SOME FACTORS INFLUENCING ADHERENCE OR NON-ADHERENCE TO TREATMENT WITH PATIENTS ON PROPHYLACTIC TUBERCULOSIS MEDICATIONS

by

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This study dealt with the question of whether adherence or non-adherence to a chemoprophylaxis program for tuberculosis was related to the patient's definition of his status as a threat of potential illness. The researcher composed a questionnaire to learn how the tuberculin converter or reactor viewed his status in relation to its being a threat of illness, his understanding and response to the treatment, and the influence others had on his adherence or non-adherence to the regimen. The sample consisted of two groups of eleven patients each; those who were and were not adhering to the medication regimen as recommended by the local health department tuberculosis clinic. The researcher made home visits to conduct the interviews. The findings indicated that there was no relationship between understanding the scientific rationale of diagnosis and treatment and adherence or non-adherence. A more critical factor with regard to cooperation with treatment was whether the patient interpreted this understanding to be a threat of potential illness.
CHAPTER I

INTRODUCTION

A major trend of tuberculosis control in the United States is the change from in-patient to out-patient chemotherapy. Prolonged hospitalization is rarely justified except to ensure the distribution and hopefully the ingestion of anti-tuberculous medications. Out-patient services are usually felt to be feasible for the reliable, middle-class patient, but have been questionable for the unreliable, uncooperative or alcoholic patient.

A limitation to the effective implementation of modern therapeutic potential is the ability to instill in the patient adequate knowledge and motivation. This is especially true with ambulant care, which takes the patient out of a supervised environment. This growing trend toward ambulatory treatment intensifies the role of the patient because compliance with the therapeutic regimen is the basis of successful treatment (Kavasch and Kane 1970, p. 314).

Frequent failure of patients to cooperate in assuring their own health has long been known, and is readily demonstrated in our society. Consider the numbers of people who are overweight, or the smoking habits of a great portion of the population—both of which contribute adversely to health and disease; but the implications of which seem grossly ignored by the persons involved.
Medicine has traditionally placed responsibility for care on the patient, but because of the community significance of tuberculosis it has been delegated to public health management. Courts can even be utilized to ensure the isolation of the individual tuberculous patient in most states. Unlike many diseases, the person with tuberculosis may be quite free of pain and have none of the symptoms usually associated with an illness. The course of treatment for a patient with tuberculosis is relatively long term, usually requires daily ingestion of medications for a minimum of one year, in addition to frequent clinical or medical evaluation.

Mohler, Wallin and Dreyfus (1955) conducted a study involving 245 patients on home treatment for beta-streptococcal infections who had been given a prescribed amount of oral penicillin for self-administration. Their findings indicated that 34 percent of the patients in the study admitted to taking less than the prescribed amount of medication. The study gave evidence that responsibility toward one's own health is poor even in "reliable" patients under short term chemotherapy (p. 1116).

The literature reveals that there are many variables associated with self-administration of medications by ambulatory patients. Professionals usually rely on certain characteristics or personality traits in determining if they think the patient will be reliable in taking his
prescribed medications. However, such traits or characteristics are poorly defined, and do not provide an accurate indicator to whether the patient will actually assume responsibility in carrying out the recommendations. It is fairly common to find that patients who are placed on medications for treatment of a short-term illness or a chronic condition vary considerably in their practice of following recommendations. Some of the practices include: omission of medication; taking incorrect dosage; taking self-prescribed medications in place of or in addition to prescription items; failing to complete the treatment course as prescribed.

When one considers the variations that occur in medication practices it does not seem unreasonable that persons with tuberculosis, who require long-term treatment, frequently become classified by health personnel as unreliable patients who are not interested in their health—the recalcitrant patient. One author suggested that the problem may be that of the recalcitrant health worker, who fails to adequately educate the patient relevant to his disease and treatment. Lack of patient education does not constitute the whole problem, as patient compliance depends on many psychological and sociological factors. Perhaps one of the most important factors is that of the patient's attitudes and ideas about his illness.
With regard to enforcing treatment of tuberculosis, most states within the past decade have either passed new legislation or updated existing legislation pertaining to the compulsory isolation of the recalcitrant tuberculous patient. A survey done by Murphy and Kass (1970) to determine the frequency of recalcitrance in the United States, revealed a low percentage of patients who do not follow through with clinic and medical recommendations.

A problem which has been identified by the Pima County Health Department is that of the tuberculin converter and reactor who is placed on prophylactic medication as a measure to prevent the development of active disease. Little has been written relative to this type of patient, and his attitude toward the recommended management. The problem is in relation to following through with the medication regimen for the designated length of time. The converter or reactor is in a curious position. He has not been diagnosed as having an illness yet is receiving a medication regimen similar to that of a diagnosed case of tuberculosis.

**Statement of the Problem**

This study dealt with the question of why some patients who are placed on a chemoprophylaxis regimen for tuberculosis adhere to the prescribed treatment and others do not. To what extent does this patient see his status as
a converter or reactor to be a threat of illness or potential illness, and is adherence or non-adherence to the drug regimen related to the acceptance of his status.

Theoretical Framework

The theoretical framework on which the study is based is that of Talcott Parsons' criteria of the role of the sick person. Briefly stated, the sick role emphasizes four points: (1) the incapacity imposed by the illness requires a therapeutic process in order for recovery to occur, (2) the sick person is exempt from his normal role and task obligations, (3) the sick person recognizes that illness is undesirable and will cooperate with others in order to become well, and (4) the sick person will seek competent help and will cooperate in their attempts to help him get well (King 1962, 209-210).

The study emphasized the last two points in Parsons' theory, and was applied in relation to whether or not the converter or reactor interpreted his positive skin test as a threat to illness in a sufficient degree to cause him to accept the treatment and continued cooperation required in the treatment. The positive skin test does not in itself incapacitate the person nor prevent him from functioning in his usual roles and obligations.
In this study, Parsons' theory was interpreted to mean that following the recommendations for care constituted acceptance of the definition of illness, or in the case of the positive reactor, a potential illness. The theory was used to test the extent of agreement with the definition of illness held by those who do and do not follow through with the medical recommendations, and how close their definition of illness came to something that was curable by western means.

Parsons' theory of the sick role seems to be based on middle class definitions and standards of health and illness, and with the "proper behaviors" that are required of a person who assumes the sick role. Since most of the medical practitioners are from the American middle-class society they advocate and establish practices based on these standards, which may not be consistent with the attitudes and beliefs of the population they are attempting to reach. Parsons' theory does not seem to allow for the influence cultural beliefs have on a person's concept of the cause-effect relationship in illness and therefore his receptivity to recommendations of the middle-class medical practitioner. Although ethnicity was not a criterion for sample selection, it
was expected that there would be persons with different
cultural backgrounds in the study. The relevance of this
variable was taken into account.

**Importance of the Study**

A statement attributed to Sir William Osler, and
quoted in *Rational Therapy and Control of Tuberculosis*,
reads, "It is just as important to know what is in a man's
head as what is in his chest, if you want to predict the
outcome of his pulmonary tuberculosis (Johnson 1970,
p. 179)." This statement lends itself well to the patient
on prophylactic medications because of the implication
his status has on the prevention of tuberculosis.

It is estimated that approximately a quarter of a
million contacts to active tuberculosis cases are processed
each year, and that approximately another twenty-five
million people are currently infected with the tuberculosis
germ and are positive reactors to the standard skin test.
This puts them at increased risk of developing tubercu-
losis (Clayton 1970). If the majority of these contacts
and reactors are placed on prophylactic medications, the
factors which influence the patient's acceptance or
rejection of the treatment regimen could drastically alter
the effectiveness of tuberculosis control.
The literature on tuberculosis treatment and control emphasizes repeatedly the importance of gaining the cooperation of the patient, and motivating the patient to accept and stay on the treatment regimen. A number of theories are put forth as to why the patients fail to follow through with the treatment. Little actual research has been conducted among patients on prophylactic medications to elicit their perceptions and understanding of their status and the treatment program. With twenty-five million people in the United States who are potential candidates for tuberculosis chemoprophylaxis, it seems imperative for the professionals to gain an understanding of how these patients view their situation. Johnson suggests four areas for further inquiry in an attempt to gain this needed understanding, and while his remarks are directed to the patient with tuberculosis they could readily apply to the person who is a tuberculin converter or reactor.

