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# An investigative study of eleven families after hospitalization of husband with tuberculosis

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AN INVESTIGATIVE STUDY OF ELEVEN FAMILIES  
AFTER HOSPITALIZATION OF HUSBAND WITH TUBERCULOSIS

BY

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## TABLE OF CONTENTS

| CHAPTER  | PAGE |
|--|------|
| I. INTRODUCTION . . . . .                              | 1    |
| Statement of the Problem . . . . .                     | 2    |
| Justification of the Problem . . . . .                 | 2    |
| Scope and Limitations . . . . .                        | 3    |
| Preview of Methodology . . . . .                       | 3    |
| Sequence of Presentation . . . . .                     | 3    |
| II. THEORETICAL FRAMEWORK OF THE STUDY . . . . .       | 4    |
| Review of Literature . . . . .                         | 4    |
| Basis of the Problem . . . . .                         | 14   |
| III. METHODOLOGY. . . . .                              | 16   |
| Selection and Description of Sample . . . . .          | 16   |
| Tools Used to Collect Data . . . . .                   | 18   |
| Procurement of Data . . . . .                          | 19   |
| IV. FINDINGS . . . . .                                 | 20   |
| Presentation and Discussion of Data . . . . .          | 20   |
| Difficulties of the Patient . . . . .                  | 20   |
| The Effect of Husbands' Illness on Wives . . . . .     | 25   |
| The Effects on Children of Fathers' Illness . . . . .  | 31   |
| Financial Needs . . . . .                              | 35   |
| The Role of the Public Health Nurse . . . . .          | 39   |
| V. SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS . . . . . | 44   |
| Summary . . . . .                                      | 44   |
| Conclusions . . . . .                                  | 46   |
| Recommendations . . . . .                              | 49   |
| BIBLIOGRAPHY . . . . .                                 | 50   |
| APPENDIX . . . . .                                     | 52   |

## CHAPTER I

### INTRODUCTION

Chronic disease is one of the major health problems in the United States today because of its high prevalence and the long duration of the illness.<sup>1</sup> In 1956, the Commission on Chronic Illness reported that in 1950 5.3 million persons were disabled for over three months. This constituted 3.5 per cent of the total population.<sup>2</sup> Randall said of chronic illness:

Not only are the problems associated with long time illness and old age already demanding more knowledge, more skill and more of our services than ever before but the predictions are that they will increase at a steady and fairly rapid rate.<sup>3</sup>

Long term illness always has serious ramifications in the family constellation. Expensive and long term care of the patient, interruption of family living patterns, additional financial burdens, loss of presence of the significant person, and disruption of emotional interrelationships of the family are just a few of the stresses that might be incurred. In view

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<sup>1</sup>Theda L. Waterman and Valorus F. Lang, Chronic Illness, (St. Louis: C. V. Mosby Co., 1955), p. 18.

<sup>2</sup>Commission on Chronic Illness, Care of the Long Term Patient, (Cambridge: Harvard University Press, 1957), p. 6.

<sup>3</sup>Ollie A. Randall, "The Problems of Extended Illness and Old Age," The American Journal of Nursing, LIV (October, 1954), p. 1220.

of the effect of chronic illness on families, the writer determined to investigate a group of families in which the husband had been hospitalized with tuberculosis within the past three years and to study the stresses occurring as a result of this illness.

#### Statement of the Problem

This study purports to answer the following six questions. What were the difficulties of the patient who had tuberculosis? What was the effect of the husbands' illness on the wives? What was the effect of the husbands' illness on the children? What were the financial stresses of the family that were created by the illness? What were the attitudes of relatives and neighbors? What was the role of the public health nurse with the family?

#### Justification of the Problem

In the total picture of chronic disease the public health nurse, because of her emphasis on the family as a whole, plays an important role. She gives and arranges for nursing care of the sick and carries out nursing skills that contribute to rehabilitation. She provides health counseling and emotional support to individuals and to families, and she refers families to appropriate community resources. In view of the above functions an investigation of the difficulties families face as a result of chronic illness would seem to have value to public health nurses.

### Scope and Limitations

This study was an investigation of the expressed difficulties of eleven wives whose husbands had been hospitalized with tuberculosis within the past three years. The limitations were: only eleven families were studied, the families varied in size, and the income levels of the families were different. Also, data were dependent on the long term recall of a situation. The data applies only to the families studied and no generalizations can be assumed.

### Preview of Methodology

An interview schedule was developed to procure the data. Directors of nursing of public health agencies in two cities were contacted and families were obtained. Then each wife was contacted by telephone and an appointment was made for an interview. The duration of each interview was approximately one hour. The procured data were analyzed and conclusions were made.

### Sequence of Presentation

Chapter II deals with the review of the literature relating to the study.

Chapter III describes the method used for collection of the data and the description and the selection of the sample.

Chapter IV presents the findings and their interpretations.

Chapter V presents a summary of the findings, the conclusions, and recommendations.

## CHAPTER II

### THEORETICAL FRAMEWORK OF THE STUDY

#### Review of Literature

The writer, after a careful search of the literature, was unable to find any reports of studies done specifically on the effect of tuberculosis upon the family, either from a nursing, a sociological, or a psychological point of view. There was, however, a great deal of literature dealing with specific chronic diseases.

The Commission on Chronic Illness, in 1957 and in 1959, studied the prevalence and estimated the needs of the chronically ill in an urban and in a rural community. Methods utilized were interviews, screening tests, clinical evaluation, and evaluation by a team composed of a physician, a nurse, a social worker, and a vocational counselor. Findings were representative of the specific locales studied; although, in certain respects the overall results of the two were identical.

In the urban project the prevalence of all chronic conditions was 1,600 conditions per 1,000 population. Less than three out of ten children under fifteen, but nineteen out of twenty aged persons, had one or more chronic conditions, and nearly two-thirds of the young adults had a chronic

condition. Needs for care were estimated for a sample of cases who had maximum disability. Some of the needs in order of importance were: general medical supervision, diet therapy, financial aid for medical care, nursing care, social needs (unmet), aid in financing subsistence, etc. Somewhat more than half of the patients were estimated to need some change in their attitudes toward their condition.<sup>1</sup>

In the sample of the rural community, 13,113 persons were interviewed in the home and one person in eight was said to have been disabled by a relatively serious or chronic illness for more than a week during the survey year. Of the eight hundred sixty-four persons studied clinically, eighty-six per cent had one or more currently or potentially disabling diseases; twenty-one per cent were restricted in their activities of daily living; twelve per cent had heart disease; twelve per cent had hypertension without heart disease; eight per cent had arthritis; five per cent had benign neoplastic conditions; one per cent had malignancies; and one per cent had diabetes. To gauge the unmet needs of the chronically ill in the county, estimates were made, not only of care needed but also whether needed care had been received. Some of the findings were: medical supervision was needed by eight out of ten persons but less than four received it; bedside nursing for one or more

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<sup>1</sup>Commission on Chronic Illness, Chronic Illness in a Large City, (Cambridge: Harvard University Press, 1957), pp. 47-71, 173-192.

