TO CONSIDER THE RESOURCES NEEDED FOR THE CARE OF CHRONICALLY ILL. A STUDY WAS CONDUCTED OF CHRONICALLY ILL PERSONS ADMITTED TO THE PUBLIC WARDS OF THE VICTORIA GENERAL HOSPITAL FROM THE METROPOLITAN AREA OF HALIFAX DURING A SIX-WEEK PERIOD FROM JANUARY 21, 1957 TO FEBRUARY 28, 1957.

by by

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CONTRACTOR OF THE SPECIAL CONTRACTOR OF THE SECOND An original research project submitted to the Faculty of the Maritime School of Social Work in partial fulfillment of the requirements for a Master of Social Work Degree ......

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May 7, 1957 Halifax, N.S.

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# CHAPTER 1

#### INTRODUCTION

Since the time of Hippocrates, there have been untold thousands of outstanding men in the field of medicine.

Discoveries of all sorts have been the results of attempts to prevent and cure sickness. Nearly all these discoveries, however, have been directed toward the prevention and treatment of acute illnesses because they were such an obvious threat to people's lives. Chronic illness flourished during that time, and today it stands as a major health problem.

During the last few years more attention has been given to the problem of chronic illness. Surveys of all kinds have been made on it in an attempt to cope with the problem.

Planning for the chronically ill gained momentum during the second quarter of this century, and by mid-century had reached substantial proportions.

In keeping with the general trend, the seven secondyear students at the Maritime School of Social Work, after
much discussion, decided to conduct their own survey on
chronic illness. The reason this group chose the topic of
chronic illness for their research project was not that they
thought they could make revolutionary discoveries, but
simply that they wanted to contribute to the work that was
already being done.

Once the topic had been chosen and the limits of the survey established, these students organized an original schedule to guide them in their study. It was not an easy task since it was their first experience in research. After much time had been spent on establishing the schedule, a pre-test was made with chronically ill people at the Victoria General Hospital. As a result of this pre-test it was realized that many questions were not worded properly. A revised schedule was then made.

On January 21st, the students began their study at the Victoria General Hospital. They interviewed only those chronically ill patients who were admitted to the public wards during the six-week period from January 21st to February 28th, 1957 and who were residents of the metropolitan area of Halifax. A face sheet<sup>2</sup> had been drawn at the same time as the schedule, which the Social Service Department of the Victoria General Hospital used to give factual data of each chronically ill person who was to be interviewed by the students. After the six-week period was over and the interviewing of chronically ill people was completed, each student tabulated his own findings from the number of people he had interviewed. Then, as a group, this body of students collected, tabulated and studied the statistics shown in the following chapters. Upon the

lsee Appendix

<sup>2</sup> Ibid.

findings of two sources — interviews with the chronically ill people and the reading done on chronic illness — each member of the group wrote his or her own interpretation, as this writer did.

The initial abstract arrived at by the students reads as follows: "To consider the resources needed for the care of the chronically ill, a study was conducted of chronically ill persons admitted to the public wards of the Victoria General Hospital from the metropolitan area of Halifax during a six-week period from January 21st to February 28th, 1957."

It can be seen that the purpose of this study is to find out what are the resources needed for the care of the chronically ill in the metropolitan area of Halifax. In order to find this out, the group had to consider the social, medical and economic aspects of the lives of the chronically ill being interviewed. Thus, questions relative to these three aspects were included in the schedule.

There are four points in the abstract which limited and helped to select the sample on which this survey was conducted. First of all, only the chronically ill residing in the metropolitan area of Halifaxl were considered. Second, only the chronically ill being treated in the Victoria General Hospital were interviewed. Third, only those chronically ill admitted to the public wards were approached and fourth, the survey was carried out during

lsee Appendix, List of Communities - Metropolitan Area

a limited period of time - six weeks. There were many reasons for having these limiting factors. Because of the fact that sick people sometimes migrate to urban settings to be closer to medical facilities, and the metropolitan area of Halifax is quite heavily populated, it was felt that a good sample could be obtained by considering people from that area only. It was felt also that, since the Victoria General Hospital is the largest hospital in Halifax, the group of students would find a good number of chronically ill people there. Hospital authorities assured the group of this. Since many chronically ill are found in the low-income group, there was a greater chance of having a better sample by interviewing only the patients admitted to the public wards. Furthermore, patients on public wards are often those whose needs are greater. Finally, there was a time factor involved. The group making this survey was a group of students, and the reports on the survey had to be completed by a given date.

Because of these limiting factors, a cross-section of all chronically ill was not available. Only the chronically ill persons were interviewed in this survey. Doctors and other people working with these sick persons were not approached with regard to determining the resources needed by the chronically ill. Thus, the results of the present survey are based only on the answers given by the chronically ill people and, in some instances, on the interviewers' opinions. When the students tabulated and studied the

findings they found that many important aspects of the life of the chronically ill had not been included in the prepration of the schedule. For example, there were no questions about the living conditions at home, and the number of dependents. Furthermore, the chronically ill were always interviewed shortly after their admission to the hospital. At that point many were very sick and emotionally upset, and this might have had a bearing on the answers they gave to the questions from the schedule. Whether or not the emotional reaction of the patients influenced their answers is not known, but it is quite possible.

From January 21st to February 28th, 1957 there were 389 admissions to the public wards of the Victoria General Hospital from the metropolitan area of Halifax. Of that number of admissions, 43.9 per cent or 171 persons were chronically ill. The hospital authorities stated that there were many chronically ill on the public wards, especially during the winter months, and the percentage of chronically ill who were admitted to the public wards during the study period definitely proves their statement. Of the 171 chronically ill persons admitted to the public wards, 39 did not participate for one reason or another. Therefore, 77.2 per cent or 132 chronically ill actually participated in the present survey. This total of 132 chronically ill will be the one this writer will consider throughout the following chapters.

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TABLE 1
Non-participating chronically ill persons

Reasons for not participating	Total	Male	Female
Total	39	17	22
Discharged	6	4	2
Too sick	10	3	7
Language barrier	2	0	2
Refused	14	5	9
Senility	3	2	1
Died	2	1	1
Transferred to private room	2	2	0

As shown in Table 1, 15.4 per cent of those who did not participate were discharged before they could be interviewed. Out of the 39 who did not participate, 36 per cent refused. Considered on the basis of the total admission of 171, 8.2 per cent refused to participate. It also must be added that four of the fourteen chronically ill who refused to participate were actually private patients who were on the public wards because there were no private rooms for them at the time of admission.

There is no widely accepted definition of chronic illness. All definitions, however, agree on several points: chronic illnesses develop slowly; in many cases the patient is incapacitated, and long term treatment is always needed. In a survey made by the Milwaukee County Council of Social

Agencies, chronic disease is defined as follows: "A chronically ill person is one of any age who has been or is expected to be incapacitated by persistent or recurrent disease for a period of at least three months." The writer, however, prefers the definition given by Morton L. Levin, M.D. He says that chronic disease is a disease "which is not self-limited in duration by its nature, such as measles or pneumonia or a broken leg, but persists either as a continuous process or by producing permanent, long-term, or recurrent durability or impairment of health."

Until quite recently, the physical needs of the sick person were the only ones which received any consideration.

Today, however, the picture is quite different. There is a growing trend to look upon the sick person as an individual and as a whole person. More and more, doctors and other people working with sick people are coming to perceive their emotional, spiritual, social and intellectual needs, as well as the physical, and also the relationships between them.

The search for knowledge is increased by sensitivity to needs and today our perception of need and our expectation of meeting it have changed. Need itself has not changed so much. The fundamental needs of the twentieth century man are not too different from those of a man living in previous centuries.

in Nova Scotia under the Federal Health Survey Grant, 1949 (Halifax: The Department of Public Health), Section 8, p. 89.

Morton L. Levin, "National Planning for Chronic Disease Control, "Social Work in the Current Scene 1950 (New York: Columbia University Press), p. 107.

What is different is the way needs are looked at, the ones which are looked at, and the manner in which efforts are made to meet them.