... The practitioner needs to know (1) how his patient interprets the fact that he has tuberculosis; (2) what he thinks he should do about the fact; (3) what relevant others in his life (in addition to his doctor, nurse, social worker, etcetera) tell him he should do about it; and (4) how he feels about the way he is being treated by those attempting to influence him (Johnson 1970, p. 179).
The findings of such inquiries could have significant implications for educational and management approaches to the treatment of patients on prophylactic medications. Is the predominantly scientific approach currently in vogue for educating patients about their status and treatment the most valuable and meaningful approach to the patient? Is the professional worker with his scientific orientation and approach the most appropriate person to use for gaining the cooperation and participation of the patient from a cultural group? Do the mechanics of coming to the clinic or medical facility to obtain medications discourage follow-up by the patient? Are the patient's cultural beliefs and practices compatible with the professional's recommendations? These and many other questions need to be explored in an effort to understand the various factors which influence the patient in accepting or rejecting the course of chemoprophylaxis for tuberculosis.

The point of view the patient holds is as important to management as the prescribed medications, for if his views are not in harmony with those held by persons trying to help him, the patient will find means of escaping or frustrating their efforts. The efficacy of the programs employed in the prevention and control of tuberculosis are dependent on the extent of cooperation attained with the patients, especially since so much of
the treatment is conducted on an out-patient basis. An understanding of how the patient views his diagnosis and plan of treatment seems essential to gaining this cooperation, as well as what factors influence him in following or not following the recommendations.

The time factor imposed on this study limited the scope and breadth of factors that could be researched. However, the intent of the study was to bring to light how patients in the sample interpreted their status as a tuberculin converter or reactor, and to what extent this interpretation influenced acceptance or rejection of treatment. The hope was that the information obtained would provide some insight into the level of understanding the patient has regarding his status and would provide a basis upon which professional workers could plan teaching and management approaches.

**Definition of the Terms**

The terms used in the study are those of the Pima County Health Department Tuberculosis Clinic. These definitions are based on criteria from *Diagnostic Standards and Classification of Tuberculosis*, a 1969 publication of the National Tuberculosis and Respiratory Disease Association.
1. Converter: A person that has, in the previous year, shown negative results to a skin test and is now positive.

2. Reactor: A person that in the past or present shows a positive reaction to a skin test.

3. Positive Skin Test: 10 mm. or more of induration at site of injection 24-36 hours after the injection of 5 Tuberculin Units (TU) of purified protein derivative (PPD).

4. Chemoprophylaxis Regimen: Daily ingestion of isoniazid, calculated on 10 milligrams of isoniazid per kilogram of body weight to a maximum of 300 milligrams isoniazid, for one year.

Limitations
The following limitations of the study are recognized:

1. The sample was composed of twenty-two English-speaking patients who resided in the metropolitan area or the immediate outskirts of the city.

2. The study excluded persons under 18 years of age, who may present special kinds of problems with follow-up.

3. The validity of the conclusions is no more accurate than the responses given by the patients.
CHAPTER II

REVIEW OF THE LITERATURE

The concern of this study was to define some of the factors that influence the patient who is placed on prophylactic medications for tuberculosis to adhere to the regimen or to discontinue therapy.

The professional literature relevant to the prevention has dealt primarily with studies to determine the effectiveness of using isoniazid as a preventive measure with people who were recent tuberculin converters, or were considered high risk, based on age, extent of exposure, and the prevalence of the disease. Some attitudinal studies have been done with tuberculosis patients which may be representative in varying degrees of the attitudes held by those persons on prophylactic treatment.

**Historical Developments in Treatment**

Historically, the theories and control measures which have been proposed and employed with tuberculosis might be considered single-approach methods. Early emphasis was on better ventilation in housing and lesser congestion of population. When Koch discovered the mycobacterium in 1882, and specified it as the causative factor of
tuberculosis, the germ theory became popular. Patients were isolated in sanatoriums to prevent and control the spread of the germ to their families and communities, a practice which continued well into the twentieth century.

The germ theory encouraged the development and discovery of chemotherapeutic agents which were employed in the treatment of tuberculosis by the 1940's. The use of the tuberculin skin test for early detection, the administration of BCG vaccine to immunize the general population, and the use of drugs to cure those persons already infected was proposed by some to mean that the eradication of tuberculosis would soon be a reality.

Although eradication was not achieved, the introduction of isoniazid in 1952 made chemoprophylaxis of tuberculosis a practical possibility. Isoniazid was found to be a safe, inexpensive drug that could be administered orally and was an effective killer of the tubercle bacilli. Within a few years of the introduction of isoniazid the possibility of using it as a preventative measure occurred independently to a number of professionals throughout the world. A series of controlled studies were initiated during the mid-50's by the United States Public Health Service to determine the effectiveness of using isoniazid as a preventative measure in the control of tuberculosis. The studies were
directed initially to individuals and later broadened to include thirty communities in Alaska where tuberculosis was occurring in epidemic proportions.

The emphasis of the studies gradually changed from using the drug as a protective antimicrobial cover during periods of unusual risk in the presence of disease to measuring the long-term effect of isoniazid on established infection. In brief, isoniazid was found to be effective in preventing complications when used in the immediate high risk period of initial diagnosis, and substantially reduced the development of infection and disease among contacts to an infectious case (Ferebee 1969).

In spite of the rather dramatic achievements resulting from the germ theory and the resulting chemotherapeutics, it became apparent by the 1960's that something more was needed. Mortality rates for tuberculosis had declined markedly, but morbidity rates seemed to be rising. The web of causation concept which this era has developed holds that germs may be necessary causes of some diseases, but they alone are not sufficient to explain distribution of most diseases among human populations (Johnson 1970, p. 178).

Current Treatment Limitations

Ferebee (1969) suggests that a point has been reached where the factors associated with the failure of using isoniazid for infection should be considered. Two facets of the problem might be called the biological
failure and social failure. "Biological failure may be visualized as the considerations involving the triangulation of the drugs, the tubercle bacillus, and the host (p. 96)." In the United States Public Health Service trials, those contacts who took at least 80 percent of their pills for at least ten months illustrated what isoniazid could do in a well administered program. Tuberculosis morbidity in this group was reduced 68 percent over a ten year period. Several alternative explanations are offered as to why the prevention was not 100 percent. Either the medication dosage (5 mg./kg.) was too low or the course of treatment (12 months) was too short. However, a trial study using a higher dose brought about a sharp increase in medication intolerance and did not show a significant increase in therapeutic effect.

Further, there is considerable evidence that the regularity of taking pills decreases with time, and those who would actually take isoniazid longer than a year are probably quite small. The costs of administration are greater than the cost of the drug, and extending the duration of treatment unnecessarily at additional expense is undesirable.

The second factor of biological failure, the physiological state of the tubercle bacillus, may be the most critical. "In vitro evidence indicates that isoniazid has no effect on non-multiplying bacilli except to inhibit
their change to a multiplying state during treatment (Ferebee 1969, p. 97)." If the same is true of the human host, the risk of developing tuberculosis would not be reduced by the year of treatment, and an intermittent treatment plan might be more effective. At present, there is no test to determine the metabolic state of the organism in persons identified as infected, but this clearly should be an area for further research in tuberculosis control.

A scientific study of the social factors would be more difficult than that of biological factors because of the components of a sociological study. These components are identified as: the problem, the subject, and the investigator (Ferebee 1969, p. 97). Inherent to the problem is motivation which in its broadest sense is defined as "something (as a need or desire) that causes a person to act (Webster 1963, p. 553)." Motivation is so diffuse and varied that it would have to be broken into a series of small studies—a course unattractive to most investigators who are looking for giant steps toward understanding.

