not.

j. Could you support your family on your salary?

Eleven respondents said yes; six said no and two women were supported by their husbands.

k. Does your wife work?

Yes	4	No	5

1. Just since your illness?

Yes..... 3

2. How does this make you feel?

I'd rather she wouldn't..... 3
Like a heel..... 1

3. What were your living conditions?

a. How many were there in your household?

Fourteen of the patients in this study lived alone while nine lived with a husband or wife. Two patients said they had three in the family and another two said there were four in the family with one patient each having five, six, and ten in their families.

Perlman, (21) Sembera, (26) and Sparer (29) all agree that unfavorable living conditions can have a poor effect on the tuberculosis patient threatened with recurrence. A large family in cramped quarters, as in the case of one patient with a family of ten living in a small cabin, can be considered a contributing factor to recurrence as are other disturbances arising from home situations such as lack of sleep and comfort, undue worry, and financial problems.

b. Where did you live?

The patients gave the following answers:

Own home.....	15	With mother.....	1
Apartment.....	7	Other (trailer, nursing	
Hotel.....	4	home, tenant cabin,	
Rooming house.....	3	farm.....	4

4. Did you ever take any of the anti-tuberculosis drugs?

Yes..... 20 No..... 13

a. Name and dosage?

Patients reported they were given one or more of the drugs listed below in varying dosages. However, those indicated here occurred most frequently.

Para-aminosalicylic acid.....12 mg daily
Isonicotinic acid hydrazide.....300 mg daily
Streptomycin.....1 gm 2x week

b. For how long?

1 month.....	1	2 years.....	5
3 months.....	1	2½ years.....	3
5 months.....	1	3 years.....	1
12 months.....	2	4 years.....	1
18 months.....	1	5 years.....	1
21 months.....	1	8 years.....	1

5. Did you have regular visits from a nurse during the time you were inactive?

In this study, seven patients had no visits from a nurse and two told her not to come; four of the 33 reported "few contacts"; two were seen "when they could find me". Three patients report visits by a nurse every six months; five report visits every four months; one, every two, three, or four months; one, every few months; another, "every so often"; one, every two-to-three months; one, every four-to-six months; one, once-a-year; one, every month; two, every two months; and one patient was overseas and had no

X-rays.

Miss South's [27] concern about inadequate nursing care for tuberculosis patients is substantiated in the above answers given by Oregon patients.

a. Were you receiving all the nursing care you needed?

Yes	31	No	2

b. What would you say was your need for a public health nurse?

None	21	No answer	2
To talk to	9	To talk to and to slow her (the nurse) down...	1

6. How frequently were you examined by a doctor?

Regular routine procedure	24
Irregular check-ups	8
No check-ups	1

a. Where did these examinations occur?

Tuberculosis clinic	22
Private doctor	8
Regional Veterans' Administration office	3
Other	4

In summary of patient responses, this survey indicates that the majority of the patients in the study were quick to recognize the reason for their reactivation indicating among their answers, use of alcohol and improper care as factors contributing toward reactivation. Fourteen of the 33 patients interviewed felt relapse

was inevitable while the remainder said they might have had some control over the disease with proper care.

Reactivation requires a major emotional adjustment according to those interviewed. Twenty-six of the patients expressed shock, disbelief or resignation to "never being well" on learning of their recurring tuberculosis.

These fiudings point toward a problem in communication with the tuberculosis patient for 13 said they have no understanding of their disease although most could describe how their illness was discussed with them by medical personnel and with whom it was discussed. Lack of understanding, or the stigma attached to tuberculosis, is of real concern to the patients and this is substantiated by other studies reported here.

While one out of three patients had what would be considered inadequate followup visits by nursing personnel, the patients themselves seemed satisfied with followup visits.

CHAPTER IV

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

Summary

This study was initiated to follow up the patients in the State of Oregon whose tuberculosis reactivated in 1963 and who returned to the active registry of the Tuberculosis Control Section, Oregon State Board of Health. The study was limited to those 38 patients. This followup study was designed to determine (1) patterns of behavior, attitude, education about tuberculosis, and post-hospital care that would guide future planning for new tuberculosis patients and those with the disease in an inactive state; (2) reasons given by the patients for reactivating.