In order to be able to understand and meet all of a person's needs, it is necessary to consider their various aspects. Keeping this in mind, the writer has decided to deal with the statistical information of this survey in the following way. Chapter II will consider the social aspects of chronic illness, Chapter III the health and welfare aspects, and Chapter IV the economic aspects. A general introduction is given at the beginning of these chapters in order to give the reader a fuller understanding of the whole picture. Finally, Chapter V gives the conclusions and recommendations which have been drawn from this survey.

a social worker, the focus throughout this report will be on the social work aspects as they are related to the needs of the chronically ill. In other words, what are the resources needed by the chronically ill and what can social workers do to help these sick people? As a social worker, the writer has no competence to make comments other than those related to social work. It is true that the medical and ecomomic aspects of chronic illness have been included in this survey, but the writer will discuss these only in as much as they are related to social work. One would expect a doctor or a nurse to put the emphasis on the medical aspects in a survey like this one. An economist would focus

his report on the economic aspects. A social worker, however, still can consider these different factors but only as they are related to the problems his training has prepared him to deal with. In the body of this report the writer will occasionally make brief allusions only to the social work resources needed by the chronically ill persons. In the last chapter, there will be a more detailed discussion of the resources needed, and the writer will make only those recommendations that he is justified to make as a social worker.

#### CHAPTER II

#### SOCIAL ASPECTS

#### Age

Even today there is a common notion that chronic illness is to be found mostly in the aged. Only a decade or so ago the terms "chronic illness" and "old age" were used interchangeably. The reason for this lies in the fact that, in recent decades, great discoveries in the field of medicine have conquered many acute diseases which formerly were killers and thus increased the average life span by twenty years.

In 1901, the life expectancy of white males was 49 years in the United States. In 1941 it was 67 years. But long life is not always an unmitigated blessing, since a person rarely reaches the age of 65 without some symptoms of chronic disease, illness, or physical or mental deterioration.

Vital statistics show us that there has been a marked decrease in the birth rate and death rate during the past few years. It, therefore, is not difficult to understand why there is a greater number of older people in our midst.

The older a person is, the greater are his chances of becoming ill and also of suffering from a chronic illness.

Henry Kessler, Rehabilitation of the Physically Handicapped (New York: Columbia University Press, 1947), p. 88.

The process of aging is an inexorable one. As people get older most of their body functions slow down their activity. This lessens older people's resistance to various illnesses. Certainly, most of us have seen people who, despite the passage of years, retain their physical vigor and mental faculties to a surprising degree, while others, at a much earlier age, are old both in body and in mind. But on the whole, the general belief still exists that chronic illnesses occur mostly in older people. This belief is not altogether true, however, because chronic illness occurs in all age groups and not just among the elderly. In recent years many surveys have been made on chronic illness in United States and Canada. According to the data of all the surveys made in the United States.

Actually the amount of chronic illness among persons under 65 years of age is far greater than that among those over 65 — because even a substantially lower rate in the 91.5 per cent of the population who are under 65 years of age means more total illness than does the higher rate among the 8.5 per cent of the population over 65.

The Commission on Chronic Illness in the United States gives the following figures in regard to age:
"...One case out of every six involves a person under twenty-five, and one out of every two involves a person under forty-five."

This certainly proves that chronic

Lester Breslow, "Chronic Illness, "Social Work Year Book, (New York: National Association of Social Workers, 1957), p. 159.

Herbert Yahraes, Something Can Be Done About Chronic Illness (New York: Public Affairs Committee, Inc., 1951), p. 4.

illness is not just the lot of elderly people but that any person, regardless of his age, can suffer from it.

The following is some data obtained from the survey made in the Victoria General Hospital.

TABLE 2
Ages of chronically ill persons interviewed

Ages	Total	Male	Female
Total	132	75	57
16 - 25	12	7	5
26 - 35	15	10	5
36 - 45	10	. 7	3
46 - 55	30	12	18
56 - 65	30	19	11
66 - 75	19	12	7
75 and over	16	8	8

Out of 132 persons who were interviewed on the public wards of the Victoria General Hospital, 16.5 per cent were over sixty-five years of age. This means that the majority of the chronically ill interviewed were under sixty-five. It is interesting to note that 45.4 per cent of the chronically ill interviewed were between the ages of forty-six and sixty-five. It would seem, according to this survey, that chronic illness occurs chiefly in middle-aged people. This might be due to the fact that chronic illness usually begins insidiously, that is, the person affected becomes aware of

symptoms only gradually and after the condition has progressed to a considerable degree. Before pain or other distress attract attention to the disease, very often the underlying disease process has caused some kind of alteration of bodily structure and functions. This is true of most forms of heart disease, cancer, diabetes, arthritis, and many other important chronic conditions.

As far as age is concerned, the findings of this survey are definitely in accord with the data obtained in other surveys made on chronic illness. Even though 45.4 per cent of the chronically ill interviewed in this survey were between forty-six and sixty-five years of age, it also must be said that 28.1 per cent, or a little more than a quarter were under forty-five years of age, which shows that chronic illness can and does occur in relatively young people. Thus, since chronic illness may attack anyone, all should be concerned with fighting it.

These findings are also very important from a social work point of view. Social workers might have a tendency to direct their services toward helping the elderly chronically ill persons only, when actually people of all age groups need and should benefit from such services. This will be discussed in greater detail in the final chapter.

#### Marital Status

Table 3 shows that seventy-one out of 132, or 53.8 per cent of the chronically ill interviewed were married.

Nearly two-thirds of these married persons were men and

slightly more than one-third were women.

TABLE 3

Marital Status of chronically ill persons interviewed

Marital Status	Total	Male	Female
Total	132	75	57
Single	28	21	7
Married	71	44	27
Widowed	24	6	18
Separated	9	4	5
Divorced	0	0	0

These findings are interesting especially from a social work point of view. Chronic illness very often causes extended disability or at least impairment of the person's capacity to carry on the kind of activities that he performed before becoming ill. For anybody, to be unable to provide for himself or for his dependents is a traumatic experience. First, let us consider the individual himself, whether he be married or single. What does it mean to a person to become incapacitated? For years, perhaps, he was able to say that he was independent, self-sufficient, and in some cases he was proud of being able to provide adequately for his family. All of a sudden he finds that he is no longer able to do this. Besides not being self-sufficient any longer, he is now also dependent on someone else for support. Sometimes, this sense of being dependent on others is probably more

upsetting emotionally to the chronically ill person than the fact that he cannot provide for himself or his family. Our society places a great value on independence. Thus, our culture is such that it causes the person who suddenly becomes dependent on someone else, because of chronic illness, to be overwhelmed by all sorts of feelings, such as failure, guilt, shame, inadequacy and incapability. More often than not, the chronically ill is left with a feeling of helplessness and hopelessness.

Change is always difficult to accept and more so when it takes place suddenly, is extensive, or comes at a time when the individual can meet it less ably. Chronic illness frequently neccessitates many changes in diet, job, housing, recreation and manner of living. The person with a chronic illness cannot carry as much responsibility as formerly, has narrower interests, has to observe regimes of rest and activity, is more vulnerable to emotional strain, and carries an increasing lead of anxiety.

Unless the chronically ill is helped to see what his feelings are and is helped in adjusting to them, his morale may be so damaged as to hinder his chances of getting better or adjusting to his disability. This is where the social worker can be of great assistance to the chronically ill individual. Training has prepared the social worker to deal with people's feelings and to help them on that level.

Second, chronic illness is also very upsetting to those who are dependent on the chronically ill. Table 3 shows that 53.8 per cent of the chronically ill interviewed

lFrances Upham, A Dynamic Approach to Illness: A Social Work Guide (New York: Family Service Association of America, 1949), p. 90.

were married. More likely these people had dependents. If it is the mother who is ill then it may necessitate the placement of the children or else having someone in the house to look after them. Who is going to help this family? Certainly not the doctor or the nurse, because it is not their role. The social worker is the person who can best help the family in such a case. If it is the father who is affected, it means other kinds of problems. These will be discussed in Chapter V.

Table 3 also shows that eighteen women as compared to six men had lost their spouse through death which indicates that, generally speaking, women live longer than men. These findings have many social work implications. The woman who is left alone with many children to care for is already confronted with many problems. She may have to go out and work in order to support her family, and in that case she will need someone to look after her children or it might be necessary to farm out the children. On the other hand, she may decide to stay home and care for her children, but then perhaps she needs more income than what Mothers' Allowances provides. When, above all this, the widow becomes chronically ill, then it is evident that the already existing problems will be increased. In either case the social worker can help such a person to accept the limitations imposed upon her, to adjust to the situation, and to make plans for the future.

# Residence

The term "residence" usually is taken to mean the place where a person makes his home. Under this heading

will be discussed where the 132 chronically ill interviewed were living at the time they came to the Victoria General Hospital.

TABLE 4
Residence of chronically ill persons interviewed

District	Total	Male	Female
Total	132	75	57
Halifax	84	47	37
Suburbs of Halifax	22	13	9
Dartmouth	14	9	5
Suburbs of Dartmouth	12	6	6

It is a well-known fact that the increased urbanization and industrialization of the last few decades have
motivated many people to move from rural to urban areas. It
seems that people in the lower income groups have a special
tendency to migrate to the city. Many reasons may be given for
this, such as a desire to increase economic and social status,
and also the desire to live in an area where it is easier to
obtain better medical care and treatment.