The factor of motivation must be dealt with in terms of the investigator as well as the subject. Investigators in the Public Health Service trials applied multiple persuasions and methods to get the participants to take
the pills, but collected no solid data on the results of
the different approaches employed.

The human subject in a research study presents a
significant variable, as they have opportunities to deviate
from the pre-arranged protocol of the study design.

In tuberculosis, there is a special problem
in the affluent countries; tuberculosis is now
a disease of the poor, who are alienated, often
hostile, to the rest of society. Communication
with this group is difficult. Their problems
of daily existence are often so acute and
immediate that little time or energy is left
to be concerned about preventive treatment
for a disease they only might have in the
future (Ferebee 1969, p. 97).

As the literature suggests, if closer control of
tuberculosis is to be achieved it will take the collective
efforts of many professional disciplines, and that not all
of the problems in tuberculosis control reside at the
patient level.

**Psychological Aspects**

The most comprehensive studies available to the
researcher were those reported in *Personality, Stress
and Tuberculosis* (Sparer 1956). For the purposes of this
study, emphasis is given to the chapter reporting the
results of a survey on how the tuberculosis patients felt
about their disease. The survey was conducted with a
group of hospitalized patients, and those aspects relevant
to hospitalization are not included.
The study was undertaken because of the felt importance of attitudinal factors in the treatment of tuberculosis. There were 570 participants in the study who completed the Madison Sentence Completion Form, a psychological form designed specifically for the evaluation of thoughts and feelings of tuberculosis patients.

While there were highly individual responses among the patients surveyed, there were also many similarities of attitude that allowed reactions to be grouped into several categories. In summary, most of the patients reacted to their diagnosis with feelings of shock, bewilderment, fear, anger, or depression. Very few of the patients expressed a fear that they might die because they had tuberculosis. The social stigma of "being like a leper," a social outcast, was experienced in varying degrees. One of the biggest fears expressed was that of recurrence of their disease. Many of the hospitalized patients resented the length of treatment and the restrictions imposed upon them by this.

Many of these findings would seem applicable to the person who is placed on a prophylactic regimen, in that he is a potential candidate for developing the disease.
In a survey undertaken by Murphy and Kass (1970) on the frequency of recalcitrance in tuberculosis control centers nationwide, an inquiry was made as to the factors which contributed to recalcitrance. The article stated that,

The Control Officer of Tennessee probably expressed the views of the majority of his colleagues when he indicated that almost all the recalcitrant patients are in some way emotionally disturbed individuals. About 40 percent of them are chronic alcoholics; others refuse to accept the fact that they have tuberculosis; some are not convinced of the value of continued hospitalization once they begin to feel better; others don't like the restrictions imposed by the prolonged period of hospitalization; finally, many are disturbed by either the unsympathetic attitude of members of the health department before admission to a hospital or they have sincere concern about the welfare of their families during their absence (p. 425).

Some of these views were supported to a considerable degree in studies reported by Derner (1953), in Aspects of the Psychology of the Tuberculous. The studies indicated that patients with tuberculosis manifest disturbed behavior which may be the result of the disease, may reflect a pre-existing condition, or may be a process of interaction. Much of the disturbed behavior is a realistic reaction to a threatening situation. It is traumatic to be diagnosed as tuberculous, and the patient response initially is one of deep concern and depression. Most patients experienced a sharp conflict between
dependence needs and independence needs, which were manifested in a variety of behaviors and were resolved more easily by some than others. Although not tested, it was felt there might be a relationship between emotional difficulties and the onset of tuberculosis, and an even more marked relationship between attitudes and relapse.

It becomes evident that the matter of control and treatment of tuberculosis encompasses a gamut of emotional, social, and psychological factors which are not solvable by a simple, single approach for either the patient or the professional worker.

**Cultural Attitudes and Beliefs About Disease**

One of the problems on the professional level is that the scientifically-oriented practitioner frequently fails to give consideration to the various systems of beliefs and attitudes about disease, and to recognize that these beliefs and attitudes become important variables in how the person perceives illness and injury, and acts toward it. These beliefs and attitudes are integrated with other important belief and practice systems, vary among cultural groups, but adequately explain and handle illness for the group. These beliefs and attitudes toward illness can be placed in one of three major categories: scientific medicine, primitive medicine, or
Usually more than one type of belief system can and does exist in any group or individual, and although one system is dominant, recourse to an alternative system is available under certain circumstances.

"The rational explanation of natural events in terms of cause and effect is the central feature of scientific medicine . . . . thus, depends on objective observation, experimentation, the seeking of natural causes, allowing in all cases for change when demanded by evidence (King 1962, p. 93)."

Magic is the basis of primitive medicine, with diseases caused by supernatural powers and cured by magical formulas or by supplication to the supernatural powers. "Even in a society that is dominated by the scientific method, magic is not as far away as we might like to think or hope . . . We may be tempted to use (it) in situations that are high in ambiguity and fraught with great threat (King 1962, p. 94)."

Folk medicine places tradition in the key role, is backed by the experience of the older generation, and is accepted on the authority of the respected members of the group who have had experience. It is derived from the practices of folk societies, and involves the group rather than the skills of a few professionals, whether they be physicians or medicine men. Folk medicine practices are
very enduring, and exist alongside scientific medicine or primitive medicine without noticeable conflict, though they seldom have practices that use magic. Folk medicine has its greatest application in prevention of disease and treatment of minor illnesses and injuries where ambiguity and threat to existence are relatively low. There is ample opportunity for the application of folk medicine in all societies, the United States included.

The influence folk medicine has is well documented in *Health in the Mexican-American Culture* (Clark 1970). While a fairly large group of scientific disease conditions are known by name to the Mexican-American people and the symptoms are recognized, their perception of the etiology may be quite different from that accepted by physicians. Tuberculosis is one of the diseases, but folk beliefs are frequently used to explain the etiology. Folk cures may be prescribed in the treatment of the scientific diseases, including tuberculosis, and faith is an important element in all curing—scientific or folk.

King emphasizes that one of the difficulties for those in the health professions in this country is realizing that there are other legitimate interpretations of disease than those encompassed by scientific medicine. Legitimate to the patient in that the interpretations are meaningful, useful, and important to him. Ridiculing and dismissing folk beliefs or primitive medicine as foolish,
unscientific superstitions does little to suppress their influence, but does adversely affect the ability of the professional in providing good medical care or help with medical problems.

The answer does not lie in outright acceptance of the tenets of folk medicine or primitive medicine, but rather in acceptance of the fact that other systems of belief about disease than scientific can be meaningful to the one who is ill. When the giver of medical care knows more about the way in which the family perceives the situation of illness, then the quality and extent of medical care can increase (King 1962, p. 130).

In recent years, various disciplines have devoted increasing attention to the study of attitudes toward health. Koos explored the relationship of socioeconomic status to attitudes toward health, and found that an indifference to symptoms is expressed more frequently as one descends the socioeconomic scale. DiCicco and Apple, who used the variables of low socio-economic status and age, found that in persons 65 years and over health was important only as it became poor: health and interfered with daily activity and maintenance of independence. Weeks, Davis, and Freeman found that apathy toward medical care was related to the economic value placed on health in comparison with other expenditures (Bauman 1965).
Either explicit or implicit in these studies is the concept that different attitudes toward health may reflect different meanings that are attached to the term. Conceivably, persons may fail to respond to measures designed to improve their health because they fail to perceive the measures as related to their conception of health (Bauman 1965, p. 207).

Many studies of the lay views on illness have focused on whether the views were compatible with the professional ideas of what the patient should know and do. The approach has been to inquire if people are properly informed about factual matters relative to health, and if they are not, to find out why. "However, for a layman to conclude that he is ill and for a doctor to diagnose him involve quite different processes of decision (Bauman 1965, p. 220)." The layman may base his conclusion of being ill on factors which are irrelevant to a professional judgment about the individual's state of health. The factors used by the patient may not be considered untrue or imaginary by the physician even though he would not use them as a basis of diagnosis.