days was needed by sixteen per cent but only six per cent had it; instruction or understanding the patient's illness was needed by eleven per cent of the evaluatees or their families but less than 0.5 per cent received this instruction; referral service to appropriate community resources could have been used by five per cent but less than 0.5 per cent had such service.<sup>2</sup>

Mack studied eighty-four white chronically ill men and women, sixty years old and over and compared them with a normal group of older people. Some of the findings concerning their characteristics were: greater unhappiness, poorer personal adjustment, greatly reduced activity, less planning for the future and less belief in after life. Some support was found for the following hypotheses: (1) Personal adjustment of chronically ill older people varies with social class and (2) unsatisfactory personal adjustment is related to unfavorable family attitudes. The latter was found in cases of men but not of women. About half of the chronically ill group felt they gave a lot of trouble to their families, and their estimates of how much trouble they were to their families appeared to be realistic.<sup>3</sup>

Of considerable value to the present writer was the

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<sup>2</sup>Roy E. Trussell and Jack Elinson, Chronic Illness in a Rural Area, (Cambridge: Harvard University Press, 1958), pp. 151-156, 194-199.

<sup>3</sup>Margery J. Mack, "The Personal Adjustment of Chronically Ill Old People Under Home Care," Nursing Research, I (June, 1952), pp. 9-30.

literature which reported about the effects on the family of some chronic disease other than tuberculosis. For clarity the reports of the literature that are to be presented will be offered under two separate headings: (1) effect of stresses including chronic illness on the family from a psychological and/or sociological orientation and (2) public health nursing service in chronic illnesses.

1. Effect of Stresses Including Chronic Illness  
on the Family From a Psychological  
and/or Sociological Orientation

Koos, from 1941 to 1943, studied sixty-two families who had low incomes, i. e. under fifty dollars per week. His purpose was to note the troubles occurring during the period of the study, to study the efforts of the families in solving the troubles and to assay the changes in family structure and functions. He defined trouble as that which created a sharpened insecurity, or which blocked the usual patterns of family action and called for new ones. In this study illness occurred fifteen times to the families during this period and caused financial problems because of loss of income of the wage earner. Chronic illness which occurred five times demanded the permanent readjustment of the family to the situation. The prognosis in these chronic cases was not hopeful and one family's feelings were poignantly expressed in the following statement: "We can stand almost anything better than having somebody in the family sick." Families encountered

many other hardships, of course, during this period, such as death, loss of job, or illegitimate pregnancies.<sup>4</sup>

An investigation during World War II, by Hill, sought to determine the effects of the absence of the husband-father on one hundred thirty-five families. Some of the findings relating to this study were that twenty-nine families had considerable adjustment difficulties because of inadequate finances, while a few had trouble because the wife was not used to handling money. Thirty-one wives returned to work. In sixty-nine cases, making the children behave was a problem. In twenty-one families, children remained more or less maladjusted during the entire separation period. Lack of social life was reported as a hardship by only one. The tendency of most wives was to increase their social contacts.<sup>5</sup>

An on-going study by a team of investigators from the National Institute of Mental Health was concerned with the impact of mental illness on the family. Their analysis was based on a study of thirty-three families in which the husband was the patient. A series of intensive interviews provided the primary source of the data. They found that the wives manifested many times the reactions of those individuals belonging to a minority or a physically injured or handicapped

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<sup>4</sup>Earl L. Koos, Families in Trouble, (New York: King's Crown Press, 1946), pp. 90-108.

<sup>5</sup>Ruben Hill, Families Under Stress, (New York: Harper and Brothers, 1949), pp. 50-72.

group, and they quote Lewin's description of this:

The position of the minority member is characterized by feelings of under-privilege and marginality. The social environment consists of many unknowns in reactions from others, as well as expected and experienced social distance. The minority member considers attempts at concealment. His tendency to interpret ambiguous social contacts as rejections or hostility based on ethnic grounds dramatizes his hypersensitivity. Ambivalent acceptance of imposed negative valuations by others exists side by side with his seeking out of we-groups for closer associations.<sup>6</sup>

Other findings in the study were that adolescent and adult sons and daughters tended to share with the mother the problem of the father's illness. In interpreting the father's illness to younger children, almost all the mothers tried to conceal the illness. Relationships between the wife and the husband's family in more than one-half of the cases had a dominant note of hostility. The wife's family on the other hand was helpful, particularly in problems of finance and caring for the children. Very few families required financial assistance. Also, although less than one-half of the wives were employed before their husbands were hospitalized, three-quarters were employed shortly after he was hospitalized.<sup>7</sup>

In a similar study, Jackson investigated the stages through which the family passes in adjusting to the alcoholism of the father. The investigator was associated in a friendship relationship with a group of approximately seventy-five wives

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<sup>6</sup>Marian Yarrow, John A Clausen, and Paul R. Roberts, "The Social Meaning of Mental Illness," Journal of Social Issues, XI (November, 1955), p. 47.

<sup>7</sup>Ibid., pp. 33-60, 61-67.

of alcoholics over a prolonged period of time. The stages through which the family passed started as a series of acute crises, probably widely spaced in time, and passed into a progressive type of crises in which the emotional involvement and the hostility previously expressed were diminished, and finally, if the family had stayed together, into a habituated crisis. There was much guilt on the wife's part if divorce action was taken, because of her awareness that her husband was a sick man. Also, if complete sobriety was achieved, there was a difficult period of adjustment because of the role changes in the family taken to compensate for the husband during the alcoholic period.<sup>8</sup>

## 2. Public Health Nursing Service in Chronic Illnesses

Public health nurses have investigated the following aspects of the problem of chronic illness: (1) the case load of a specific chronic illness in a public health agency, (2) the physical limitations of chronically ill patients, (3) the needs of patients with a particular long term illness correlated with functions of public health nursing, and (4) the role of the public health nurse and an evaluation of her service.

A study done in 1937 by Downes and Price experimented

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<sup>8</sup>Joan K. Jackson, "Adjustment of the Family to Alcoholism," Marriage and Family Living, XVIII (November, 1956), pp. 362-366.

with studying the quality of nursing service in quantitative terms. The time spent on visits to eight hundred fifty-six families by seven nurses for seven months was matched with the nurses' purpose for visiting. The authors concluded that nurses had concentrated their visiting in families where needs were greatest and in these families all members received some service.<sup>9</sup>

Peterson studied the cancer case load of the Visiting Nurse Society in Philadelphia for the year 1948 by an examination of nursing records. Seven hundred sixty-three patients were included. She attempted to ascertain: (1) the cancer case load in relation to the total load, (2) the relationship between the cancer patient and the chronically ill older patient, (3) the source of referrals, and (4) the nursing services given, etc. Her analysis showed that each cancer patient received an average of fifteen visits, the same average as other chronically ill patients. Cancer patients comprised three per cent of the agency's case load. Eighty-three per cent of the patients were fifty years of age or older. The nursing services most often given were general care, enemas including colostomy irrigations, dressings, and hypodermics. Sixty-one per cent of the patients were referred by families, nineteen per cent by physicians, and eighteen per cent by