As shown in Table 4, 63.6 per cent of the chronically ill interviewed in the Victoria General Hospital came from the city of Halifax, and 16.7 per cent came from the suburbs of Halifax. Living in the town of Dartmouth were 10.7 per cent of these chronically ill, and 9 per cent came from the suburbs of Dartmouth. According to these figures, the ratio

between the chronically ill coming from Halifax and its suburbs and those from Dartmouth and its suburbs would be approximately 8:2. These figures do not mean too much unless they are compared with other figures. According to the 1956 Inter Census Report from the Dominion Bureau of Statistics. Halifax and its suburbs has a population of 114,492, while Dartmouth and its suburbs has a population of 45,184. In other words, the metropolitan area of Halifax has a population of 159,676, with 71.7 per cent being on the Halifax side of the harbour and 28.3 per cent on the Dartmouth side. The ratio there is approximately 7:3 which is not too great a deviation from the ratio of the chronically ill people on whom this survey is based. It, therefore, is the writer's opinion that the group of chronically all persons who were approached in this survey is fairly representative and a good sample of the metropolitan area of Halifax, as far as residence is concerned.

# Living Arrangements

As can be seen in Table 5, ninety out of 132 or 68.2 per cent of the chronically ill were living with their immediate family. The term "immediate family" means husband or wife, son or daughter, father or mother. This finding is valuable to show that our highly industrialized civilization is still not too materialistic. It would seem that family unity has prevailed very well in the face of opposition and that it is to stay for a long while yet. The findings in Table 5 gain considerable importance, however, when they are

seen in connection with Table 6 which shows housing after hospitalization.

TABLE 5

Type of Living Arrangement of chronically ill persons interviewed

Before Hospitalization	Total	Male	Female
Total	132	75, 20,	57
Alone	7	1	6
Immediate Family	90	46	44
Relatives	3	2	1
Friends	5	4	1
Boarding House	12	11	1
Rooming House	10	8	2
Nursing Home	1	0	1
Home for the Aged	2	1	1
City & County Home	1	1	0 -
City Prison	1	1	0

"Same place" in Table 6 means that the 122 chronically ill patients in that category were planning to go back to live in the same place they were before they came to the hospital. From a social work point of view, this is probably the most important finding in this survey. What does it mean to the chronically ill person to go back to live in the same place he was before? Naturally it depends on each individual case, but some general implications can be pointed out. Because of

the nature of his illness, the chronically ill requires special care when he is home. In many cases, he needs care on a 24-hour basis. The person who has a family might be in a better position because he has somebody to look after him, but this is certainly not true of all cases. The additional care required by the person suffering from a chronic illness or disability can be a great burden for the rest of the family. The chronically ill person often needs to be looked after just like a child even though he is an adult. For a person who has been able to look after himself all his life, it can be very difficult to accept help from others and have them look after him as if he were a child.

TABLE 6
Housing after hospitalization for the chronically ill persons interviewed

Housing after Hospitalisation	Total	Male	Female
Total	132	75	57
Same Place	122	72	50
Different Place	6	2	4
No Place To Go	0	0	0
Do Not Know	4	1	3

Other kinds of problems can also arise. People in the low-income groups do not always have adequate housing accommodations. For example, a chronically ill patient who is at home may need to have a room to himself, due to the nature of his illness. But if such a room is not available and the person has to share his room with someone else, then the lack of proper living arrangements simply adds to the already existing problem of providing adequate care. Furthermore, how many people know what care should be given the sick person at home and how it should be given? It would seem then that a home care program is the resource most needed for the chronically ill persons interviewed in this survey, since 122 of them were returning to live in the same place and 90 of the 132 chronically ill had been living with their immediate family previous to hospitalization.

The chronically ill person who is living alone, whether in a boarding house or a rooming house, in some ways is not in a better position if he needs care at home because of his chronic illness, unless he has the money to pay somebody to look after him. Very often, however, his illness outlasts his savings. Such a person might also benefit from a home care program. Or perhaps it would be better for him not to return to the same living arrangements. If such is the case, then this person might need help in deciding where it would be better for him to go and in finding such a place. Because of his training in dealing with emotional problems, the social worker would be the person best suited to help the chronically ill reaching a decision; and because of knowledge of community resources, the social worker could also help the sick person to plan for the future.

#### Group Belonging

TABLE 7
Group participation of chronically ill persons interviewed

Group participation	Total	Male	Female
Total	132	75	57
Belong	40	32	8
Do not belong	92	43	49

The question about group belonging was included in the schedule with the preconceived idea that many chronically ill were alone because they were old. Since there were a relatively small number of chronically ill who were old, such an idea did not stand anymore. The fact that 69.7 per cent of the chronically ill did not belong to any group would seem to indicate a sad picture from the sociability point of view, but then it must be remembered that 90 out of 132 chronically ill lived with their immediate families. Many of the patients interviewed by the writer said they preferred staying home with their families in the evening to going out to group meetings and fatherings.

These findings show that these people did not belong to groups to any great extent. If, however, their illness forces them to stay home all day for a long period of time, then certainly some kind of social activities would be beneficial to them. The social worker could help the chronically ill person see the values of participating in group activities, and take interest in life again despite

his illness. In this way the chronically ill would not feel so different from other people. If it is a case where the chronically ill has limited physical ability due to his illness, then he will need help in accepting these limitations and using them constructively. The social worker has a good understanding of human behavior. He knows the values for a sick person at home to be able to socialize and to be one of the group again despite his illness and his disability. He also knows how difficult it can be at times for the chronically ill to mix with other people. With this knowledge the social worker is prepared to help the chronically ill to express his feelings and to give him the confidence he needs in order to maintain his status among his peers.

#### CHAPTER III

#### HEALTH AND WELFARE

Even though chronic illness has great social and economic ramifications, it is primarily a medical problem. One of the major reasons why chronic illness has become the greatest medical problem of our day is the fact that during the last few years interest has been almost completely centered in the treatment and prevention of acute illnesses, and great discoveries have been made in this field. Before the discovery of microscopic organisms, people died from all kinds of illnesses, both acute and chronic. But following this discovery, medical men concentrated their efforts on acute illnesses because they were recognized as such an obvious threat to peoples! lives. Not so long ago a great many people died from such diseases as typhoid fever. whooping-cough, diphtheria and small-pox. These and many other diseases were considered to be "killers." Because of this, the medical science turned its attention toward these diseases in an effort to mitigate their effects, until today few people die as a result of them. But while acute illness was in the lime-light, chronic illness was flourishing, and now it is our number one health problem.

According to the United States Commission on Chronic Illness one out of every six people is chronically ill; three out of four hospital beds are occupied by victims of long-term illnesses: two-thirds of all deaths and sixty per cent of all disabilities are caused by chronic illnesses. In the light of these data, it would seem reasonable to expect greater care to be given to the chronically ill. Yet it is generally recognized that people suffering from chronic diseases are not cared for so effectively in our present-day hospital system as are the acutely ill. Exceptions to this, however, must be made for the mentally ill and tubercular patients. Our present hospital system is geared to the prevention and treatment of acute diseases, with the result that those who suffer from chronic disease do not always receive all the care and treatment required by their conditions.

Not all the chronically ill need to stay in hospital for long periods of time. Once they have benefited from the required hospital services, many of them would be better off at home, provided that adequate professional care is available for them. Others do not need hospital care at all, but may require additional services besides those which are usually associated with general hospitals. Medical supervision, domiciliary nursing care, social service, educational and religious opportunities, homemaker's service, recreation,

Herbert Yahraes, Something Can Be Done About Chronic Illness ( New York: Public Affairs Committee, Inc., 1951),p.3.

intensive and continuing rehabilitation are some of the services the chronically ill are likely to need at home, whether they are convalescing after coming out of the hospital or their condition is such that it did not require hospitalization.

In discussing the findings of the present survey, the writer will consider the following aspects: diagnosis and disability, length of illness, hospitalization, health insurance and use of health organizations.