To find out the conditions under which the layman thinks of himself as being ill would therefore seem important for the professional. "The decision by a person who has something wrong with his health that he is ill and not merely ailing is a turning point in his subsequent behavior (Bauman 1965, p. 220)."
Summary

In reviewing the literature pertinent to control and prevention of tuberculosis, the emphasis was placed on procedures and practices of administering medications, determining the minimum dose required for adequate control of the disease, the advisability and efficacy of immunizing the general public against tuberculosis, the use of the drug during periods of high risk in active disease, and the effectiveness of the drug in preventing infection. While the importance of such studies will not be disputed, it also seems essential to gain a better understanding of the beliefs and attitudes of those patients who are being treated. Johnson (1970) suggests that,

It is apparent ... that tuberculosis cannot be brought under control solely through the development of new laboratory procedures or chemotherapies. Only at such time as we are able to obtain the full cooperation of the people we are attempting to serve will it be possible to reap the benefits of such medical technologies (p. 183).

One of the preventive measures for the control of tuberculosis is the administration of prophylactic medication to those persons at risk of developing the disease. This will only be an effective measure if the patient adheres to the regimen. An understanding of the tuberculin reactor or converter's attitude toward his status seems an essential ingredient in enlisting his cooperation with the preventive treatment program.
CHAPTER III

METHODOLOGY

The focus of this study was the patient who is designated as a tuberculin reactor or converter and is subsequently placed on a chemoprophylaxis treatment regimen to prevent the development of tuberculosis. The study dealt with the question of why some patients adhere to the prescribed treatment and others do not. Does the tuberculin reactor or converter interpret his status as a threat of illness in a sufficient degree to cause him to accept the prescribed treatment?

The hypothesis of this study was that there is a relationship between the patient's definition of illness and his cooperation with medical recommendations.

Research Design

The study was conducted in a southwestern urban community. The researcher made home visits to persons who had been randomly selected from the tuberculosis register at the local health department until eleven patients had been interviewed for each of two pre-established categories, those who were adhering to the medication regimen and those who were not, bringing the total sample to twenty-two patients. Patients residing
two miles or more beyond the city limits were excluded from the population prior to selection of the sample.

Permission to conduct this study was sought and obtained from the nursing and medical directors of the county health department tuberculosis clinic. Verbal permission was sought from those patients who were willing to participate in the study.

A simple explanation of the study was presented to the patient. He was told that the researcher chose his name by chance from the records at the tuberculosis clinic on the basis of his having had a skin test. The researcher identified herself as a graduate student at the University of Arizona who was doing a study with this group of patients, and inquired as to whether the patient was willing to participate in the study by answering some questions about his skin test and treatment.

Sample

The individuals were selected for the study on the basis of having had a conversion from negative to positive in their tuberculin skin test within the past year, or a reaction of 10 millimeters (mm.) or more induration to a skin test. In this particular clinic the medical policy is to place a converter of any age on prophylactic treatment
for one year. During the time period when the patients in this sample were skin tested, the policy of the clinic was to place persons with tuberculin reactions of 10 mm. or more induration on prophylactic treatment for one year. As of January 1972, the policy was that tuberculin reactors under the age of 20 years, or reactors who have diabetes, reticuloendothelial disease, silicosis, postgastrectomy status, or are receiving immunosuppressive drugs are placed on chemoprophylaxis as opposed to all reactors.

The clinic procedure is to administer the skin test intradermally and to ask the patient to return in two days for reading of the test. If the test is significantly positive—10 mm. or more in diameter—a chest x-ray is done and the patient is given an appointment to see the physician within one to two weeks. The patient is interviewed by the clinic nurse prior to seeing the physician, an explanation of the skin test is given, the possibility of placing the patient on medications is discussed, and a pamphlet, "Pills to Prevent", usually is given to the patient.

The patient then sees the physician who reviews the x-ray findings and determines the necessity for placing the patient on the medications. If the patient is placed on medication, the purpose and regimen are discussed with
the patient by the physician. In most instances, a prescription is given to the patient and he is asked to report to the county hospital pharmacy department to get the medicine. If the patient expresses that he would have considerable difficulty getting to the county hospital, a supply of medication is given to him—usually a three month supply—along with a prescription for refills which he must obtain at the county hospital pharmacy. Although both are a part of the health care delivery system of the county, the county hospital is located approximately two miles from the health department clinic.

The patient presents his prescription to the pharmacy department, at which time his name is added to a current list of patients to whom tuberculosis medications have been dispensed. The list is sent to the health department at the end of each month, and is received by the record room. The record room clerk checks to see if there is a file on the patients listed. If there is a current file, a form is completed and filed in the record which indicates that the patient did pick up his medication. A record is not initiated if the patient is under the care of a private physician.
New patients are added to the tuberculosis registry, and information relative to medications and clinic appointments is updated on the registry each month, both for health department and private physician patients. Computer print-out sheets are available monthly on all patients included in the registry. At present there are a total of 1,000 patients, classified as converters or reactors, of which only 100 are converters.

The sample for this study consisted of two groups of patients: (1) those who were adhering to the clinic recommendations in taking their prescribed medications, and (2) those who were not taking their prescribed medications. Patients who, according to the registry, failed to pick up one or more medication refills were classified as not having followed through with medical recommendations. All patients in the study were in the prophylaxis program for a minimum of six months in order that the researcher could classify them as following or not following the recommendations.

The following criteria were employed in selecting individuals for the sample: (1) the skin test was done prior to September 1971 and the patient had been on medication for at least six months; (2) the patient was 18 years of age or over; (the study was limited to adult patients on the assumption that they assume...
responsibility for their own follow-up, where the parent usually assumes the responsibility for medical recommendations for the child); (3) the patient had to speak English; (4) the patient had to reside in the city or within a two mile radius of the city limits; (5) the patient was classified as a converter or reactor according to the definition presented in Chapter I.

The sample was selected by taking from the current tuberculosis registry the name of every individual who met the above criteria. Patients were further categorized according to whether they were or were not adhering to the medication regimen as indicated on the registry. The total numbers of individuals in both the adhering and non-adhering categories were then divided by ten to arrive at the interval number for selecting the final sample. Those individuals not chosen were retained as alternates to use in the event that some of the original eleven patients in each category were not found or did not want to participate in the study.

The individual patient records of those selected to be in the sample were reviewed to verify the information given on the registry. Six patients were eliminated as potential interviewees on the basis of the record review when it was found that the registry information had not been updated or was incorrect.
Data Collection

Whenever possible the researcher made telephone contact with the patients selected for the sample to explain the study, to determine their willingness to participate, and to arrange a time when they could see the researcher. In instances where a telephone number was not available, one or more home visits were made in order to contact the patient. Visits were made to a total of thirty-three subjects who met the study criteria. In visits to thirty-three individuals, five of the patients were not located, two other patients refused to participate in the study, and four were eliminated on the basis of having been placed incorrectly into the non-adhering category when by self report they did adhere to the prescribed regimen.

The final sample was representative of a wide range of socio-economic levels, and of geographic location throughout the city. Ethnic distribution was fairly even between patients with Spanish surnames and white Anglos. There was only one Negro patient in the sample.

Most of the patients were receptive to giving the researcher information to complete the questionnaire, and only one patient seemed suspicious of the researcher's motive. This particular patient asked for identification before granting the interview. One of the patients who
refused to participate in the study called the Director of Nursing at the health department for further clarification of why and how the researcher got her name.

All of the patients were informed that their names would not be used in the study, and that they had been selected by chance from the register at the health department. Most of the interviews were conducted in the homes of the patients, although several were conducted at the patient's place of employment.

Unless a pre-arranged time had been established for the interview, the researcher found late afternoon hours most conducive to finding the patient at home. The purpose of the interview was to ascertain the patient's response to his tuberculin positive status and the prescribed treatment regimen.

Data Collection Instrument

The researcher composed a questionnaire to aid in determining the patient's response to his status as a converter or reactor, and to see if his attitude and understanding of his status influenced adherence or non-adherence to the medication regimen.