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<sup>9</sup>Jean Downes and Clara R. Price, "A Study of Public Health Nursing Service in Tuberculosis Families in the Mulberry District of New York City," Milbank Memorial Fund Quarterly, XVII (January, 1939), pp. 29-49.

hospitals. The author concluded that families were more cognizant of the patients' needs for nursing help than were hospital personnel and/or physicians, or else they were more aware of community resources.<sup>10</sup>

An investigation of the physical limitations of long-term illness patients and the role of the public health nurse in their care was made by Wilcoxson. Eight hundred and seventy-two questionnaires concerning case loads were completed by public health nursing agencies of different sizes in the State of Connecticut. The findings revealed that women with long term illness outnumbered men three to one; two-thirds of these patients were sixty years of age and older; three hundred thirty-two patients were unable to perform one or more activities of daily living; and the great majority of the patients needed help with the task of dressing and toileting. In sixty per cent of the cases, the persons responsible for care between nurses visits were the family members. Nurses gave general care and/or treatment to fifty per cent of the patients, parenteral therapy to thirty-eight per cent, and advisory services to ten per cent.<sup>11</sup>

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<sup>10</sup>Rosalie I. Peterson, "Study of a Cancer Case Load; An Analysis of the 1948 Cancer Case Load of the Visiting Nurse Society of Philadelphia," Public Health Nursing, XLIII (October, 1951), pp. 566-572.

<sup>11</sup>Harriett Wilcoxson, "A Study of Long Term Illness Patients Under Care of Public Health Nursing Services" (unpublished report), (Connecticut: Department of Health, January, 1954), pp. 1-5.

Wolff, the Mental Health Nursing Consultant, studied a sample of the questionnaires of the preceding study. She selected cases in which there was a problem in either the patient's or the family's attitude toward rehabilitation. Fifty-two cases were studied and twenty-four nurses were interviewed. The author concluded that no single factor seemed to be of decisive influence upon the outcome of the rehabilitation process, but rather that the outcome depended on all of the following factors: the degree of functional impairment, the age of the patient, the kind of person he was, the quality of his human relations especially his familial relationships, and the attitude of physician and nurse toward rehabilitation. The cases studied showed that nurses were rehabilitation-minded and showed awareness of the principles involved in rehabilitation.<sup>12</sup>

Gelber studied the needs of one hundred mental patients released from the hospital on tranquilizing drugs. She made a detailed analysis of clinic records and requested state mental hospital authorities to complete a questionnaire. Her purpose was to determine if public health nurses could be of value in follow-up programs. The results of the investigation showed that forty-eight identified needs of such patients were related to twenty-eight of the forty-four accepted functions of

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<sup>12</sup>Ilse S. Wolff, "Nursing Needs of Patients With Long-Term Illness," (unpublished report), (Connecticut: Department of Health), pp. 1-7.

the public health nurse. These needs affected the patient's readjustment and reintegration into the community. She concluded that there was a major role for the public health nurse in follow-up programs of discharged mental patients.<sup>13</sup>

An evaluation of public health nursing service to two hundred forty-five families of the mentally ill was made in Georgia by Beasley and Rhodes. Questionnaires were sent to thirty-nine public health nurses, and letters and reports were examined. Data indicated that nurses provided a variety of services such as, explaining the patients' illness and the meaning of his behavior, assisting in commitment procedures, referring families to agencies for help when needed, and visiting discharged patients to help them to adjust to the home situation. Many families were found who needed services other than the ones provided in relation to mental illness. As a result of the visiting by the public health nurse, the families appeared to be more accepting of the patients.<sup>14</sup>

#### Basis of the Problem

The previous studies have amply documented the complexi-

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<sup>13</sup>Ida Gelber, "An Investigation of Needs of Released Mental Patients on Tranquilizing Drugs in Relation to Recommending a Public Health Nursing Follow-Up Program" (abstract of unpublished Ed. D. Dissertation, New York University, 1957), Nursing Research, VIII (Spring, 1959), p. 109.

<sup>14</sup>Florence R. Beasley and William C. Rhodes, "An Evaluation of Public Health Nursing Service for Families of Mentally Ill," Nursing Outlook, IV (August, 1956), pp. 444-447.

ty and the importance of the family needs associated with chronic illness of a family member. Also, the contribution of the public health nurse in families with chronic illness has been explored. Since there has been no study of the needs of families in which tuberculosis occurred, the writer determined to make an investigation of families of this type. It was hoped that a study of this kind would provide further clarification of the stresses a group of families experienced as a result of tuberculosis.

## CHAPTER III

### METHODOLOGY

#### Selection and Description of Sample

Eleven wives of patients with tuberculosis were selected in two communities in southeastern Massachusetts. The distance between the two cities was about twenty miles. Both cities had a predominantly white population; the population of one was 83,835, and of the other, 62,820. Each city had one major industry at which many of the citizens were employed, ship building in one city, and shoe manufacturing in the other.

The initial step taken by the writer was an interview with the nursing director of a visiting nurse association which provided nursing service to tuberculosis patients, through a contractual agreement with the health department. At this time, the purpose of the study and the criteria for selecting families were explained. The criteria were: that the patient be male, that he be married with a family, and that he be either a patient in a hospital or have been discharged from the hospital within the past two years. The nursing director then discussed the proposed study with the health officer. A few days later, permission was granted for the writer to interview families, provided the families gave permission. This

permission was necessary because the diagnosis of tuberculosis was confidential information. Families meeting the criteria were selected by the director of the agency and visits were made by the public health nurses to obtain the families' permission. Six families were obtained from this community. However, when the writer telephoned to make an appointment for the interviews, one wife stated that her husband did not wish her to participate in the study.

The director of the public health nursing division in the health department of the second community was contacted by the writer and six respondents were selected. The only variation in the procedure in this community was that the families meeting the criteria were selected jointly by the nursing director and by the writer.

The eleven families had a total of thirty-two children; the number of children per family ranged from one to nine, with a median of two. Their ages ranged from ten months to thirty-six years, with a median of fifteen. Three families had married children living out of the home. The time from the patients' discharge from the hospital to the time of the interview ranged from one year and six months, to one patient who was still hospitalized. The median time since hospital discharge was six months. At the time of the interview, the working status of the eleven men was: six at work full time, one at work part time, one retired, two at home on partial rest, and one in the hospital. All the families had been

visited by a public health nurse. In four families at least one visit by the nurse had been made before the patient's hospitalization. In seven families the nurse visited only after hospitalization. Three families lived in single dwellings, seven in multiple dwelling houses, and one in a housing project.

All respondents were receptive to the interviewee. A great many asked questions about where the writer was studying, how did she like it, did all students have to do this, etc. In only one instance a respondent's husband asked, "You aren't from the city, are you?" When assured that this was not the case, he appeared more relaxed. All respondents appeared willingly to answer questions frankly and in detail. Some seemed to enjoy retelling their experiences and many times the difficulty was in terminating the interview rather than in obtaining information.