A questionnaire was developed as an interview guide for use in gathering data for the study. Background for the interviews was provided by the Tuberculosis Register card from the Tuberculosis Control Section of the Oregon State Board of Health; the patient folder from each county public health department; the patient hospital and clinic record giving the interviewer personal and medical data upon which to base her questions. Patients were visited personally and asked for their personal evaluation of their reactivation during 1963. Data were tabulated and tables constructed from the analysis of the data. This

information appears in Chapter III of this report.

From the personal data it was found that 24 of the patients studied were residents of the Portland metropolitan area and the remainder lived elsewhere in the state. More men, 30 in number, than women reactivated during the year with the age 50-59 most critical for the men studied. For women the important age for reactivation was 40-49 years. The Oregon study shows the highest percentage, 63.3 per cent, of patients reactivating between the fifth and fourteenth years after completion of treatment with only 2.6 per cent recurring between the first and fifth years. This is in contrast to studies by Rasmussen and Wenge [22] in which 48.5 per cent of the patients reactivated between three and four years after becoming inactive and Bøyum's [5] study in which 75 per cent of the patients studied reactivated within the first five years. A possible explanation for the difference in statistics could be that patients for the Oregon study are not considered "inactive" until their names are removed from the current central case registry file, that is, when the disease is inactive for two years.

Thirty-three of the 38 patients listed with the registry were interviewed during the study. Three had died before they could be contacted and two were in mental hospitals, unable to be interviewed.

In general, most of the patients surveyed had attempted to

follow the regimen prescribed for them but ten patients exhibited a "don't care" attitude about their illness. Alcohol, improper care, and mental or emotional stress were listed by the patients as the major factors contributing toward their recurrence. This would seem to agree with the findings in the Los Angeles survey (27) that not only do patients need to be told more fully and more definitely about the proper regimen for inactive tuberculosis patients, but they need more help in tolorating stress than is now being provided. Although many patients exhibited the attitude that they might have helped themselves, it would seem important to point out to them that in some cases reactivation is inevitable. This would better prepare the large percentage who were shocked by reactivation.

The subject of education of the tuberculosis patient to his disease and how to handle it seems to recur not only in the literature but in this study. Thirteen patients in this survey said they had no understanding of their disease; however, some of these same patients indicated they had talked with medical personnel about it. Fear of reactivation is important to consider and 26 patients expressed this feeling. Fear of the stigma of tuberculosis on the part of the patient is another important consideration.

Post-hospital care given these patients is far from adequate according to recommendations given in the Task Force Report (32)

which recommends lifetime followup for all tuberculosis patients. In Oregon, one in three patients indicated he had post-hospital followup. Most patients felt they had enough visits from the public health nurses. Whether or not additional care would have, in their minds, helped in preventing relapse, was not discussed with the patients.

Specifically, patients in this study listed alcohol, improper care and mental illness as the major factors in contributing to reactivation. Seven patients said they had felt "good" prior to reactivation; nine answered "fair", and eight added they had no pep. In addition, 25 responded they were "irritable" during the onset of reactivation.

To other questions about their general health, the subjects indicated their appetites were generally good as were sleeping habits, but the majority had no opportunity for rest periods. Noise was a factor in less than half the cases but a feeling of fatigue during reactivation and since, was experienced by the majority of those interviewed. Crisis or emotional upset prior to reactivation seemed to be a factor often mentioned by patients in determining the cause of their reactivation with only ten revealing "no crisis". This further substantiates the contention in the Los Angeles survey (37) that more attention needs to be given to patients' psycho-social problems.

Nineteen respondents indicated acceptance by their families with only two answering that family attitude was a problem. Only

ten of those questioned had a family history of tuberculosis.

The question, "Did you contract other diseases, complications, or trauma while in the inactive state?" brought 99 responses with 11 patients indicating "emphysema" and 11 answering "frequent upper respiratory infection"; nine said "pneumonia" and in seven cases the answer given was "chronic alcoholism".

The emotional effect of reactivated tuberculosis seems to be an important factor in the treatment of the disease with eight patients indicating they "didn't believe the disease had recurred; seven were "discouraged"; and five "resigned to never being well".