## Diagnosis

TABLE 8
Diagnosis of chronically ill persons interviewed

Diagnosis	Total	Male	Female
Total	132	75	57
Gastro-Intestinal	14	10	- 4
Genito Urinary	5	4	1
Cardiovascular	33	21	12
Central Nervous	7	3	4
Locomotor	12	7	5
Pulmonary	15	6	9
Metabolic	13	5	8
Cancer	26	13	13
Tuberculosis	1	1	0
Cellulitis	2	2	0
Leukoplakia	3	3	0
Lupuseryth	1	0	1

been classified under headings. The two major chronic disease from which most of the persons interviewed in this survey suffered were those of the cardiovascular system and cancer. Exactly 25 per cent suffered from diseases of the cardiovascular system. Of the 132 chronically ill, 19.7 per cent had cancer. Thus the fact that cancer is still one of the major health problems of our time was brought out by this survey. It must be said of cancer that the need for denial is still very strong today in regard to that condition because most individuals still associate cancer with a hopeless prognosis. Because of recent medical advances, however, the fear of a hopeless prognosis is not necessarily well-founded.

It still remains, however, that many people refuse to accept the diagnosis of cancer. This is where the social worker is of help in the hospital team. In an hospital it is the duty of each department head to see to it that his department offers to the patient the best skill that the particular specialty affords. The social service department exists to work with the patient to help him use hospital treatment and also to work with the doctor so that his particular skill may be made accessible to the patient in a more beneficial way.

In the case of cancer, for example, the wisest of medical instructions may be useless unless the patient can

<sup>1</sup> see Appendix, Classification of Diagnosis

be helped to accept the fact that he has such an illness. The doctor may use all his skill to convince the patient and still the sick person might not admit to himself, other than in an intellectual sense, that he has cancer. The social worker, however, working with such intangibles as attitudes and feelings may actually start the patient on the road to recovery by helping him to acknowledge the facts to himself and accept his present condition.

This may be the ideal but the fact remains that doctors often do not tell patients that they have cancer. The doctors are guided by their own attitudes, knowledge of the patient, and family feelings. In certain cases it might be better not to tell the patient he has cancer, but if the doctor's own attitude toward cancer is the only reason why the patient is not told of his diagnosis, then the social worker might be of assistance. The social worker may ask that the doctor at least entertain the notion that after all it is a person, a human being, who is being treated. This may seem strong language, but it is justified when occasional evidence indicates the failure to co-ordinate medical treatment and social case work skill.

# Disability

The fact that 49 out of 132 chronically ill persons had no apparent disability as a result of their illness is rather encouraging as it speaks well, to a certain extent, of the care and treatment that are given to the chronically ill in the Victoria General Hospital. Preventing chronic

illness is very important, but preventing the disability from taking place as a result of it is also of great importance, as it might affect the sick person for the rest of his life.

TABLE 9
Disability of chronically ill persons interviewed

Disability	Total	Male	Female
Total	132	75	57
Chairbound	4	1	3
Bed Bound	5	5	0
Other	74	35	39
None	49	34	15

"Other" in Table 9 means a restriction of normal activities, which might range in degree from the person who is not allowed to climb stairs anymore because of his condition to the one who has to use crutches in order to get around. That 56:1 per tent of the chronically ill were in that category shows that chronic illness often causes a certain degree of disability, even if it only involves a minor restriction of activities.

Whatever the degree of disability may be, the fact remains that it is a change, and change is always difficult to accept. When the degree of disability is such that it involves the curtailment of working capacities, then it can be very damaging to the sick person regardless of whether it is looked at from the economic, social or emotional point

of view. This is why rehabilitation is of primary importance as a service designed to help the individual to live and to work to the best of his capacity in spite of his disability. The whole question of rehabilitation will be discussed in the next chapter in connection with job retraining.

#### Length of Illness

TABLE 10

Length of illness in chronically ill persons interviewed

Length of illness	Total	Male	Female
Total	132	75	57
l year or less	58	38	20
Over 1 to 2	14	6	8
Over 2 to 3	9	4	5
Over 3 to 4	4	1	3
Over 4 to 5	7	4	3
Over 5 years	40	22	18

Chronic illness is also some times called "long-term illness" and there is a good reason for it. In contrast to acute illness changes often take place so slowly in the chronically ill that they can be noted only over a long period of time. At times, their illness seems to be at a standstill, only to recur in a more pronounced way. This type of progress of chronic illness makes its treatment very complicated, since it must be modified according to the progress of the illness.

Because the course of chronic illness is long it presents many problems for the patient, his family and society. The patient and his family often do not have sufficient resources — financial and emotional — to cope with the situation. Society is also affected when one of its members is in such a condition that he is unable to contribute anything towards it.

As shown in Table 10, 30.3 per cent of the chronically ill were sick for more than five years. This indicates that the course of chronic illness is long in many cases. One of the persons interviewed by this writer had diabetes for 18 years. He had been in the hospital for an average of five days every year because of his condition. A fifty-eight year old man with a coronary diagnosis had been ill for ten years. A young man of twenty had a congenital defect which had hindered his activities all during his life. Had this young man sought the attention of doctors early enough he would probably not have had a chronic condition, because only a minor operation was necessary to correct the congenital defect. Many surveys have shown that a great number of people are chronically ill because they did not receive medical attention early enough, when it would have been relatively easy to stop the progress of their disease. A thirty-two year old man with a diagnosis of uremia had been ill for eleven years. A middle-aged man had gastric ulcers for ten years. Asthma had been a health problem for sixteen years for a thirty-six year old

man. These are only a few examples to indicate the fact that chronic illness often exists for a very long time.

It is important to consider that 43.9 per cent of the chronically ill interviewed in the present survey had been sick for less than a year. Although many people are chronically ill because they did not seek medical help early enough, it is encouraging to see that many others do seek help as soon as they realize that they need it. This may indicate the development of a new attitude toward chronic illness: it would seem that more and more people today realize the importance of getting medical help before their illness has progressed to the stage where it will likely cause disability. On the other hand, some of the chronically ill who had been sick for less than a year did not realize the severity of their illness. The fact that many of them talked about their plans to return to the same kind of activities as they undertook before they became sick seemed to indicate that either they did not realize the limitations that their illness might place on their normal activities, or else they were unable to accept them. In view of these findings, it would seem to be advisable to have greater social service facilities for these people in order to help them to accept and to adjust to the new kind of life that their illness may require them to lead.

### Hospitalization

A general hospital, for example, is likely to operate at a tempo primarily designed for emergencies and acute problems — a tempo quite unsuited to the chronically ill. Except in hospitals with a well-rounded and active teaching program, professional interests tends to gravitate to the more acutely ill. Attention to nonacute

phases of chronic illness is inclined to be transient and minimal, and professional services to the long-term patient are often meager.

Preventing the disease itself is certainly of major importance. Of no less importance, however, is the treatment of chronic diseases. Thanks to medical research, many diseases can now be almost completely controlled and others can be partially controlled. Even though the outlook for more and better means of control is brighter than it has ever been, the fact remains that a great number of people still suffer from chronic illnesses. Adequate facilities to provide proper treatment for these people are greatly needed. As the writer mentioned previously, the present hospital system is devoted primarily to the prevention and treatment of acute illnesses.

During the survey of hospitals in Nova Scotia, the one defect in the present hospital system upon which almost every hospital superintendent and head of the medical staff commented was the great need for improved facilities for the care of the chronically ill.

The Commission on Chronic Illness in United States in its report also pointed out the great need for improved facilities, just as Dr. C. B. Stewart did, which shows that this problem is widespread.

But why ask for improved facilities when good general hospitals are already available for the care and treatment of

<sup>1</sup> Commission on Chronic Illness, Chronic Illness in the United States: Care of the Long-Term Patient (Cambridge: Harvard University Press, 1956), Volume II, p. 13.

<sup>2</sup>Dr. C. B. Stewart, Report on the Survey of Hospitals in Nova Scotia under the Federal Health Survey Grant, 1949 (Halifax: The Department of Public Health), Section 8, p. 90.

sick people? After all, the type and quality of care required by the chronically ill is not so different from that needed by the acutely ill. It is true that in many cases there is not too great a difference, except for the length of time spent in hospital. Besides, the chronically ill at times do need special services, especially if permanent disability is to be prevented and if rehabilitation is necessary. For instance, social services are probably more greatly needed in the case of the chronically ill than in the case of the acutely ill. To be acutely ill is not always easy to accept, and some people need help in order to accept and adjust to the idea of being ill a few days or even a few weeks. But the individual who is confronted by the anticipation of a long-term illness really needs more than medical and nursing help. Among the facilities needed in a hospital for the care of the chronically ill is a well-trained and adequately staffed social service department.

Table 11 gives the total length of previous hospitalization, including hospitalization with the same and other
chronic illnesses. This Table is self-explanatory and shows
that the stay of the chronically ill in hospital is quite
long when compared to the stay for the acutely ill. It is
true this Table shows the total length of previous hospitalization, but still 32.6 per cent of these chronically ill had
spent over three months in hospital.