#### Tools Used to Collect Data

From the writer's experience and discussion with individuals in nursing and in sociology, the writer developed an interview schedule to procure the data and to insure that the same topics would be covered with each respondent. Questions were designed to provide information on the six questions that comprised the problem of the study.

The first respondent was a "try-out" for the interview schedule. All necessary data were obtained without difficulty from the first respondent. Consequently, no changes were made

in the interview schedule and the data of the first interview were included in the study.

#### Procurement of Data

Since all families had agreed to participate in the study, the writer telephoned each family and arranged definite times for the interview. All interviews were made in the family's home, between 9:00 A.M. and 5:30 P.M. Each interview lasted about one hour. Answers to the questions were jotted down briefly during the interview. A more detailed write-up was completed in the investigator's car just after leaving the immediate environs of the home.

## CHAPTER IV

### FINDINGS

#### Presentation and Discussion of Data

The data will be presented under the following major categories: difficulties of the patient, effects of the husbands' illness on the wives, effects of the fathers' illness on the children, financial difficulties, attitudes of relatives and neighbors, and the role of the public health nurse with these families.

#### Difficulties of the Patient

The initial pronouncement of tuberculosis may create violent shock, or at the other extreme, apparent apathy in patients. Because of this possible effect on learning the diagnosis, respondents were asked who informed them about the disease. Responses indicated eight patients were informed by their physician, one by a public health nurse, one by a nursing student, and one by friends at the suggestion of the physician. In the families where the physician was the informant, only one was dissatisfied:

The doctor called by 'phone Sunday night and told him. He was so shocked he didn't know what the doctor said. I called him back. We had a big argument because I didn't think he should have told my husband the way he did. He is an excellent doctor but very rude.

The patient who had been told by very close friends had been persuaded by them to see their physician. Later the physician called the friends and they mutually agreed that they could best inform the patient. This worked out satisfactorily.

In the family where the public health nurse was the informant, the wife commented:

This is the one thing that shouldn't have happened. She (the nurse) told me that he had it. Then I was so confused, I hoped she would go before my husband came home. He came in and she told him. She told him to use a separate face cloth and stay away from the family. If he had been with us before, what was the point of doing this for a few days? She should never have done this.

This respondent also stated that she was afraid that her husband might commit suicide after learning he had the disease. She called the family physician who stated that her husband did have tuberculosis. "I didn't understand either why he didn't call us."

The patient informed by a nursing student had been X-rayed on admission to a general hospital for surgery on his hand. The student came in to set up isolation technique and apparently in response to his questions told him his diagnosis. His wife, after visiting her husband that day, called her doctor who confirmed it. "It hurt him to learn this way."

These last two respondents appeared to object to the manner with which their husbands were informed about the diagnosis. Since both called their doctors to confirm the diagnosis, it was evident that families expected to receive this information from the physician. Difficulties in telling the

patient his diagnosis can be increased when this function is not recognized by nurses as being the physician's responsibility.

Methods for controlling the spread of any disease are dependent on knowledge of how the disease is caused and transmitted. Therefore, the wives were asked what they thought caused the disease in their husbands. Four respondents mentioned fatigue and over-work. Two stated that relatives had tuberculosis. Three "didn't know." One respondent said, "He might have got it in the service." The final response was, "He had bronchitis when he was a baby." The majority of respondents were vague about the cause of the disease and the last two responses indicated marked confusion.

Five patients returned to work for two days after learning the diagnosis. Six remained at home. None remained in bed and all continued to care for their personal needs. Since all the patients were admitted to the hospital within one week after the diagnosis and were put on complete bed rest, the question arises as to the reasons why complete bed rest did not begin at once. Reasons for this may have been that arrangements for hospitalization, provision for the families during the husbands' hospitalization, financial matters, and employment ties had to be taken care of. This may have been of sufficient importance to the patients' emotional equilibrium so that disadvantages, such as delayed treatment and the presence of an active tuberculosis patient in the community, might have

been outweighed.

Individuals accustomed to activity, to work, and to responsibility go through a period of adjustment before they can accept their dependence on others. Also, tuberculosis is a dangerous disease, and the diagnosis frequently evokes fear in the patient, and because it is long drawn out it may cause depression. However, a realistic acceptance of prologed care and a cooperative and hopeful outlook play an important role in recovery.

. . . there is almost universal agreement among physicians that the attitudes and feelings of the hospitalized patient are major contributing factors in treatment and prognosis.<sup>1</sup>

Respondents were asked about the patients' attitude during hospitalization. Responses varied from "wonderful" to "very low." Eight patients had favorable attitudes. Some of the comments were: "Wonderful, he was a morale builder," "Very good, he's very realistic." One response pointed to ambivalence of patient's outlook, "sometimes good, sometimes blue." One respondent said her husband's spirits were "very low and he was dying to get out." In summary, only one response indicated an attitude that might be classified as unfavorable.

Respondents were asked if they felt something more could have been done for their husband, when they were in the hospi-

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<sup>1</sup>Phineas J. Sparer, ed., Personality, Stress and Tuberculosis (New York: International Universities Press, 1956), p. 275.

tal. Nine participants reported satisfaction with his care. "Everything that could be done, was." "Excellent care, you couldn't get better care." One reply showed ambivalent feelings.

He had a good doctor. He was very honest and told us what to expect. Some of the doctors fool around and don't tell the patients the truth. There was a nurse who used to check bags to see if you brought food in. She was nasty.

One reply was unfavorable. "They thought he had TB on both lungs, then they found out only in one. This should have been done sooner."

To summarize, nine responses indicated satisfaction, one was pleased with her husband's physician but displeased with other physicians and with a nurse, and one reply indicated dissatisfaction about the patient's diagnosis.

After hospital discharge, patients may still need further treatment, and may still be on partial bed rest. There also may be many adjustments for the patient in intra-family relationships, in his physical limitations, or in his partial employment. At the time of the interview eight wives considered that their husbands were doing well since discharge from the hospital. One patient was still in the hospital. Two indicated some difficulty. "His scar still bothers him." "It's hard to say, he had a gastrectomy six months ago."

To the question of what changes respondents saw in their husbands since hospitalization, six referred to an improvement either in health habits or in physical condition. "He rests an hour every day and he eats well." "He is not as tired."

Two indicated that the patient was more nervous. "He's very nervous now." "He gets very nervous and cross, especially before his X-ray." Two reported that the husbands were more fatigued. "He tires easily." In summary, four replies indicated that the adjustment of patients after hospitalization may have been difficult, indicating a need for an understanding attitude in physicians and nurses and realistic instructions to the patient about his physical limitations.

#### The Effect of Husbands' Illness on Wives

Reactions of wives on day of hospitalization.--Extended hospitalization with its loneliness, social isolation, and its disruption of family life, is difficult for most patients to accept. When a husband is facing prolonged hospitalization, how does his wife feel? It was assumed by the writer that the actual day of hospitalization might be a critical period for wives, so respondents were asked whether they had accompanied their husbands to the hospital and how they felt after their return home. All the wives accompanied their husbands to the hospital. The predominant state of mind reported by all respondents on return from the hospital was that of being lonely, upset, and worried. Four also mentioned feeling sorry for their husbands. The most extreme degree of distress was indicated in the following remark: "I couldn't believe he had it. I thought they made a mistake and would find out he didn't have it. If my oldest son hadn't been here I would have collapsed."