Basic identifying information was obtained from the patient's record with regard to age, sex, date of skin test, size of reaction, date treatment began, and status
classification—converter or reactor. The researcher wondered if the size of the reaction would prove to be a significant variable with regard to following or not following recommendations, and hypothesized that the larger the reaction the more closely the patient would adhere to the recommendations.

The composition of the questionnaire, the rationale behind the questions, and the anticipated response categories were as follows:

1. Why did you have your skin test?

   The researcher hoped to elicit from this question the motivating factor on the part of the patient. Responses were anticipated to fall into one of four categories:

   a) By request — a health professional advised the patient to have the test.

   b) Self-referral — the patient himself requested or had the test for some reason.

   c) Routine — the test was done as part of a routine physical examination.

   d) Required — done as a prerequisite or condition of employment.
2. What is your understanding of why the skin test was given?
This question was asked to assess the patient's knowledge of the scientific purpose of the test. Answers were anticipated to fall into the following categories:
a) Unknown — if patient responded by saying he did not know why.
b) Incorrect knowledge — includes testing for allergies or conditions unrelated to tuberculosis.
c) Partially correct — if patient responds that it was done to see if he had tuberculosis.
d) Correct knowledge — if response indicates that patient was being tested to see if the TB germ was present.

3. What is your understanding of the results of your skin test? If patient responded, "It was positive", he was asked what positive meant. This question was asked to see if the patient understood his status as a positive reactor or converter, and if his understanding reflected the scientific explanation of cause-effect relationships. Responses were categorized as:
a) Unknown — if patient was unable to offer an explanation.
b) Incorrect knowledge — if patient stated that it
meant he had an allergy or condition unrelated to tuberculosis.

(c) Partially correct — if patient stated that he has tuberculosis, or was susceptible to tuberculosis.

d) Correct — if patient explained that it meant the tuberculosis germ was in his lung, but he did not have the disease.

4. What were you told at the clinic about the red area on your skin?

This question was asked to determine if the local reaction elicited an inquiry from the patient and what kind of information he was given about the reaction. Responses were categorized as:

a) Nothing — the patient received no explanation.

b) Unclear explanation — did not include scientific rationale for local reaction, although patient may have been given some explanation. Either the clinic failed to give explanation, or the patient did not understand.

c) Correct — that it indicated the germ was present and might develop into active disease.

5. Why do you think you were given pills to take?

This question was asked to learn what the patient’s understanding was of the scientific rationale relevant
to the treatment recommendations. Responses were categorized as:

a) Unknown — if patient unable to give response.
b) Incorrect — if patient stated that it was to make the skin reaction "go away", or was in some other way unrelated to prevention of tuberculosis.
c) Partially correct — if patient responded that it was to cure his tuberculosis or kill the germ.
d) Correct — if patient responded it was to prevent him from developing the disease.
e) Denial — if patient stated he was not given pills.

6. How do you feel about taking the pills? If response was vague, the patient was asked if he thought he should take the pills, and why.

The researcher hoped to elicit from this question the patient's attitude about the recommendations from the point of view of whether he saw his status as a threat of illness. The responses were anticipated to fall into one of four categories:

a) Compliance/no threat — patient was taking the pills but did not think he would get tuberculosis if he stopped taking them.
b) Compliance/threat — patient was taking pills
because he did not want to get tuberculosis and saw the pills as a preventive measure.

C) Non-compliance/no threat -- patient may or may not have started medication regimen, but at time of interview was not taking pills because he did not see them as necessary for prevention of tuberculosis.

d) Non-compliance/threat -- patient may or may not have started medication regimen, but at time of interview was not taking pills although he thought he should in order to prevent tuberculosis.

The next three questions were asked to determine the patient's understanding of the frequency and duration of the prescribed treatment, and what routine he followed in taking his medications.

7. How often were you told to take the pills?
   a) Correct -- daily
   b) Incorrect -- other than daily
   c) Unknown -- if patient did not know

8. How long were you told to take the pills?
   a) Correct -- one year, or longer on clinic recommendation
   b) Incorrect -- less than one year
   c) Unknown -- if patient did not know
9. Can you tell me your routine for taking the pills?
   a) Once daily
   b) Twice a day
   c) Three times a day

10. Are there times when you don't take the pills? If yes, when and why?
    This question was asked to see what factors may have influenced the patient adherence to the regimen. The responses were anticipated to fall into the following categories:
   a) Forgets — occasionally forgets to take pills.
   b) Out of medication — does not take during interval of running out of medication and obtaining a refill.
   c) Inconvenient circumstances — away from home, or stops briefly because of side-effects.
   d) Other — patient terminated medications or never started taking them.

11. (If patient has discontinued medication) Why did you stop taking the pills?
    Responses were anticipated to fall into the following categories:
   a) Did not understand treatment instructions — the duration of the medication program was not understood by the patient.
b) Saw no need to take medication -- patient did not feel he would get tuberculosis if he stopped the medication.

c) Failure to get refill -- patient has not returned to refill prescription.

d) Developed side-effects -- patient terminated medications himself because of side-effects.

12. Did (or do) the pills make you feel different in any way? If side-effects, describe the symptoms.

This question was asked to elicit if there was a physical response, either positively or negatively, to taking the medication and if there was a correlation between physical response and adherence or non-adherence to the treatment regimen. Anticipated responses included:

a) No difference

b) Developed side-effects

c) Increased feeling of well-being

13. What do you think (would happen if) (will happen since) you stopped taking the pills? If response was vague, patient was asked, do you think you will get tuberculosis?

This question was asked to elicit the patient's understanding of the cause-effect relationship with regard to his status and if this influenced his acceptance of the prescribed treatment as a preventive measure.
Responses were rated:

a) Doesn't know
b) Feels nothing would happen, would not develop tuberculosis.
c) Felt he would or might develop tuberculosis.

14. What happens when you go to get your medication?
This question was asked to elicit if and what kinds of problems the patient encountered when he went to the county hospital for his medications, and if this procedure was a factor in adhering or not adhering to the regimen. Answers were categorized as:
a) Has not been for refill yet -- was given more than three month supply of medication.
b) No problems -- patient stated nothing happened.
c) Encountered problems -- presented complaints about system.

15. Is there any other kind of medication that you take on a regular basis? If yes, what kind? Responses were anticipated to fall into one of three categories:
a) Preventive -- if patient was taking birth control pills.
b) Therapeutic -- medication prescribed by a physician to treat an established condition.
c) Self-prescribed — includes vitamins which were taken by the patient for maintenance of his health, and were self-prescribed.

The next five questions were asked to see if the patient was influenced in adhering or not adhering to the treatment regimen by knowing someone with a like status. The researcher was also interested in whether cultural beliefs and practices were an influencing factor since it was anticipated that the sample would contain patients with different ethnic backgrounds.

16. Have you ever known anyone else who had a positive skin test? If yes, who?

17. Was (he) (she) told to take anything or do anything because of the positive skin test? If yes, what was done or given?

18. Did (he) (she) see anyone other than a doctor or nurse? If yes, who?

19. Was anything else done or given? If yes, what?

20. What was the result of (his) (her) treatment?

21. How has (his) (her) experience influenced what you have done?

Analysis of the Data

Responses to the questionnaire were reviewed by the researcher and two other registered nurses, at inde-
pended times, to validate the response category. The data were then tabulated for each question to establish the distribution of responses between the adhering and non-adhering groups. Adherers were those patients who were following the treatment regimen and non-adherers were those patients who had started the medications, but stopped, or had never started the medications.

The Fisher Exact Probability Test (Siegel 1956) was used to establish the significance level of the following relationships: (1) age of patient to adherence or non-adherence, (2) interpretation of status as a threat of illness to adherence or non-adherence, and (3) interpretation of pills as a preventive measure to adherence or non-adherence.
CHAPTER IV

PRESENTATION OF THE DATA

In the present chapter the findings of the study are presented in four parts: (1) demographic characteristics of the sample, (2) the relationship between the patient's definition of illness and the extent to which he cooperated with medical recommendations, (3) the patient's understanding of and response to his status, and (4) the influence of others on acceptance or rejection of the treatment.