It is no secret today that many of our general hospitals are often crowded and even overcrowded. As soon as patients are no longer in danger and are well on the way to

recovery they are discharged from the hospital so that others who require urgent care and treatment will be able to enter. It cannot be emphasized too strongly that the present hospital system is geared to acutely ill persons. If a chronically ill patient were to stay in the general hospital for the total length of time that his condition actually requires, he would perhaps be taking up a bed badly needed by the acutely ill.

TABLE II

Total length of previous hospitalization of chronically ill persons interviewed

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Previous Hospitalization	Total	Male	Female
Total MADILE 1	98	55	43
Less than 3 months	66	34	32 mt
3 mos 6 mos.	20	13	7
Over 6 mos 9 mos.	11-4	1	3
Over 9 mos 1 year	2	2	0
1 year and over	6	5 -	1

Dr. C. B. Stewart says in his Report on the Survey of Hospitals in Nova Scotia,

Many superintendents stated that they tried to exclude chronic cases, but some added that they were not very successful. Other limited the stay to 3 or 4 weeks, and enforced discharge at that time regardless of home conditions or the status of the patient. The Victoria General Hospital admits patients with chronic diseases who require active treatment and keeps them so long as progress is being shown, but will not retain them for custodial care only.

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lDr. C. B. Stewart, Report on the Survey of Hospitals in Nova Scotia under the Federal Health Survey Grant, 1949 (Halifax: The Department of Public Health), Section 8, p. 92.

Undoubtedly many chronically ill today have to leave the general hospital while they still require the care and treatment that only the hospital can give. A few of the chronically ill interviewed by the writer made the remark that if they could have stayed in the hospital longer when they were there previously for their chronic condition, probably they would not have had to return again for the same illness.

Even though these remarks are very subjective and may not be fully justified, they probably contain an element of truth.

Here again the social service department has an important role to play in the hospital. Where chronically ill patients are hospitalized in a hospital for acute diseases, the social worker can prepare and help the patient to accept the fact that he has to leave the hospital, even though the patient feels that he should stay longer. This is one limitation of the hospital that the patient must understand and accept, and very often he will not be able to accept it unless he is helped.

# Health Insurance

Of primary importance is the fact that 97 of the 132 chronically ill or 73.5 per cent did not have any health insurance, chiefly for economic reasons. One man said that he had Blue Cress and Blue Shield for years, but the rate had increased so much in the past few years that he could not afford to keep it any longer. Another one said that he had paid into Blue Cross for years but never had the occasion to make use of it, so he dropped it. He would

like to have it now, but he could not afford it anymore.

Still another said that he had been very dissatisfied with
the health insurance he had, because it did not cover certain
expenses. He also dropped it.

TABLE 12

Health Insurance covering chronically ill persons interviewed

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Health Insurance	Total
Total	144
Blue Cross	21
Blue Shield	2
Maritime Medical Care	16
Other Health Insurance	8
None	97

One thing that impressed the writer when he approached chronically ill patients with the schedule was the number of times that they asked this question: "Is this for the National Health Insurance Program?" And then they would make the comment that they hoped Nova Scotia would enter into this plan. Judging from their remarks, it seems that chronically ill people at least would be very pleased if the Province of Nova Scotia joined the National Health Insurance Program.

# Health Organizations

TABLE 13
Health Organizations used by chronically ill persons interviewed

Organizations	Total	Male	Female
Total	176	87	89
Red Cross	9	3	6.
Victorian Order of Nurses	13	4	9
Arthritis and Rheumatism Society	1	0	1
Maritime Paraplegic Society	1	. 1	0
Halifax Visiting Dispensary	. 9	2	7
Dalhousie Public Health Clinic	20	5	15
Walter Callow Bus Service	1	1	1
Polic Foundation	0	0	0
Any Hospital Outpatient Department	39	13	26
Cancer Society	2	1	1
Other	0	0	0
None	81	58	23

Many of those who used health organizations had used more than one. On the whole, however, the health organizations mentioned in Table 13 were used to a very limited extent, since 81 of the 132 chronically ill or 61.3 per cent did not make use of any of them.

When inquiring about the use of health organizations, the interviewer would ask: "Have you used any of the following health organizations?" and then he would name them. In many instances the writer had a chronically ill person ask him "What did you call that organization?" or "What do they do?" In most cases, however, they would simply say "I have never heard of it." These questions and remarks strongly indicate that the reason why 61.3 per cent of them did not make use of these health organizations was primarily because they were not aware of their existence, or knowing that these organizations existed, they did not know exactly what functions they performed or if they were qualified to take advantage of their services.

It, therefore, can be said that there is a great need for public education about health organizations and also for some kind of Information Bureau, where people could make inquiries and be directed to the organization whose services they require.

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#### CHAPTER IV

#### ECONOMIC ASPECTS

Economic problems enter very readily into the life of the chronically ill patient. This is easy to understand when one considers the duration of chronic illnesses. When a person becomes acutely ill, he and his family often have sufficient financial resources to cope with the situation. The patient who is confronted with the prospect of a long-term illness, however, soon sees his financial resources dwindle to nothing. Furthermore, he often finds himself in a position in which he will not be able to work for a long time, and sometimes he may never be able to work again. The longer the illness lasts, the less able is the chronically ill to afford proper medical care and treatment, with the result that the severity of the illness increases and the person becomes less and less able to provide for himself and his family.

Chronic illness creates not only economic problems for both the affected individual and his family but an economic problem for society. The National Health Survey made in the United States during the years 1935-1936 showed that: "Time lost annually from productive activity because of chronic disease totals more than a billion days — or

the equivalent of 3.800,000 persons working five days a week for a solid year." The employment market operates to the severe disadvantage both of persons with chronic illness and of those in the incipient stage of such illness. Most of the large firms or employment organizations are quite strict in their health requirements when interviewing candidates for a position. Some will employ only people who are in perfect health and are not hindered by any sort of disability. Certain types of work certainly require a person to be in perfect health and have the use of all his faculties. On the other hand, a great number of people with chronic disabilities could be gainfully employed and contribute to society, if only they were able to obtain proper rehabilitation services and also if the employment market gave them a chance to prove themselves. It is comforting today to see a new trend developing whereby more and more employers hire people with a chronic disability. It is hoped that such a trend will continue for the good of individuals and of society as The whole question of rehabilitation will be discussed later in this chapter.

In Chapter IV the writer will consider the results of the present survey in regard to, (1) employment, (2) working possibilities following hospitalization, (3) income and its relation to chronic illness, and (4) means of support following hospitalization.

Herbert Yahraes, Something Can Be Done About Chronic Illness (New York: Public Affairs Committee, Inc., 1951), p. 2.

### Employment

TABLE 14
Employment of chronically ill persons interviewed

Employment	Total	Male	Female
Total	132	75	57
Employed	65	52	13
Unemployed	67	23	44

of the 132 chronically ill interviewed in the present survey, 49.2 per cent were employed previous to their hospitalization and 51.8 per cent were unemployed. As shown in Table 14, there were four times more men than women employed and 34.3 per cent of those who were unemployed previous to hospitalization were men as compared to 65.7 per cent women. This Table is valuable as a preliminary table, since it helps in the understanding of the following tables by giving the proportion between employed and unemployed persons and also between men and women in both categories.

Table 15 shows the type of employment held by the sixty-five chronically ill mentioned in Table 14. It can be seen that only a small proportion of the chronically ill employed had a white-collar job, while the majority of them had a relatively strenuous type of work. This point should be kept in mind as one thinks about the limitations imposed on the chronically ill patient by his illness and the possibilities for him to return to the same kind of work.

TABLE 15

Type of employment held by chronically ill persons interviewed

Туре	Total	Male	Female
Total	65	52	13
Proprietary or Managerial	4	4	0
Professional	1	1	0
Clerical	5	3	2
Agricultural	1	1	0
Trapping, Fishing, Hunting	0	0	0
Logging	2	2	0
Mining & Quarrying	0	0	0
Manufacturing and Mechanical	9	9	0
Construction	6	6	0
Transportation and Communication	11	11	0
Commercial, Financial, Trade	2	2	0
Service: Personal	20	9	11
Protective	2	2	0
Other	2	2	0

Considering the fact that 27 out of 44 women shown in Table 16 were housewives, it is easier to understand why 65.7 per cent of those not gainfully employed were women. Chronic illness can be the cause of many problems when the housewife is the one affected, especially if she has children

to care for. If the housewife's illness is of very long duration, she might have to hire somebody to do her housework and care for her children. Unless her husband has a very high income, it will not take long before the family is faced with a financial problem. This is where a homemaker's service program for the chronically ill would be very helpful.