Wives need someone to lean on during this difficult

period. Questions were asked about who was with them at that time, why they were with them, did having somebody with them help, and how it helped. Also, if no one was present, would they have liked somebody with them? Responses indicated that relatives or older children were present in seven instances, friends in three instances, and one woman was alone. Nine responses indicated that the reason relatives or friends were present was to drive the husband and wife to the hospital. One respondent said, "They came to help me." To the query of whether having somebody with them helped, eight responses were affirmative and two were negative. Of these two, one respondent whose mother-in-law was with her would have preferred her own mother; the other whose son was with her said, "I prefer to be alone when I am upset and crying." Responses to the question of how these people who were present assisted them, indicated that the eight who felt they were helped received a kind of emotional support. This was evidenced in the following remarks: "I talked to them and they helped me get over my loneliness," "I'm glad I wasn't alone, that I had someone of the family who felt as badly as I did," "I'd rather talk to him than any one if I have troubles." The respondent who was alone said, "I would have preferred to go to my oldest sister's house because there is always so much activity with her children there."

A responsibility of physicians, nurses and social workers is to assist the patient in the anxiety, confusion, and de-

pression experienced during the early stages of hospitalization. The possibility of extending this service to families of hospitalized patients was the reasoning behind the following question: "Would you have liked a professional person with you at that time (after hospitalization) and why?" All respondents replied in the negative. Some of the reasons given were: "You want someone close to you," "You want somebody that you know real well, anybody else would be too distant," "No, but they could have helped me when I was trying to get him into the hospital."

The data indicated that on the day of the husbands' hospitalization, the wives were anxious and upset. For help in handling these feelings, the greater number turned for support to their families or friends. This bears out a statement by Gerald Caplan when he speaks of the family "as a kind of emotional nest for the individual." He adds, "The sharing of the problems means that the other people understand what you've had to put up with and this understanding implies support."<sup>2</sup> This also points to the resources existing within some families to handle crises. Also, it indicates that when such resources exist, families may not feel the need for professional help.

Changes in wives' living pattern.--The prolonged illness

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<sup>2</sup>Gerald Caplan, Mental Health Aspects of Social Work in Public Health, Proceedings of an Institute (Berkeley: University of California, 1955), p. 49.

of a husband may cause wives to seek employment to supplement income or simply to keep themselves occupied. There may be a disruption in their usual recreational patterns. Respondents were asked how their lives had changed since their husbands' hospitalization. All respondents reported that visits to their husbands constituted the major change in their daily living. To the more specific question about changes that had occurred in their social life or recreation, all respondents again indicated that the hours spent visiting their husbands took up most of their spare time. One woman visited every day over a period of twenty-two months. Most of the wives visited five times a week. In two cases, the patients were in hospitals which were too great a distance to visit more than once or twice a week. All respondents except one had children at home to care for.

Only two wives changed their living quarters. Both moved into their parents' homes, one for companionship, and one for financial reasons.

Two respondents who had been working full time previous to their husbands' hospitalization continued to do so. One was employed in a factory, the other in a funeral parlor as a receptionist. Of the other nine participants, none of whom had been employed previous to the patients' illness, only one went to work and this was on a part-time basis, as a store clerk.

The liberal visiting policy of hospitals today is reflected in the data that visiting patients was the major change in respondents' lives. This liberality in visiting hours may

be evidence of increasing recognition by medical and allied professions of individual and family emotional needs, such as needs for companionship, affection, sharing of problems, etc. Of interest was the finding that eight of eleven wives did not supplement incomes by working. Two of these respondents were receiving Aid to Dependent Children. The other six were receiving help from the Veterans' Administration, or some, or all, of the husbands' salary was continued. Five of these six respondents had young children, and this undoubtedly was the major reason for their not working.

Medical follow-up.--In view of the shock and emotional upheaval that frequently occurs to the patient and the family when the diagnosis of tuberculosis is made, it was assumed that wives, because of their close relationship to their husbands, would experience some fear and worry about their own medical follow-up. Responses to this question indicated that two regarded their follow-up as important, as expressed in the statement, "I have always had X-rays. I think they are very important." Five respondents considered it routine. "It had to be done." "Just thought it was routine." Four expressed fear or nervousness, as evidenced in the following responses: "I thought for sure I had it since I had lost weight," "I was petrified," "I was frightened since I knew my husband's condition was so serious."

Respondents were informed about their own X-rays and medical follow-up by the public health nurse in five instances,

and by the physician in four. Two respondents stated they knew of the need for X-ray and took steps to obtain one before being advised of the necessity.

To determine if respondents still had areas of doubt or concern about tuberculosis, they were asked if they had any questions now (at the time of interview) about the disease. All respondents said no. Two respondents indicated they had received help from the public health nurse. "The visiting nurse answered a lot of my questions." "I always went to the (nurse's) office to ask them questions. They were the most help of all." One respondent pointed out that the patient's father had had the disease for two years and they had learned a great deal then. One said, "The doctor at the hospital answered all my questions, he was very good."

To summarize the preceding findings, only four respondents expressed anxiety or fear about their medical follow-up. That seven expressed a lack of apprehension was of interest, since some concern and fear would seem to be a normal reaction. However, this expression of concern by four respondents indicates the need of medical and nursing personnel to be sensitive to and supporting of individuals who may not be ill but are extremely worried. Diagnostic procedures, physical examinations, etc. may be frightening experiences and careful explanation of necessary procedures and an understanding manner by personnel are essential. That no respondents had questions concerning the disease might point to the fact that

information suitable for their needs had been available.

The Effects on Children of Fathers' Illness

Childrens' reactions to fathers' illness.--The effect of prolonged absence of the father on children may vary according to the age and developing stage of the child, previous father-child relationships, and the mother's response to the husband's illness.

All children old enough to understand were told about the father's illness, by both parents in four families, by the mother in six. One family had an infant. Children in three families whose age varied from four to eighteen had questions about his illness such as: "When is he coming back?" "How long will he stay in the hospital?" Children in the other seven families had no questions. Their ages varied from five years to beyond eighteen years. This finding seems questionable in view of the normal interest and curiosity of children. The question on this point invited an answer of yes or no, and a different wording of the question might have brought forth other information.