Demographic Characteristics of Sample

There was a total of twenty-two patients in the sample, thirteen females and nine males. Distribution by sex between the adhering and non-adhering groups was fairly even. There did not seem to be a relationship between sex and adherence or non-adherence to the treatment regimen.

The sample was tabulated according to adherence or non-adherence by ethnic group. Ethnicity was designated as Anglo or non-Anglo for purposes of this study. In the adhering group there were seven Anglos and four non-Anglos, and in the non-adhering group the distribution was four Anglos and seven non-Anglos. Although there seemed to be
a tendency for adherers to fall within the Anglo group, the Fisher Exact Probability Test showed the difference was not statistically significant.

The sample was comprised of four patients with a converter status, those having had a conversion from negative to positive in their skin test within the past year. The remaining eighteen patients were tuberculin reactors. The distribution of the reactors between the adhering and non-adhering categories was eight and ten respectively. Of the four patients with a converter status, three were adhering to the medication regimen. Because the number of patients with a converter status was small, it was not possible to determine if the converter would be more likely to adhere than the reactor, even though three out of four did in this sample.

Tabulations were done according to the size of the skin reaction and adherence or non-adherence. While the researcher hypothesized that a large reaction would influence adherence, there did not seem to be a relationship between size of reaction and propensity to adhere. The patient with the largest reaction—52 millimeters—was in the non-adhering group, and was one of the patients who reported no understanding of the results of her test or the purpose of the medications.
Age of the patients in this sample was found to be a factor affecting adherence to the regimen. The age range was from 18 years to 67 years. The Fisher Exact Probability Test, a nonparametric technique for analyzing nominal or ordinal data when the independent samples are small in size, was chosen. These data are shown in Table I.

Table I. Age of Patient According to Adherence or Non-Adherence to Medication Regimen.*

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Adherers</th>
<th>Non-adherers</th>
</tr>
</thead>
<tbody>
<tr>
<td>29 years or under</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>30 years or older</td>
<td>10</td>
<td>4a</td>
</tr>
</tbody>
</table>

*Significant at .025 level

*With sample sizes of eleven for both adherers and non-adherers, the observed value of 4 for Cell D, non-adherers, who were 30 years of age or older, was significant at the .025 level.
The first question of the interview was to elicit the motivating factor for having the test done. The reasons were fairly well distributed among four categories for both the adhering and non-adhering patients. These data are shown in Table II.

Table II. Reasons Reported by Twenty-Two Patients for Having Their Skin Test Done*

<table>
<thead>
<tr>
<th>Adherers</th>
<th>Non-Adherers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Requested by Dr. or nurse</td>
<td>4</td>
</tr>
<tr>
<td>Self-referral</td>
<td>1</td>
</tr>
<tr>
<td>Part of Routine Physical Examination</td>
<td>2</td>
</tr>
<tr>
<td>Required for Employment</td>
<td>4</td>
</tr>
</tbody>
</table>

*Examination of the reasons given by adherers and non-adherers shows that all (4) of those who were required to have the skin test for employment were adherers.

**Definition of Illness and Cooperation with Treatment**

The majority of patients interviewed were able to give responses that indicated an understanding of the scientific basis for the purpose and results of their skin test, as well as the reason for taking the medications.
In explaining why the test was given, ten of the adhering group gave a correct or partially correct response, as did eight of the non-adhering group. Understanding the results of the test was correct or partially correct with nine of the adherers and seven of the non-adherers. All eleven adhering patients gave a correct response to why the pills were given as did eight of the non-adhering patients.

The findings indicated that there was no relationship between understanding the scientific rationale of diagnosis and treatment and adherence or non-adherence to the medication regimen.

The degree to which the patient interpreted this understanding to be a threat to his health was significant with regard to adhering or not adhering. When the patients were asked if they thought they should take the pills, and why, ten of the eleven adhering group attached a threat of getting tuberculosis to their reason for adhering to the regimen. The eleventh patient was adhering, although he felt "abstaining from alcohol and taking care of myself" were of greater import than the medications.

Eight of the non-adhering patients did not see their status as a threat to their health, while the other two patients did feel they should take the medications to prevent development of tuberculosis. The eleventh patient stated he had not been given medications to take. These data are shown in Table III.
Table III. Relationship between Patient's Perception of His Status as a Threat of Illness and Adhering to Drug Regimen.*

<table>
<thead>
<tr>
<th></th>
<th>Adherers</th>
<th>Non-Adherers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Threat of Illness and Compliance to Regimen</td>
<td>10</td>
<td>2</td>
</tr>
<tr>
<td>No Threat of Illness and Non-compliance to Regimen</td>
<td>1(^a)</td>
<td>8</td>
</tr>
</tbody>
</table>

\(^a\)Significant at .005 level

*Using the Fisher Exact Probability Test a statistically significant relationship was shown, at the .005 level, between the patient's feeling that he was under threat of developing tuberculosis and his adherence to the drug regimen.

When the patients were asked if they thought they would get tuberculosis if, or since, they stopped taking the medications those who did not see their status as a threat of illness had no fear of developing tuberculosis if they did not take the medication. Three of the adhering patients who did see their status as a threat of
illness felt they would not develop tuberculosis if they stopped taking the medication, while a fourth adhering patient perceived neither threat nor fear of tuberculosis. In spite of this discrepancy, all four of these patients were taking their medications. These data are summarized in Table IV.

Table IV. Relationship of Perceived Threat of Illness to Discontinuation of the Medication.*

<table>
<thead>
<tr>
<th></th>
<th>Adherers</th>
<th>Non-Adherers</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Fear of Tuberculosis</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>Fear of Tuberculosis</td>
<td>7</td>
<td>1^a</td>
</tr>
</tbody>
</table>

^aSignificant at .025 level

*Using the Fisher Exact Probability Test, a statistically significant relationship was shown, at the .025 level, between perceived threat of illness and discontinuation of the medication.

Understanding and Response to Status

A series of interview questions were composed to aid in learning the patient's understanding of his status and the treatment regimen. The first part of the interview dealt with the patient's understanding of why the
test was given, the results of the test, and the purpose of the medication.

The majority of the patients in the study gave responses that indicated a high degree of understanding of the scientific explanation for the purpose of the test. Eighteen of the twenty-two patients stated that the purpose was to see if they had tuberculosis. Only four of the patients were unable to give a response to this question.

With relation to understanding the results of the tuberculin skin test, there was a greater variety of responses, although most of the responses were in the correct or partially correct categories. Of the twenty-two respondents, six were unable to offer an explanation of their test results. Only three of the patients gave responses that the results indicated the presence of the tubercle bacillus, but not active disease. The remainder attributed their reaction to having been exposed to or in contact with someone who had tuberculosis, having had tuberculosis as a child, having a "tendency" for tuberculosis, or "Because the x-ray showed I have a spot on my lungs."

The majority, or twenty, of the patients indicated that the medication was given to prevent development of active disease. Two of the respondents did not know the reason for the medication, and one patient indicated the
purpose was to make him immune. Three of the patients responded that the medication was to cure the spot on their lung or prevent it from getting larger.

Each patient was asked what he was told about the local skin reaction site. The responses fell into two main categories. Nine of the patients replied that they were given no information at all. Ten respondents were given explanations which were unclear or incorrect. It was not possible to verify if the explanations were unclear or incorrect as given by the clinic personnel, or if the patient heard them as such. Some of the responses placed in this category were: "It showed I had tuberculosis;" "It was because I scratched the area;" "That it meant nothing;" "Not to touch the area;" and that, "Further investigation was needed." Three of the patients stated they were told that the local reaction indicated the presence of the germ but not the disease itself.

The responses to the skin reaction question were fairly evenly distributed in all categories between the adhering and non-adhering patients.