Chronically ill persons interviewed who were not gainfully employed

Туре	Total	Male	Female
Total	67	23	44
Housewife	27	0	27
Student	2	2	0
Retired	25	19	6
Other	13	2	11

Twenty-five out of sixty-seven chronically ill
persons were retired. Whether these people had retired
because of their age or because of their illness is not
known. Regardless of what the rase may be, chronic illness
still presents a great problem to the retired person because
he is less likely to have sufficient income to cope with the
situation. He no longer has either the opportunity or the
capacity to earn as he used to and economic problems can
become very great, unless he has other means of support.

The matter of retirement also has great social work implications. Retirement means a great change in the lives of people. To a person who has worked all his life and who suddenly finds himself doing nothing, life may seem useless or worthless. Many people may have a feeling of rejection, that nobody wants them and that they are of no value anymore. Others may have feelings of failure. When chronic illness adds itself to this, then the person definitely feels that he is of no more use to himself, to his family or to society. He feels he is a burden to everyone else, and his feelings may be so strong as to damage his morale and hinder his chances of recovery. Such a person greatly needs the help of a social worker. He needs to be understood and to be encouraged to express his feelings. The social worker can also help the retired and chronically ill person by encouraging him to use rehabilitation services if these are available, or perhaps just take up a hobby. In brief, the social worker can help the retired and chronically ill person to regain his place in life as a useful member of society.

### Working Possibilities following Hospitalization

To the 65 chronically ill who had been employed before coming to hospital, the question "Do you think your health will allow you to work again?" was asked. It must be understood that this was a very emotionally charged question, and whether or not the answers given to it are valid is questionable.

Working possibilities fellowing hospitalization for chronically ill persons interviewed

Possibilities	Total	Male	Female
Total	65	52	13
Able to work	56	44	12
Unable to work	1	1	0
Do not know	8	7	1

Knowing what curtailment of normal activities chronic illness can involve and the great amount of disability it can cause, it is rather surprising to see that 86.1 per cent of the chronically ill who had been employed before hospitalization said they would be able to work again. But knowing how difficult it can be for a person to face the idea that he may never be able to work again, or at least be able to do the same work or as much work as he used to do, this high percentage is not so surprising. Whether these people were optimistic or could not face the reality of their situation, one cannot discover. This high percentage could also be interpreted in another way. and one could say that it is very encouraging to see that so many people would be able to work again despite their chronic condition. In the writer's opinion, this was not the case for all of them because it was evident in some of the cases that the person would never be able to do the same work that he did before, or even a different kind of work. This was true especially of those people who had heart diseases and

who had been employed in strenuous labour. The fact remains, however, that 56 out of 65 chronically ill said they would be able to work again and undoubtedly a number of them would return to work.

TABLE 18

Job retraining for chronically ill persons interviewed

Retraining 1 and 1	Total
Total	132
Necessary	8
Unnecessary	124

In the present survey, the interviewers and not the patients gave their opinions on the matter of job retraining. In the interviewers' opinions eight chronically ill persons needed job retraining if they were to keep on working and earning a living. Actually there might have been more than eight persons who needed such retraining, for the people making this survey were not authorities on matters of medicine and rehabilitation.

Job retraining in the case of chronically ill is basically rehabilitation. Since only 6.1 per cent of the chronically ill in the present survey needed rehabilitation, it might not seem a very important matter. As a social worker, it is the writer's opinion, however, that even if only one person needed rehabilitation it should be provided. In fact, rehabilitation procedures should be available to all long-term

patients as needed. Rehabilitation is not only the restoration of the handicapped to the fullest usefulness of which they are capable, but it is also a very important element in adequate care, and it should begin with the diagnosis. If eight chronically ill persons can be rehabilitated to the extent that they will be able to lead a normal life again, work, and earn a living for themselves and even provide for somebody else, then it is worth considering having rehabilitation facilities for the chronically ill. "The real worth of rehabilitation can't be calculated, for there is nothing like the dollar, ounce, or other unit to measure individual and family happiness when a disabled person finds he can still be useful."

Not only is rehabilitation of great value to the individual and his family, but society also gains from it. Considering what it might cost to keep one individual on relief, for years perhaps, it would still cost less to provide rehabilitation facilities so that the individual might become self-supporting again. Furthermore, the money that society puts into a rehabilitation program is far from being lost. The rehabilitated person can earn again, and as he does he repays in income taxes alone every cent spent on him.

Getting a person rehabilitated is not only a matter of getting him to work again. In some cases the person will

Hervert Yahraes, Something Can Be Done About Chronic Illness (New York: Public Affairs Committee, Inc., 1951), p. 16

never be able to work again even if he has rehabilitation. A chronically ill person might not ask anymore than to be able to live with his family again, be in the midst of familiar things, be able to meet his neighbours once more and hail the man across the street. These are things that he was used to and they are essential to his happiness. If a person cannot be restored to his work, he will need some kind of recreational activities. Undoubtedly some people never thought of recreation too much when they were working, but once they cannot work anymore they need something to pass the time. Rehabilitation might mean simply getting the person to sit at a table again and play cards with his friends or sit with his family and watch television, but to the chronically ill person it might be the difference between life and death. He feels that he is able to do something again and it gives him a new interest in life.

Social workers have an important role to play in rehabilitation. They have the knowledge and training to prepare the person for the rehabilitation program, to prepare the family so that every member will help him in adjusting to his limitations, and to support him while he is making use of the rehabilitation program. The patient might be very enthusiastic when he starts to take rehabilitation, but as time goes by he may get discouraged if his efforts are not met with immediate results. With their knowledge of human behaviour, social workers understand

how the person feels in such a case. By recognizing his feelings, by giving him support and reassurance, social workers can help the chronically ill patient to continue with his efforts in getting rehabilitated.

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### Income

TABLE 19
Income of chronically ill persons interviewed

Income	Total .
Total	132
\$0 to \$999.	38
\$1000. to \$1999.	30
\$2000, to \$2999.	27
\$3000. to \$3999.	20
\$4000. to \$4999.	9
\$5000. and over	3
Do not know	3
Refused to tell	2

Studies elsewhere have shown that chronic illness is more prevalent among the low-income groups.

The National Health Survey (1935-1936) showed that, in urban areas, the disability rate from diabetes among families receiving public assistance was four times as high as among families with incomes of \$3,000 or more a year; the rate for rheumatism were both more than three times as high in the public assistance group. The same survey revealed that the chronic disease disability rate varied from 2.87 per cent among public assistance families to 1.44 per cent among families

with incomes under \$1,000 a year, to 0.46 per cent among families with incomes of \$1,500 to \$2,000 per year.

One of the reasons for this is the fact that poverty often predisposes people to the development of certain chronic diseases. Poverty often involves under-nutrition and malnutrition, with the result that the body does not have enough stamina to fight a disease when it occurs. Over-crowding and emotional stress often accompany poverty, and it is generally recognized that these factors are closely related to certain chronic diseases. Very few of the homes in which people of the lower-income groups live are equipped with proper sanitation, ventilation, lighting and heating facilities. It is well-known that these conditions have an adverse affect on health.

More important perhaps, is the fact that many people are chronically ill because they did not seek the attention of doctors early enough. The individual whose livelihood depends on his day-to-day work often will keep on working when he is ill and should be under the doctor's care. He feels that he cannot afford to lose time at work, but in the meantime the disease might progress to the point where it becomes chronic.

Thus, chronic illness has a dual relationship to poverty. On the one hand, certain chronic diseases occur with much greater frequency among persons of the low-income

<sup>1</sup> Frances Upham, A Dynamic Approach to Illness: A Social Work Guide (New York: Family Service Association of America, 1949), p. 87.

groups than among people who are better off financially; on the other hand, many chronic diseases cause such extended disability, loss of earning capacity, and heavy medical expense that they impoverish the individuals and families affected.

Before discussing the findings of Table 19, one point must be made clear. Five people out of 132 either did not know or refused to tell what their income was. In figuring the percentage for this Table, the writer did it on a total of 127 chronically ill instead of 132.

Table 19 definitely supports the widespread notion that chronic illness occurs more frequently in people from the low-income groups than among more fortunate segments of the population. Because people attach different values to wealth, live in different communities and thave different responsibilities, the term "low-income" does not mean the same thing for everybody. It is impossible to draw the line where low income ends and average income begins. Considering what the cost of living is today in the metropolitan area of Halifax, if an income less than \$2,000. a year is considered as a low income then 53.5 per cent of the chronically ill interviewed were in the low-income group. If, however, an income less than \$3,000, a year is considered as low, then the percentage jumps to 74.8. Whatever is the figure used as being representative of low income, the fact still remains that a relatively great percentage of the chronically ill interviewed in the present survey belonged to that group.