Perhaps the most serious effect of this illness on a child was the case of a five year old child who was diagnosed as having active tuberculosis three weeks after her father was hospitalized. She was admitted almost immediately to a children's sanatorium, and at the time of the interview had been in the hospital one year. She had shown considerable improvement, and the mother in general seemed optimistic about

her condition,

Responses to the questions of how the fathers' absence affected the children and their subsequent changes in behavior indicated wide variation. Six participants did not feel that the children were affected adversely, as evidenced in the following comments: "My son grew up more and assumed responsibility," "They seemed to understand. They knew he was sick." One respondent, while indicating difficulty with her children, did not relate it to the illness. She said, "They weren't affected by it. I have crazy kids anyway. They are hard to manage and very active." Four participants indicated adverse reactions. One felt that her sixteen year old daughter took it hard because of the close relationship she had with her father. Another stated that her six year old son developed the habit of sucking on his collar and appeared more nervous and jumpy. In one family the four children "played less, had less pep, and were less relaxed." The fourteen year old girl stopped going to her school dances. The fifteen year old boy stopped playing basketball. The mother stated that "they stayed close to me" and she indicated to the interviewer that she considered this a good thing. Another respondent with sons fifteen and eighteen, said that they were harder to manage and after awhile rebelled against having to visit their father so often. This respondent had thought she would collapse after her husband was hospitalized if her oldest son had not been there. Noteworthy in the last two cases mentioned was some

evidence of the mother looking to the children for help. In a study of the psychological effects on children of the 1953 Vicksburg tornado, it was found that a statistical association seemed to exist between the childrens' experience with a type of parental relationship and later emotional disturbance. They called this relationship "dissociative-demanding" when the parent demanded attention and support from the child, and the child had to look after his parent.<sup>3</sup>

Responses to the question of how the father kept in touch with the children showed that children in all families visited the hospital or the father visited the home. There was no instance in which the father had not seen his children during hospitalization. Frequently, depending on his stage of recovery, he saw the children only through a hospital window. Children in three families wrote letters in addition to visiting.

To summarize the above findings, all the children capable of understanding were informed of the illness, by both parents in four families, and by the mother in six. Children in three families had questions about the father's absence. One five year old developed active tuberculosis. In four families children indicated some emotional distress: nervousness, depression, less sociability, and rebellion. All

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<sup>3</sup>Steward E. Perry, Earle Silver, M. D., and Donald Black, M.D., The Child and His Family in Disaster: A Study of the 1953 Vicksburg Tornado, (Washington: National Research Council, 1956), p. 31.

children were able to see their fathers during his illness.

More information about the degree of disturbance of the aforementioned children would have to be obtained before determining if and how they might have been helped. However, the functions of the public health nurse to lend emotional support, to make available resources known to families, and to provide health guidance, would appear to correlate with these needs. Nursery schools, or a child guidance clinic, might have been of assistance. Perhaps a greater understanding in the mothers of developmental needs of children also would have been valuable.

Medical follow-up of children.--Information about the children's X-rays and medical follow-up was given by the public health nurse in six families, by the physician in three. One respondent reported that her children, all over eighteen years of age, were aware of the necessary supervision before any professional person informed them. Another respondent contacted the public health nurse, "I called to have them come down and put a patch on her (the child)." Evident in the above findings was the activity of the public health nurse, in case findings, health teaching, and carrying out diagnostic procedures.

When participants were asked how they felt about the children's need for follow-up, eight considered it important and/or routine. "I thought he (the baby) was OK." "I thought it was necessary." Three expressed fear or concern. "I was worried." One of these, the mother of the child found to have

active tuberculosis, said, "I wanted it done but I got a heck of a shock when Cathy had it." Attitudes of these respondents were similar to those expressed about their own X-rays.

#### Financial Needs

A major burden of chronic illness of the breadwinner is the loss of all, or part, of his income and the expense of medical and hospital care. There may be a need for financial assistance and careful management of the reduced income.

Financial assistance.--Respondents were asked if they were receiving financial help, from whom they were receiving it, and, if it was from an agency, how they had gotten in touch with the agency. Financial assistance was received from the following sources, for the following number of families: Veterans Disability -- five families; Aid to Dependent Children -- two families; Social Security Disability -- one family. Full or part salary continued in three families. Agencies were contacted for assistance by wives in four instances, and by husbands in four. In the three families where the salary continued, these arrangements were made by the husband.

Three of the four wives who contacted an agency for financial assistance expressed difficulties. One woman sought aid from the Veterans Administration. She said, "They are supposed to help you and they act just the opposite." When she tried to get an increase in the amount given her she commented, "They practically called me a liar." The second

participant contacted Aid to Dependent Children. The amount given her was insufficient to live on and she discussed this with her parish priest. He contacted the social worker at Aid to Dependent Children and the amount was increased. The third wife also had sought assistance from Aid to Dependent Children and was refused assistance because of a three hundred dollar savings account and her ownership of an automobile. "They were the coldest people I've ever met in my life." This woman felt that her car was an essential in order to visit both her husband and her five year old child. The child was in a tuberculosis hospital at some distance from the father. After an eight month period and three refusals, there was a bus strike in the community. The agency then deemed the car essential and provided aid. The family had managed up to this time by moving in with the wife's parents and by accepting financial help from the wife's brother. The above difficulties were expressed spontaneously by these three women since no question concerning this was included in the schedule. This confusion may have arisen because agencies providing financial assistance are limited by policy, and frequently by law. Also, the necessary investigation process may have been a new and perhaps threatening experience for many applicants. Expectations concerning the amount of aid may also have been unrealistic.

Management of finances, especially in cases of reduced income, may be the major factor in determining if family needs

will be met. Respondents were asked who usually handled finances in the home, who was taking care of them now, and what were their feelings and difficulties? Six respondents had always managed family income and felt that it was no problem. Two of the three who had managed finances jointly with the husband, prior to his hospitalization, expressed a dislike for doing it alone. Their comments were: "The burden fell on me," "I didn't like the responsibility." In two families where husbands had been the sole manager, one respondent felt that she did a better job than her husband; the other did not like the responsibility. To summarize, three participants expressed some reluctance or dislike of the management of family income. Assistance from the public health nurse, by suggestions concerning budgeting principles and low cost nutritious foods might have been of value to them. Also, current literature on this subject and the services of a nutritionist, if available, might have lessened the wives' difficulties.

None of the eleven families received a hospital bill. Four had insurance that paid part of the bill. Others received free hospitalization in tax supported hospitals. Four wives discussed their difficulties concerning hospital bills with hospital social workers. One wife kept in touch with a friend in the Veterans Administration who had helped her arrange for her husband's hospitalization.

#### Attitudes of Relatives and Neighbors

The communicability of tuberculosis can cause concern to

those who have been in close contact with the patient. Their anxieties may produce strained relationships. Frequently, patients and their families may feel like social outcasts because of this fear of the disease. Questions about the attitudes of the people who made up the respondents' social environment were asked. In four instances, the wives' parents were deceased. Five participants indicated that their parents were concerned and were helpful, especially in caring for the children and driving them to the hospital. "My mother is used to heartaches. She took it well and tried to help." "They were shocked and felt badly. They helped me a lot." The tenth respondent said, "My mother never said anything." The final respondent remarked, "Sometimes they were sympathetic, but sometimes they blamed me for marrying my husband when I knew there was tuberculosis in his family."