The second part of the interview focused on the patient's understanding of the instructions for, and his physical and attitudinal response to taking the medication. Only one of the patients interviewed responded that he had
not been given medication. The remainder of the patients understood that the medication was to be taken daily; three were uncertain as to how long they were to take the medication but the remainder understood that it was to be taken for a period of one year.

Most of the patients found it more convenient to take all of their pills at one time during the day, as opposed to intervals throughout the day. Only three of the patients reported that they never failed to take their medications. Six of the patients who were adhering to the medication regimen reported that they occasionally forgot to take their pills, though not in excess of one to two days time. Two of the adhering group have short intervals of three to five days where they do not take their medications, both because of side-effects. One of these patients experiences the side-effects when he drinks beer, so will skip taking the pills when he plans to be drinking.

When the adhering patients were asked how they felt about taking the pills, only the above patient responded in the negative. All of the others stated that taking the pills was no problem or they did not mind taking the pills. In the non-adhering group, six of the patients started the medication and remained on it for varying
periods of time up to three months. Of this number only one expressed negative feelings about taking the pills, stating, "It was a nuisance."

When the non-adhering group was asked why they had stopped taking the pills, the responses were: "The nurse said the pills weren't necessary;" "I became lazy and didn't want to go after the medication at first then decided that I didn't want to take them at all;" "Just have never gotten a refill yet;" "Kept forgetting to take the pills so stopped completely;" "I felt well and nothing was wrong;" "I was taking a lot of other pills for my pregnancy, so stopped the INH." Two patients discontinued their medications when they were informed that their x-ray was negative.

Of the eleven patients on medication, five reported side-effects. One of the patients who had started but discontinued the medication reported side-effects. The most common side-effect reported was nausea, which usually occurred at the onset of the regimen and was of short duration. Two of the patients reported drowsiness, but felt this might have been caused by their personal rest habits and not the medication. One patient reported increased nervousness which developed nine months after starting the medication.
Nine of the patients interviewed were taking some additional kind of medication on a regular basis, and the distribution was fairly even between the adhering and non-adhering groups. The only patient taking a preventive medication—birth control pills—was from the non-adhering group. Three of the patients were taking therapeutic medications, and five others were taking vitamin pills.

None of the patients expressed dissatisfaction with the process required in obtaining medication refills. While a short wait was usually involved, it was not felt to be unreasonable. One of the patients was rather creative in his approach, which required no waiting at all. He informed the pharmacist that his mother, who had just been discharged from a hospital, was waiting in the car and he had to get her home immediately. The technique worked on two occasions for this individual but was not tested further in that he discontinued taking the pills.

**Influence of Others**

The last part of the interview was conducted to learn if the patient had been influenced by others in adhering or not adhering to the treatment regimen. Two-thirds, fifteen of the twenty-two patients interviewed, did know someone else who had a positive skin test. In most instances it was a family member who had also been
placed on prophylactic medications. Only three of the patients stated that knowing someone else with a similar status had influenced what they did. The influence was positive with two of the patients in that the people they knew were tuberculosis cases who required hospitalization. Not wanting the same to happen to them, both patients saw the value of taking the medications. The third patient was influenced negatively in that her brother who was taking the pills had a significant weight gain. She related his weight gain to the medication, and did not want the same thing to happen to her so did not start the pills. None of the patients related that anyone other than professional medical personnel were consulted, or that other than scientific medical remedies were employed.

The data as presented represent, essentially, the findings of the study. The next chapter will present the conclusions and recommendations.
CHAPTER V

CONCLUSIONS AND RECOMMENDATIONS:

This chapter presents the conclusions and recommendations of the study with twenty-two patients who had been placed on chemoprophylaxis medications for tuberculosis. The demographic data collected in the study indicated that only the age factor seemed significant in relation to adhering or not adhering to the medication regimen. Patients under the age of 30 years were less likely to adhere than those over 30 years of age. While the factor of ethnicity was not of significance statistically, the raw data did show a tendency toward better adherence from the Anglo group. Further investigation of the ethnic factor might be of value to the professional staff of this health department in that many of their patients are non-Anglo.

The findings of the study indicated that understanding of the scientific explanation of the cause-effect relationship had little influence on whether or not the patients adhered to the regimen. There is considerable emphasis placed upon the necessity and value of teaching, and many professionals operate on the popular assumption
that if the patient is informed of facts, he will cooperate with the prescribed treatment. The findings of this study would seemingly dispute such assumptions; and indicated that the patient also has to attach a definition of illness or threat of illness to the facts in order to accept the treatment recommendations. In a study done by Sweetser (1966) the evidence showed that "...whatever the number of correct health facts which the participants knew, and regardless of their age, sex, educational or occupational level within the middle class, there were some important non-medical characteristics of the kind of health problems which they considered to be illness (p. 226)."

In Sweetser's study the kind of health problems that the respondents considered to be illness were those of recent onset which interfered with their normal activities. If the illness was ambiguous, medical care was usually sought. The findings from Sweetser's study may account for the fact that converters in this study had a better adherence rate proportionately than did the reactors. Having contracted the germ at some point within a time period of one year may be much more threatening than knowing it could have been present for a number of years. There may also be some relationship between adherence to the medication if the recency of onset factor described by Sweetser is applied, even
though the second factor of incapacitation is not involved.

The tuberculin reactor or converter does not have the factors of recent onset or interference with activities as baselines for defining his status as a threat of illness. The establishment of his status as a threat of illness may be likened to the findings of a study conducted by Bauman (1965) who explored people's conceptions of health and physical fitness. She found that for many people health is a multi-dimensional concept comprised of various orientations, all of which may be operating at the same time although may occur with different frequency (p., 217).

Further studies to determine what concepts are used by reactors and converters in establishing their status as a threat of illness might provide valuable information to those working in tuberculosis programs.

The findings of this study do support the hypothesis that there is a relationship between the patient's definition of illness and his adherence or non-adherence to the medication regimen. Ten of the patients in the adhering group were following recommendations because they saw their status as a threat of potential illness. The patients in the non-adhering group saw no threat, and felt that if they maintained their health nothing would
happen. One patient assigned more importance to taking vitamins as a measure of prevention than she did to the medication. Sweetser's findings support the attitudes of the non-adhering patients in that "when the health problem was not judged to be illness, many thought it alright to do nothing or to try a home remedy (Sweetser 1966, p. 226)." While these findings do not negate the need for presenting factual information to the patient, they do indicate that counseling should include an attempt to understand how the patient views his status on an illness-ailment-wellness continuum.

In giving factual information to patients some consideration might be given to a more thorough interpretation of the negative x-ray findings. Two of the patients in the study based discontinuation of their medications on their negative x-ray report, attaching the most significance to this finding. One of these patients had a reaction measuring 52 mm. in size. Steinfeld and Cohen (1967) reported that there is accumulating evidence supporting the direct relationship between the size of the reaction and the risk of developing the disease (p. 410). Perhaps patients with large reactions should be considered for intermittent follow-up counseling, either in the clinic or through home nursing visits.
If the experience of two of the non-adhering patients is found to be common, in that they stopped the medication because it became powdery or because they thought it had become outdated, counseling relative to these factors might be helpful to the patient.

Since three of the non-adhering patients related they had no understanding of their status or the treatment rationale, one might assume that the lack of adequate information was a factor influencing their behavior. Since the patient's definition of illness is based on a number of concepts, the inclusion of scientific and medical explanations would seem essential. The findings of the study indicated a need for better understanding of the results of the skin test, including the site of the reaction. The variety of incomplete or inadequate responses led the researcher to surmise that the teaching was sketchy and superficial with regard to the test results and the site of reaction as based on the patient's perception.

One of the non-adhering patients attributed not starting the medications to the inability of the clinic personnel to provide her with an accurate account of the pharmacodynamics of the medication. She pursued this information independently, and concluded that the possible
side-effect of hepatitis was a greater risk than the possibility of getting tuberculosis. This patient also verbalized criticism of the physical aspects of the clinic, stating that "They put everyone in the same room and if you didn't have tuberculosis you'd probably get it there."