This correspond with the findings of many other surveys on chronic illness.

Of the thirty-eight persons who had an income of less than a thousand dollars a year, six were employed in personal services and were receiving payment in kind (not shown in Table 19). One of them was a 54-year old widow interviewed by the writer. She said that she had no money and she could not depend on her children because they themselves were not in a financial situation to help her. This woman was very much concerned about the cost of hospitalization; she was one of the fourteen chronically ill persons to be referred to the Social Service Department in the Victoria General Hospital. Also not shown in Table 19 is the fact that most of the people who had an income less than one thousand dollars a year were those on categorical assistance. Table 20 reveals that the number of people on categorical assistance is approximately the same as the number of people in the \$0 to \$999. income bracket.

# Means of Support following Hospitalization

As can be seen from the grand total of 187 in Table 20, a few of the chronically ill interviewed said they would have more than one means of support following hospitalization. For instance, a seventy-one year old man interviewed by the writer said he had some savings and was getting his Old Age Security. In addition, he would have Workmen's Compensation and Unemployment Insurance Benefits to help him after he came out of the hospital. Another

said that besides the savings and a personal insurance he had, he was getting a company pension and the Disabled Persons Allowance.

TABLE 20

Means of support following hospitalization for chronically ill persons interviewed

Means of Support	Total	Male	Female
Total	187	113	74
Salary	39	34	5
Family Support	47	14	33
Personal Insurance	9	8	1
Company Pension	16	14	2
Rentals	5	2	3
Savings or Securities	15	10	5
Old Age Security	31	16	15
Old Age Assistance	1	1	0
Mothers' Allowances	1	1	0
Disabled Persons' Allowances	3	3	0
Blind Persons' Allowances	2012	1	0
War Veteran's Allowance	2	0	2
Workmen's Compensation	4	4	0
Unemployment Insurance	3	3	0
No Income	10	2	8

Only fifteen people said they had savings or securities. This seems to support the previous statement

that chronic illness impoverishes both the individuals and their families. A young man who had diabetes for eighteen years told the writer he had been in the hospital so many times for the same condition that following every hospitalization he went back to work in order to pay his hospital bills.

Ten out of 132 chronically ill, or 7.6 per cent had no income or means of support at all. What help can a social worker give in such cases? He cannot help these people financially, but knowing the community resources better than anybody else working with the patients, he can refer these persons to an agency or an organization which could help them. The social worker can also help the indigent chronically ill from an emotional point of view. He knows how difficult it can be for people to accept help, especially financial help; They may feel guilty about it, they may look upon it as a shame or they may consider themselves failures. Because of these feelings they may also deny completely that they need help. Recognizing these feelings, the social worker will help the persons to accept and adjust to their situation. Not only will the worker refer the destitute chronically ill to an agency where he can get help, but he can also make the contact with that agency. Thus, the social worker can release the anxiety in the person who needs financial help, he can help the person to face the reality of his situation and take the next step in order to meet his need. at this good it agreets but the

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# CHAPTER V

### CONCLUSIONS AND RECOMMENDATIONS

The purpose of this report has been to interpret the results of a survey made by the second-year students at the Maritime School of Social Work. This survey was conducted in order to consider the resources needed for the care of the chronically ill in the metropolitan area of Halifax. It must be understood that since the group making this survey was a group of social work students, therefore the writer can draw only those conclusions and make those recommendations which, directly or indirectly, are related to the field of social work. The writer has no competence to make other recommendations than those of a social worker.

It is the writer's opinion that many conclusions can be drawn from this study and, in the light of these conclusions, that important recommendations can be made from a social worker's point of view.

Chronic illness is not a health problem for the aged only. The results of this survey show that people of all ages can be and are affected by it, with chronic diseases occurring more frequently among people of the middle-age group. This is a point that social workers must be aware of when working with chronically ill people. Because of the notion that chronic

illness exists mostly in old people and because social workers are keenly interested in the problems of aging people, they might have a tendency to focus their attention on elderly people only, when actually chronically ill persons of all ages need the help that social workers can give them.

It is seen in the present survey that 90 of the 132 chronically ill persons lived with their immediate family and that 122 out of 132 chronically ill planned to return to the same place following hospitalization. This survey also shows that chronic illness definitely is related to poverty — a dual relationship. Certain chronic diseases occur with greater frequency among persons in the low-income groups. Chronic illness also impoverishes the individuals and their families because it causes heavy medical expenses, loss of earning capacity, and loss of time at work. Furthermore, this study shows that many housewives were chronically ill. In the light of these conclusions, the writer recommends that a Home Care Program for chronically ill persons be established by health and welfare agencies in the metropolitan area of Halifax.

Such a program would provide home visits by a doctor.

Many chronically ill do not need hospitalization, but they do need professional medical care. Or, having been hospitalized, they need to be followed once they return home. If the patient receives suitable medical care the progress of his illness may be retarded and the recurrences limited. The patient may also need sick room equipment or drugs and, upon the doctor's recommendation, these should also be provided in a Home Care Program.

This program would also include skilled nursing care. Certain procedures employed in caring for the sick, such as full bed baths, enemas, application of dressings and bandages and the carrying out of other treatments prescribed by the doctor require nursing skill beyond that possessed by an ordinary untrained person.

Restorative services would also be included in the Home Care Program. The writer has already pointed out in the body of this study the importance of restoring the patient, if not to his complete usefulness, at least to a degree where he will not feel a burden to everybody and he will still have a certain interest in life. Such restorative services could include recreational services, physiotherapy, and vocational guidance.

maker's services. If the mother is the sick person in the house, it can mean that the family will break. Either the mother will keep on working despite her illness and then she may require hospitalization or her illness will progress to a point where she will be incapacitated for the rest of her life or she will die. On the other hand, the mother may choose not to keep on with her work but then the children will likely be neglected, with the result that sooner or later the children will have to be taken away from their home and placed in an institution or in a foster home. This survey has shown that family unity was still strong in our community and it is too great a wealth to lose. Thus, in order to keep the family

together, homemaker's service for the chronically ill is badly needed.

Most important of all in the writer's opinion, a Home Care Program must include social services. Chronic illness has great emotional implications for the individual and for the family. Not only must the long-term patient adjust himself to the realistic limitations imposed by his illness. He may be called upon to modify his conception of himself as a useful person able to carry his own weight and make a contribution to his world. Often he is regarded by himself and others as inferior. He may feel shame, inferiority, guilt, and even worthlessness as a result of his chronic illness. The chronically ill may also deny completely that he is sick, with the result that he will not take the help he needs. He may become confused, fearful, depressed. If he has a communicable disease he may feel anxiety and guilt about its effect upon the other members of his family. The services which can help in these situations may involve more time, effort, and skill than the purely medical care, but the chronically ill patient desperately needs them, and he needs them promptly while he still wants to make the effort.

This is where the social worker can help in a Home Care Program. The social worker sees the patient as a sick person and his approach is on the basis of the patient's needs. Because of his training the social worker understands what illness and disability mean to the patient, the loss of status in the home and the community, the feeling of not being

wanted, the feeling of being a burden and inferior to other people. What the patient will do about his illness, how he will be able to face the diagnosis and what it may mean to him, how he will carry out the doctor's recommendations and make the necessary adjustments in his life are decisions which every sick person must face. But the chronically ill may be so blocked by his feelings that he cannot make these decisions alone and it is the role of the social worker to help him make those decisions. By recognizing the person's feelings, by helping him to talk about them, by accepting the person as he is, by giving support and reassurance the social worker can help the chronically ill to help himself. It is the doctor's job to provide medical care; it is the social worker's job to help the patient to utilize medical care so that health will be achieved.

In a Home Care Program the social worker does not work with the individual only. Unfortunately chronic illness does not usually affect the patient alone. It also affects the family. The social worker is familiar with the tragedy of the broken family, whether it is broken because the mother is stricken or the father of a dependent family is rendered helpless. Even if suitable care can be secured, the patient will not benefit by it if he is worried about unfulfilled responsibilities. Here again the social worker is the person who can best help in such a situation. He knows of the community resources where help can be obtained in order that the family unity be maintained. If it is

absolutely necessary to break up the family, the social worker is the person who knows best how it can be done constructively.

The social worker can still help in another way in a Home Care Program. Members of the family where there is a chronically ill person may have great many feelings about it. They may feel guilty themselves, they may feel that they cannot care for the sick person or they may feel that he is a burden. The social worker can help the family understand the illness of the patient, the importance for him and for them all that he should get better and how they can help the patient. The social worker can help the family to budget if it is necessary and he can help them to make plans intelligently and participate responsibly in the patient's care. The social worker can also act as liaison between the different disciplines involved in the Home Care Program and thus co-ordinate the whole program for the benefit of the individual and his family.