Physicians and books ranked as most helpful to the patients in explaining the ramifications of life as a tuberculosis patient with seven respondents adding, "nurses didn't have time" to discuss the disease and two finding doctors at fault. Of the patients surveyed, eight said they were told "nothing special" which seems to indicate a serious lack of communication between the medical team and the patient and further supports the concerns expressed by both Ward (34) and South (27). Six patients answered "they (medical team) gave no clear answers" and four further responded "they (medical team) answered questions only". This is borne out by the fact that 13 indicated they had "no understanding of their disease and 11 said they understood their illness only "fairly well." In partial contradiction, 12 patients said they

needed no additional information to help them better function as recovered patients with the remainder giving a variety of answers. The major need for additional information was in the area of limitation of activity during the inactive period.

Fourteen of the patients interviewed felt their reactivation was inevitable with the remainder giving various answers to the question, "Do you think anything could have been done to prevent your relapse?" Worry, alcohol, and inadequate care were also important causes.

Public understanding, stressed by Calder [6] and Ward [34] is the most difficult problem tuberculosis patients have to face with hospitalization, separation from family, and post-hospital adjustment causing worry.

Fifteen patients were unable to work after their first bout with tuberculosis and eight were able to return to the same or similar jobs; however only 13 had worked full-time prior to onset and five part-time. Types of employment varied from office help to janitor with ten indicating their work was difficult, 11 saying they liked their work and 11 working indoors. One patient had been employed in his job for 35 years with length of service for other patients ranging downward to one year. Three patients worked 12-hour days, one a 10-hour day, nine regular 8-hour shifts and four part-time. The majority of respondents to these questions worked for firms giving them vacation, holidays off and sick leave pay. Eleven indicated they supported families on their earnings while

four wives worked, three since the husband's illness, to make ends meet. The four husbands indicated this was not to their liking.

Fourteen patients live alone, nine with one other person and one had ten in the family. Fifteen own their own homes, seven live in apartments with the remainder in rooming houses, hotels or other accommodations. Twenty-two patients were interviewed in or near their places of residence and of these many could be described at best as either "low income" or drab, noisy, dirty, overcrowded, poorly ventilated, and unheated.

At some time, 20 patients had taken anti-tuberculosis drugs, some for only a month and one for as long as eight years with the majority on this kind of medication for two years.

In spite of the fact that seven patients had no visits from a nurse during their inactive period, two "told her not to come" and four others indicated "few" contacts, 31 patients said they received all the nursing care they needed. Nine admitted their major need was for "someone to talk to". Patients having regular check-ups numbered 24 with eight indicating only irregular visits to a physician or clinic. The majority were seen in either a tuberculosis clinic or by a private physician.

All the patients interviewed had had tuberculosis more than once.. Many appeared far from well at the time of interview. The unanswered question is "how soon will they reactivate again?"

Conclusions

Three factors seem to be of major importance in this study. The need for closer contact with the patients and their families by medical and nursing personnel for the purpose of educating them to the disease is immediately apparent from the patient responses. Too often did patients respond to questions with answers indicating an unnecessary lack of knowledge about their disease, their physical limitations, and post-hospital care, the importance of a calm environment, proper followup care, the need for proper diet, rest, and abstinence from alcohol. Further, this educational program needs to be extended to patients' families and to the community since the stigma of tuberculosis seems to be an important factor to the patients.

Second, the fact that so few patients work following their hospitalization suggests the need for a stepped-up vocational rehabilitation or occupational therapy program that will allow the inactive patient employment within his limitations. This would provide income, relief from some of the emotional stress resulting from unemployment and a sense of contribution and accomplishment.

Finally, there is an urgent need for the long range followup program that is strongly recommended in a Report to the Surgeon General of the Public Health Service by a Task Force on Tuberculosis Control (32) which says in part, "Furthermore, having active tuberculosis and recovering from it increases rather than lessens the likelihood of having the disease again...a person who has had

tuberculosis is far more likely to have it again than one who has never had it."

Recommendations for Further Study

1. Followup study of all reactivating tuberculosis patients for a minimum of five years.
2. Study of a specified group of newly diagnosed patients to determine their reasons for contracting the disease.
3. Development of a tool for testing patients' knowledge about tuberculosis, the prescribed regimen, and future expectations, prior to discharge from the hospital.
4. Development of a tool to test patients at the time of hospital admission and again just before discharge for changes in attitude, tuberculosis information, and the like.
5. A study of hospital patient education programs and a study of selected patients taking part in the programs some years after discharge to determine the effectiveness of the teaching.

Recommendations

1. Financial support should be given to state and local health departments in the form of adequate appropriations to follow up all inactive tuberculosis patients. A stronger public education program would be necessary to promote greater

interest in tuberculosis that would eventually lead to this increased support.