The parents of the husband in six families were deceased. There was no contact with them in another. Three respondents indicated parental attitudes of deep concern. "His mother, who was very ill, cried when she heard the news." "They felt awfully bad and blue. They visited him every day." The most extreme degree of distress was evident in the following statement:

His father was in the hospital (with tuberculosis). He thought that he had given my husband the disease. Actually, it killed him. He was quite upset. He died two months after my husband was in the hospital (the same hospital). My husband wasn't with him. He was in another ward.

The final respondent said, "His father accepted it but

his mother sometimes acted as if she might catch it."

In six families, neighbors inquired about the patients' condition. Three of these offered assistance, either in taking care of the children, or in driving the respondent to the hospital. One of these had her children X-rayed at the respondent's suggestion, and a fairly close relationship continued between them. Four reported that they either did not know their neighbors or were not involved with them. Only one indicated strained relationships with her neighbors.

One neighbor saw the nurse come with the sign on the car and she hollered out the window to ask me if she could do anything. This made my husband and I mad. I didn't tell her (about husband's illness) until a long time after.

To summarize, the predominant attitude of the majority of the parents and the neighbors appeared to be interest and concern for the patient and the family. Of interest was that five participants mentioned their own parents as offering help. This was not mentioned about the husband's parents. Only one parent, a husband's mother, showed fear of the disease. One respondent's parents had a blaming attitude. Respondents' comments concerning attitudes of husbands' parents indicated rather severe reaction in three of the four cases. This finding underscored the emotional and perhaps physical effects of the diagnosis of tuberculosis on families as well as on the individual.

#### The Role of the Public Health Nurse

Public health nurses frequently plan home visits as soon

as possible after the diagnosis, since the reaction by the patient to the diagnosis of tuberculosis may be one of emotional disturbance. Also, the patient may need nursing care and information about the disease. Four families were visited prior to hospitalization by the public health nurse, seven after hospitalization. Four respondents replied to the question of who sent the nurse by stating they did not know. Three reported that she was sent by the "city." Two mentioned "the hospital" and two the "health center." Only five of these respondents indicated some understanding of the public health nursing agency in their communities.

When asked what the public health nurse did on her visits, eight stated that she gave them information about the disease and/or X-rays. "She told us about X-rays." "She took a case history and advised me not to over-do." "She explained about the disease. When I (the wife) was sick she came every day and also talked to my husband about me. He was very concerned." Of these eight, one participant expressed some dissatisfaction: "She talked about mattresses and how long he was sick. I felt she was negligent about making appointments. I called for my own X-ray appointments." The final three respondents gave a variety of answers. One said, "She asked about my husband." Another stated, "She told me my husband had tuberculosis." The last respondent understood that the nurse came only to see her new born infant. She said, "She talked about the baby." The public health nurse was still visiting

in three homes at the time of the interview. "She visits occasionally and asks how things are going." In eight homes she was no longer visiting.

To summarize the above findings, four families were visited by the public health nurse prior to the husband's hospitalization, seven after hospitalization. Five responses indicated awareness of the agency in their community responsible for public health nursing service. The predominant concept of what the nurse did on her visits was that of giving advice and instruction.

Throughout many of the interviews there was evidence of the contribution of the public health nurse. This can be seen in the comments of respondents that were made, without specific questions being asked. One participant said, "She helped me get my baby straightened out." This remark was in reference to the infant's feeding and sleeping schedule. Another comment was, "The nurse always came by to tell us our X-rays were O.K." Another respondent said, "The visiting nurse answered a lot of my questions. She came once or twice a month. She dropped in to see if I needed anything." In the following two statements were evidence of the public health nurse making an adjustment to an individual situation and making referrals for continued nursing service: "She came to see me on Saturday since I work every week day. After I moved from Braintree, the nurse in this city came to see me." Another respondent said, "The nurse still comes by occasionally. She asks how things are going and

if we are all still having X-rays."

By assistance with child care, by informing individuals of X-ray reports, by answering questions, by adjusting her visits to the family's pattern, by referral for continued nursing service, the public health nurse appears to have provided necessary and valuable service to these families.

Of interest were the similarities of some of the findings in this study and those reported in the literature. Financial problems appeared to be a very common difficulty of families with chronic illness. Funds were inadequate, or there were problems associated with management of income. Also, some wives supplemented their income by working. Another similarity noted was the helpfulness of the parents of the wife, especially in caring for the children. This was not a finding of the parents of the husband. Of interest also was the fact that a change or a lack of social activities was not a difficulty to the women. Their lives apparently continued to be active, perhaps because of outside employment, the care of their children, or visiting their husbands. Another finding that was noteworthy was the maladjustment of some children as a result of the absence of the father. Various types of behavior difficulties appeared to be the result such as, resistance to the mother's authority, emotional depression, and/or the development of nervous habits. Also, there appeared to be a difficult period of adjustment for some patients after their return to the family.

While there was evidence of similarities in findings, there was also evidence that a particular chronic illness may evoke particular difficulties. For example, the mothers tried to conceal the illness from their younger children when the husband was mentally ill. This was not evidenced in this study when tuberculosis was the problem.

Throughout all the studies are findings pointing out the numerous effects on the family as a result of chronic illness. Adults and children alike feel its burden and all must make adjustments of varying kinds. The ease with which the adjustment is made can be and frequently is facilitated by the activities of the public health nurse.

## CHAPTER V

### SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

#### Summary

The prevalence of chronic disease in the population is estimated at such magnitude that it has become one of the leading health problems. Also, chronic illness has serious effects on the family unit such as, financial burdens and readjustment of individual lives. This study was an investigation of a group of families in which the breadwinner had experienced a common chronic disease. Its aim was to investigate the difficulties of the patient, the effect of the illness on wives and children, the financial difficulties incurred, the attitudes of relatives and neighbors, and the role of the public health nurse. Eleven wives whose husbands had been hospitalized within the past three years were interviewed, using an interview schedule. Cases were obtained by contacting the Director of a visiting nurse association in one city and the Director of public health nursing in the health department in the other city.

The literature, especially two studies, one of an urban and one of a rural community, clearly documented the scope of the problem and the needs for care of this group. Studies that

investigated the effects of stresses, including chronic illness on the family, underscored the problems that may be created by chronic illness to families. Studies of public health nursing service in chronic illness revealed that public health nurses provided a great deal of assistance to families with chronic illness. For example, they provided nursing care to the patient and also assisted in his rehabilitation process, and aided families in their adjustment to the illness.

The criteria for the selection of families in this study were that the patient be male, that he be married with a family, and that he either be a patient in a hospital, or have been discharged from the hospital within the past two years.