The findings of the study indicated that the instructions for taking the pills was readily understood by all but two of the patients. Taking the medication was well accepted by the majority, and only a few patients experienced side-effects. Frequency and duration for ingesting the medication did not seem to be of significance with relation to adherence or non-adherence. Only one patient expressed embarrassment about taking the medication. Her embarrassment was not related to ingestion of the pills but to getting them free of charge. This patient felt she should be paying for the medications since she was financially able to do so, but stated, "I sort of like the idea of socialized medicine."

Since six of the patients experienced side-effects, nausea being the most common, some consideration might be given to advising the patient to take the medications with meals or at bedtime to avoid the nausea.

The study did not reveal any identifiable cultural attitudes or practices, and all of the patients seemed to
follow the middle-class trend of seeking professional medical advice. The failure of the study to produce cultural information could be attributed to the lack of homogeneity of the sample and to the brief, one time, contact the researcher had with the patient.

Of the twenty-two patients interviewed, only three stated they were influenced by knowing someone with a similar status. The remainder of the patients related it did not influence their decision to adhere or not adhere to the recommendations.

During selection of the sample and through conducting interviews it became evident that there were many discrepancies between the reporting and recording of information at the clinic, and what the patient reported he was doing. The researcher found that many of the patients listed on the tuberculosis registry as not adhering to the treatment recommendations were in fact taking the medications as prescribed.

There was inconsistency in the amount of medications dispensed at a given time to the patients, with some receiving a two month supply and others up to a ten month supply. In reviewing records the researcher could not always identify the amount that had been given or the reason for this practice. However, it was found that patients were often labeled as not adhering because
the pharmacy list did not include their name, when in reality they had received a large supply of medication initially. On the basis of these findings, this particular health department might consider evaluating their recording and reporting system in an effort to assure the accuracy of their statistical data.

Recommendations

Based on the findings and conclusions of this study the following recommendations are made:

1. Incorporate into patient counseling an exploration of whether he sees his status as a converter or reactor to be a threat of illness, and use this as a basis for interpreting the medical regimen. Interpretation within the patient's frame of reference would probably be more meaningful to him and increase the probability of cooperation with the treatment program.

2. Offer a more thorough explanation of the results of the skin test, and how this relates to the local reaction as well as the x-ray findings.

3. Determine the extent to which patients are concerned about taking the pills because of the crumbling and powdering which can occur, or because of the concern that the pills may be outdated. Include this
information in counseling.Alternate ways to package medication, if problem is extensive, should be considered.

4. Develop further research to establish if there is a relationship between size of reaction and risk of developing disease. If this likelihood is probable, establish visit priorities for reactors and converters with large areas of induration to provide intermittent counseling regarding the medication regimen.

5. Consideration might be given to advising the patient to take his medications with meals or at bedtime as a measure to minimize any side-effects.

6. This particular health department might want to evaluate their recording and reporting system to improve accuracy and completeness of information relative to the converter and reactor patient classifications. Perhaps the problem of non-adherence is not as wide-spread among this group of patients as the clinic statistics would indicate.

7. Further study with reactors and converters to determine additional factors which may influence the acceptance of their status as a threat or non-threat of illness.
8. Further study among converters and reactors who are under the age of 30 years to explore further the factors which influence adherence or non-adherence, and establish any special teaching or counseling needs required by this group. Such information might be relevant to the child on prophylactic treatment whose adherence or non-adherence may be dependent upon the views of his parent.

9. Further study with a more homogeneous group to explore the possible cultural influence on the converter or reactor.
CHAPTER VI

SUMMARY

Statement of the Problem

This study dealt with the question of whether adherence or non-adherence to a chemoprophylaxis program for tuberculosis was related to the patient's definition of his status as a threat of potential illness.

Procedure

The subjects of this study were those patients classified as tuberculin skin test reactors or converters by the local health department tuberculosis clinic, on the basis of having had a positive reaction of 10 mm. or more induration to the injection of 5 TU's of PPD. Converters were differentiated from reactors on the basis of having had, in the previous year, negative results to a skin test but were now positive.

The sample for the study consisted of two groups of patients: (1) those who were adhering to the clinic prophylaxis program of daily ingestion of 300 mgm. isoniazid for a period of one year, and (2) those patients who were not adhering to the prescribed medication regimen. Other
criteria used in selecting the sample were that the patient had been on medication for at least six months, was 18 years of age or older, spoke English, and resided in or near the city. The sample consisted of a total of twenty-two patients, divided evenly between adhering and non-adhering.

The researcher made home visits to complete a series of interview questions. The first part of the interview dealt with the patient's understanding of why the skin test was given, the results of the test, and the purpose of the medication. The second part of the interview focused on the patient's understanding of the instructions for, and his physical and attitudinal response to taking the medication. The last part of the interview was conducted to learn if the patient had been influenced by others in adhering or not adhering to the treatment regimen. The questionnaire also contained demographic data about each patient, the size of his reaction, and his classification as a converter or reactor.

Findings

There was a total of twenty-two patients in the sample, thirteen females and nine males, with distribution by sex between adhering and non-adhering being fairly even. The ethnic distribution between adhering
and non-adhering was: seven Anglo—or four non-Anglo, and four Anglo—seven non-Anglo, respectively. In proportion to the distribution of the sample there were more patients in the converter category who were adhering to the medication regimen, with the ratio being three adherers to one non-adherer. The distribution of the reactors between adhering or non-adhering was fairly even. None of the above data were found to be statistically significant.

Although it was hypothesized that the patients with large skin reactions would be more likely to adhere to the treatment regime this was not validated by the study. The size of reaction was not found to be an influencing factor in adherence to the recommendations.

The age of the patient was of significance with this sample in relation to following recommendations, and it was found that those patients under 30 years of age were less likely to follow recommendations than those over 30 years of age. The age range for this sample was 18 to 67 years, with eight patients under the age of 30 years and fourteen patients 30 years or older.

The majority of patients interviewed were able to give responses that indicated an understanding of the scientific basis for the purpose and results of their skin test, as well as the reason for taking the medications.
However, the findings of the study indicated that there was no relationship between understanding the scientific rationale of diagnosis and treatment and adherence or non-adherence to the medication regimen.

A more critical factor with regard to adhering or non-adhering was whether or not the patient interpreted this understanding to be a threat to his health—that he would develop tuberculosis if he did not follow the treatment recommendations. When the patients were asked if they thought they should take the pills, and why, ten of the adhering group attached a threat of getting tuberculosis to their reason for taking the medication. Eight of the non-adhering patients stated they did not think they would get tuberculosis if they didn't take the medication, while two of the non-adhering patients felt they might develop the disease.

The findings indicated there was poor understanding by the patient of the local skin reaction site. Half of the patients stated they had been told nothing about the local reaction, with the remainder revealing unclear or incomplete information. Two of the patients discontinued medications on the basis of their negative x-ray report, giving this greater significance than other factors.
When the adhering patients were asked how they felt about taking the pills the majority stated it was no problem and they did not mind taking the medications. The instructions for taking the medications were readily understood by both the adhering and non-adhering groups, and was not a factor with regard to non-adherence. In the non-adhering group six of the patients had taken the medication initially but discontinued it because they saw no need to take the medication, while two others had not obtained a refill although stated they planned to do so.

Six patients reported side-effects from the medication, the most common of which was nausea, occurring at the onset of the regimen and were of short duration.

While most of the patients knew someone else who had a positive skin test the majority related it did not influence their decision to adhere or not adhere to the recommendations.

Conclusions

Since there was a relationship between the tuberculin reactor's or converter's definition of illness and his adherence or non-adherence to the medication regimen, it would seem advisable to further explore the factors
that influence this relationship. The study gave evidence that having an understanding of the scientific facts associated with diagnosis and treatment of the converter or reactor status does not necessarily constitute or equate to a threat of illness or potential illness.

While this finding does not negate the need for presenting factual information to the patient, it does seem to indicate that cooperation with treatment recommendations is more dependent on the degree to which the patient sees his status as a threat of illness.
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