2. Exploration of a means of improving the use of undergraduate curriculum time allotted to tuberculosis in schools of medicine and nursing.

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APPENDIX A

Interview Guide

The purpose of this interview is to gather expressions of attitudes and statements of opinion regarding reasons why inactive tuberculosis patients became active again in 1963.

The interviewer will make an effort to give the patient a concise explanation of the purpose and objectives of the visit, emphasizing the anonymity and confidentiality with which his statements will be treated.

The interview will be guided by questions and comments about specific items.

1. What do you think caused you to become ill again?
    a. How did you feel?
    b. How was your appetite?
    c. What were your sleeping habits?
        1. Did you have adequate rest periods?
        2. Was there too much noise?
    d. Did you experience any feeling of fatigue prior to the onset of your reactivation?
    e. Did you experience any crisis or emotional upset prior to the onset of your reactivation?
    f. How do your wife and other members of your family feel about your illness?
    g. Have any other members of your family had tuberculosis?

h. Did you contract other diseases, complications, or trauma while in the inactive state? If so, what?

i. How did you feel about having to face tuberculosis again?

j. Who was most helpful to you in explaining your disease, medications, and tests?

k. What was said and why was it helpful?

l. What was done?

m. How well do you think you understand your disease?

n. What additional information do you think might have prepared you to function better as a recovered patient?

o. Do you think anything could have been done to prevent your relapse? If so, what?

p. What is the most difficult problem a person with tuberculosis has to face?

2. How did tuberculosis affect or change completely your thinking about the kind of work you should do?

a. Were you working while inactive?

b. What was the nature of your work?

c. Was the work difficult?

d. Did you like your work?

e. Did you work in doors or out-of-doors?

f. Did you work for yourself or a company? Under supervision?

g. Had you been on the job long?

h. What were your working hours?

i. Did you have vacation time, holidays, and sick leave?

j. Could you support your family on your salary?

k. Does your wife work?

1. Just since your illness?

2. How does this make you feel?

3. What were your living conditions?

a. How many were there in your household?

b. Where did you live?

4. Did you ever take any of the anti-tuberculosis drugs?

a. Name and dosage?

b. For how long?

5. Did you have regular visits from a nurse during the time you were inactive?

a. Were you receiving all the nursing care you needed?

b. What would you say was your need for a public health nurse?

6. How frequently were you examined by a doctor?

a. Where did the examinations occur?

APPENDIX B

4131 S.W. View Point Terrace
Portland, Oregon
July 16, 1964

Dear Dr.

At the present time I am engaged in gathering information for a thesis in partial fulfillment of a master's degree from the University of Oregon School of Nursing, Portland.

The basic problem of this research is to study the major characteristics in the profile of the tuberculosis patient who reactivated in 1963 and was returned to the active registry of the Tuberculosis Control Section, Oregon State Board of Health.

Information obtained from Dr. Ambrose Churchill, Director of the Tuberculosis Control Section, Oregon State Board of Health, lists (number) names from (name) County.

The names are:

May I have your permission to review the records and to have an interview with these patients? Your helpful cooperation will be sincerely appreciated.

If this wish is granted, I would like to arrange an appointment with you or the public health nurse to review the records and to interview the patient(s).

Thank you.

Sincerely,

(Miss) Mary E. Blake
Instructor
University of Oregon
School of Nursing

FORM S-26

STATE OF OREGON
OREGON STATE BOARD OF HEALTH
STATE OFFICE BUILDING
1400 S. W. 5TH AVENUE
PORTLAND, OREGON 97201

MAILING ADDRESS:
P. O. BOX 231
PORTLAND, OREGON 97207

TELEPHONE:
AREA CODE 503
DAYS---226-2161
AFTER HOURS---222-1500

APPENDIX C

Dear Doctor:

Your cooperation will be greatly appreciated in providing Miss Mary E. Blake an opportunity to review any records on or request information of tuberculosis patients that reactivated and were returned to the active register of the Tuberculosis Control Section, Oregon State Board of Health in 1963.

An accompanying letter from Miss Blake will give further explanation of the important research study which we have encouragingly and heartily endorsed. She will identify those patients in your jurisdiction who have been included in this project.

Sincerely yours,

[redacted]

Director, Tuberculosis Section

ASC:dt