The results of this investigation revealed that the difficulties of the patient evolved around the diagnosis, the continued activity of the patients after the diagnosis, the patients' attitudes and care during hospitalization, and the patients' adjustment after hospital discharge. The effects of the husbands' illness on the wives were feelings of loneliness after the husbands' hospitalization, and the need for emotional support from their families and/or close friends on the day of the husbands' hospitalization. The free time of the wives was consumed with visiting the husbands. Anxiety and fear were expressed by some wives about their X-rays and medical follow-up. There was a lack of questions concerning the disease on the part of the wives at the time of the interview. The effects of the fathers' illness on children were as follows:

all children were informed of the illness by parents, some had questions about it; one five year old developed active tuberculosis; some indicated emotional distress such as nervous habits, less sociability, and rebellion against authority; and all children were able to see their fathers during the illness. The attitudes of some respondents toward the childrens' X-rays and medical follow-up indicated concern and anxiety. Financial difficulties as a result of the illness were the necessity of receiving financial aid from various sources, difficulties in procuring aid, and management of income. No family received a hospital bill. The predominant attitude of the majority of relatives and neighbors appeared to be interest and concern; only one husband's parent indicated fear of the disease. Wives' parents were more helpful to the families; however, husbands' parents appeared more deeply concerned about the patient. The role of the public health nurse appeared to be that of giving advice and instruction, and there was much evidence of families receiving assistance from the nurse. There was a lack of awareness of some respondents concerning the agency in their community responsible for public health nursing service.

#### Conclusions

The findings indicate the complexity of needs of families created by chronic illness. Patients need assistance in accepting their diagnosis. They also need assistance with arrangements for such matters as income for the family, so that

bed rest and care may begin for the patient as soon as possible after the diagnosis. Visits to families by the public health nurse should be made as soon as possible after the diagnosis to assist the family with these arrangements and to provide information concerning the communicability of the disease and methods of preventing its spread to others. Since there is frequently a long period of medical care and supervision after hospital discharge, and there are many adjustments to be made by the patient and the family, the needs of each patient and his family should be evaluated by the public health nurse. Her emotional support and health guidance may be of assistance at this time.

Public health nurses and all personnel in the allied professions must remain sensitive to the fears and anxieties of individuals concerning medical examinations and medical and nursing procedures. Reassurance and an understanding manner and explanation of treatments and procedures may do a great deal to relieve this apprehension. The responsibility for informing individuals about needed follow-up and the resources available in the community for this care is a joint one shared by nurses and physicians. There was much evidence in the study to indicate that individual needs for this type of information are met when both groups mutually carry out this activity.

That a child in a family was found to have tuberculosis only stressed the necessity of X-ray and medical follow-up of contacts of tuberculosis patients. The adverse reactions in

some of the children as a result of parental illness revealed their needs and those of the mother for assistance. The public health nurse should be alert to such needs on her visits and can make community resources, such as a Family Service Association, known to mothers. Also, the nurses' continued emotional support and instruction concerning the needs of children at the various developmental stages might prove of benefit to a parent.

No serious deprivation was evidenced by inadequate income in these families. The difficulties centered around the manner in which respondents felt they were treated or the amount of aid received. Frequently, the public health nurse because of her close relationships with families provides emotional support by the simple process of listening to their difficulties about finances. Occasionally, she may discuss the situation with the particular agency personnel if the family are either unable to or request her to. Some participants expressed dislike of or difficulty with management of their finances. Through her knowledge of budgeting principles and low cost nutritious foods, the public health nurse can frequently provide help to such individuals.

Negative attitudes on the part of those who make up the family's social environment were markedly absent. Only one parent showed fear of the disease. Health education programs and the marked drop in the tuberculosis death rate within the past fifty years undoubtedly account for the lessening fear of

tuberculosis.

The lack of awareness of the agency in the community responsible for public health nursing service reveals needs for increased knowledge of community agencies. Public health nurses by their discussion to individuals and groups can aid this. Also, programs on radio and television and public displays concerning public health nursing service must be continued and perhaps extended.

#### Recommendations

On the basis of the findings of this study, the following recommendations for further study are made:

1. That a similar study with a larger sampling be done to confirm the findings
2. That a similar study of families with other chronic diseases be made to supplement the findings.

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APPENDIX

QUESTIONNAIRE

1. What date was your husband hospitalized?
2. How many children do you have? Boys \_\_\_\_\_ Girls \_\_\_\_\_
3. What are their ages?

PERSONAL REACTION OF WIFE

Now I wonder if you would try to recall what happened to you or how you felt the day your husband was admitted to the hospital.

4. Did you accompany him?
5. How did you feel after he left or when you returned home?

Could you explain further?

Could you give me an example?

Anything else?

6. Was there an adult here with you the day your husband was hospitalized?
  - a. If yes, who?
  - b. Were they here for any particular reason?  
What?

c. Do you feel that having somebody here helped in any way?

How?

Could you explain further?

d. (If answer to question 3 is no) Would you have liked somebody to be here?

e. You say.....could you tell me why?

f. Would you have liked a professional person with you that day?

b. You say.....could you tell me why?

7. Can you tell me how your life has changed since your husband was hospitalized?

a. Are you working?

b. Is it full time, or what?

c. Were you working before your husband's illness?

d. Now, about your social life or recreation; has there been any change in this?

How?

Could you explain further?

Anything else?

8. Now, about your medical check up and X-ray, did anybody talk to you about it?

Anybody else?

9. How do you feel about this X-ray and medical check-up?

You say.....could you explain?

10. Did the nurse come to see you before or after your husband was hospitalized?

Who sent her?

What did she do?

Is she still coming?

HUSBAND'S ILLNESS

11. How do you think your husband is doing now?

a. Do you see any change in him?

What?

Do you mean?

Could you explain further?

b. Do you feel that there is something more that could

be done for your husband?

What, for example?

You mean?

Anything else?

c. In general, how would you say your husband's spirits are?

You say.....would you explain?

12. What do you think caused this illness?

Do you mean?

Anything else?

13. How did your parents feel about his illness?

Do you mean?

Anything else?

14. How did his parents feel about his illness?

Do you mean?

Anything else?

15. About your neighbors, did they concern you in any way?

How?

You say.....do you mean?

16. After your husband knew he had the disease, who talked to you about it; the cause, how to take care of it, etc.?

Anybody else?

a. Do you still have any questions about it?

What, for example?

17. What care did your husband have to have before he was hospitalized?

a. Did he continue to work?

b. If not, was he confined to bed?

c. If care was given, who gave it to him?

Anybody else?

d. (If wife gave care) Who taught you?

e. (If wife gave care) How do you feel you managed?

CHILDREN

18. Now, about the children; do they know about their father

being in the hospital?

a. Who told them about it?

b. Do they have questions about it?

What, for example?

c. How do you feel it has affected them?

You say.....would you give me an example?

Anything else?

d. Was there any change in their behavior?

Could you explain?

e. Is your husband able to keep in touch with them?

How?

f. Do the children write to him?

19. Now, about the children's check-up; who told you about it?

Anybody else?

a. How do you feel about this check-up?

You say.....would you explain?

FINANCES

20. Who usually handled money matters in your home?

21. Are you taking care of them now or how have you worked this out?

Could you explain further?

- a. How do you feel about this arrangement?

Could you explain further?

- b. Are you having any difficulties now?

What, for example?

22. How have you been able to meet the extra expense of hospitalization?

- a. Are you getting any financial help?

- b. (If yes) From whom?

Anybody else?

- c. (If an agency) How did you get in touch with them?

23. Were you able to talk to anybody about some of these difficulties?

- a. Who?

- b. Anybody else?