In the writer's opinion it is very important for the chronically ill person to live in his own home, with his loved ones if it is at all possible. Living with his own family in familiar surroundings may at times be more beneficial to the sick person than the medications he takes.

Thus, the writer strongly recommends that a Home Care Program be established in the metropolitan area of Halifax for the benefit of chronically ill people.

It has been shown in this study that the majority of the 132 chronically ill persons interviewed were not too familiar with the health organizations existing in the metropolitan area of Halifax, chiefly because they did not know about these organizations. The writer recommends, therefore, that an Information Bureau within the Welfare Council be established where chronically ill and other people in the metropolitan area of Halifax could obtain information and be directed to the existing health organizations. He also recommends that more community education be done through radio, television, press, published material, public meetings and lectures, for it is essential if progress is to be made in the field of care and treatment for the chronically ill people.

This survey definitely supports certain findings made by other surveys on chronic illness. In the present survey it has been shown that chronic illness is of long duration. Of the total number of chronically ill interviewed, 30.3 per cent had suffered from chronic illness for more than five years. Also chronic illness is recurrent and causes many periods of hespitalization. Of the 132 chronically ill interviewed 74.2 per cent had had previous hospitalizations with the same or other chronic illnesses and 32.6 per cent spent over three months in the hospital during their lifetime because of chronic illness. According to these findings it would seem that the recommendation made by Dr. C. B. Stewart in his Survey of Hospitals in Nova Scotial that a wing

lDr. C. B. Stewart et passim, Report on the Survey of Hospitals in Nova Scotia under the Federal Health Survey Grant, 1949 (Halifax: The Department of Public Health), Section 8.

directly connected with the Victoria General Hospital be built is a desirable project. In connection with this recommendation made by Dr. Stewart, the writer recommends that an adequate and properly staffed social service department be established for the benefit of chronically ill people if and when such a wing is built.

Social work is of prime importance in the care of the chronically ill. The person suffering from chronic illness needs, in addition to definitive medical care, the kinds of services that will restore his morale, keeping him intellectually and emotionally in the stream of life. What sometimes happens in a hospital is that the hunt for the disease becomes so intense that the person is overlooked. Once the discovery is made, then the disease gets treated and once again it is the disease and not the patient that gets treated. These statements do not apply to all hospitals nor to all doctors, but they are descriptive of enough hospitals and physicians to make necessary the service of a social worker in a hospital setting.

People react differently to illness and hospitalization. In the majority of cases fears are aroused: fear of death, prolonged hospitalization, having to wear appliances, being unable to pay for services received. Others cling to illness because of what it gives them; with their illness they get attention, without it they are mediocrities. Still others deny illness completely and by not admitting their illness they do not take the responsibility of getting well.

These are matters of attitudes and feelings and only the social worker has the professional understanding and skill to deal with such matters. Social workers are ready to admit that the hospital does not exist for them, but they do insist that many people do not get well even with the best of medical care. The social worker, by permitting the patient to express such feelings as fear, guilt and failure or by taking him for what he is, by instilling confidence in him, by thinking out some of his difficulties with him, by being there to help him work out plans for the future if need be, provides releases that enable the patient to take his own next steps.

#### FACE SHEET

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#### APPENDIX

### FACE SHEET

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# Social Research

### CHRONIC ILLNESS SURVEY

January -February, 1957

Social Work

## Maritime School of VICTORIA GENERAL HOSPITAL

SCHEDULE

1.	In what community were you living before you came to hospital?
2.	What were your living arrangements before you came to hospital?
	☐ A. by yourself ☐ B. with immediate family ☐ C. with relatives ☐ D. with friends ☐ E. in a boarding house ☐ J. in a City or County Home
3.	How long have you been living there?weeks; (or)months; (or)yrs.
4.	When you leave hospital where do you plan to live?
	A. the same place  B. a different place  C. no place to go  D. don't know
5.	Do you know many people in this area where you plan to live? Yes No
6.	Do you belong to any groups?  Church groups Social Service clubs Crecreational Sother Social
7.	Have you any (other) hobbies or interests?  (Take first three named)
Tra	ansition: (something like) "Now we'd like to talk about your work before you got sick."
8.	Were you employed before you came to hospital?  employed unemployed
9.	Were you employed on a I full time, part time, or seasonal basis?
0.	What kind of work were you doing before you came to hospital?
	A. proprietary or managerial B. professional C. clerical D. agricultural F. logging G. mining and quarrying H. manufacturing and mechanical I. construction  J. transportation and communication K. commercial, financial and trade L. service) personal D protective Not gainfully employed M. housewife Not gainfully employed M. housewife Not gainfully employed ON. student ON. retired
11.	Is your husband (or wife) working? Tyes No

- 2 -

12.	What was the total yearly income (If husband and wife were workin add income together)		\$ 0 to 999 1000 to 1999 2000 to 2999 3000 to 3999 4000 to 4999 5000 and over	9
13.	Were you able to manage on this?	Yes	□ No	
14.	A. Do you think your health will B. If yes, do you plan to return C. If B is no, do you have anoth D. What kind of job is it? OR	n to the sa ner job in	me kind of work? view?     Yes	Yes No
15.	What means of support will you h	nave when y	ou leave hospita	1?
	☐ A. salary ☐ B. family support ☐ C. personal insurance ☐ D. company pension ☐ E. rentals ☐ F. savings or securities ☐ G. Old Age Security ☐ H. Old Age Assistance	□ J. □ K. □ L. □ M. □ N.	Mothers! Allowa Disabled Person Blind Persons A War Veterans Al Workman's Compe Unemployment In no income	s Allowance llowance lowance or Assistance nsation
16.	Do you have Health Insurance?		Shield time Medical Car r Health Insuran	
17.	How long have you had this illne	ess?	months;	years
	AHave you been in hospital before Chronic illness? Tyes No No B. If yes, how many times? C. How long were you in hospital First: Second: Third: Fourth Etc.	times each time?		No; with other  months "" "" "" ""
	Preamble			,
19.	Have you used any of the following	ing health	organizations?	
	☐ A. Red Cross Society ☐ B. Victorian Order of Nurses ☐ C. Arthritis and Rheumatism S ☐ D. Maritime Paraplegic Associ ☐ E. Halifax Visiting Dispensar	Society Clation	lG. Walter Callo ]H. Polio Founda	tion outpatient dept.

- 3 -

•	Were you satisfied with the help which you received from this (these) organizations?				
	A. Was there some medical help which you needed and did not get?   O Yes  B. What was it?				
	When you leave hospital what medical help do you think you will need?				
	□ A. Doctor's care □ B. Nursing care □ C. Drugs and dressings □ D. Special diet □ D. Special diet □ E. Homemakers' service □ F. Physiotherapy □ G. Medical appliances and equipment □ H. Don't know				
	Interviewer's Comments				
	A. Patient after leaving hospital needs -				
	□ a. Doctor's care □ e. Homemakers' service □ b. Nursing care □ f. Physiotherapy □ c. Drugs and dressings □ g. Medical appliances and equipment □ d. Special diet □ h. Don't know				
	B. Degree of Disability -				
	Chair bound  Co. Other				
	C. Is job retraining necessary or feasible?    necessary				
	D. Patient was				
	Junable to participate and no information obtained				
	Refer to Social Service Yes No				

### List of Communities - Metropolitan Area

ARMDALE

BEDFORD

BIRCH COVE

BOULDERWOOD

BURNSIDE

Maphrolitale\_1s

and Francisco

COLE HARBOUR

DARTMOUTH

EASTERN PASSAGE

FAIRVIEW

FERGUSON'S COVE

HALIFAX .

IMPEROYAL

JOLLIMORE

KLINE HEIGHTS

LAKESIDE

MELVILLE COVE

MILLVIEW

PORT WALLIS

PRINCE'S LODGE

PURCELL'S COVE

ROCKINGHAM

SPRYFIELD

TUFT'S COVE

WESTPHAL

WOODLAWN

WOODSIDE

# Classification of Diagnosis

### GASTRO-INTESTINAL SYSTEM

Rectal abscess
Caecostomy
Ulcerative colitis
Dyspepsia — functional
Hernia
Ulcer — peptic & perforated

#### GENITO-URINARY SYSTEM

Nephrolithiasis
Acute retention
Undescended testicles
Uraemia

#### CARDIOVASCULAR SYSTEM

#### 1. Cardiac

Cardiac disease
Cardiac infarction
Congestive heart failure
Coronary thrombosis
Hypertension
Myocardial infarction
Rheumatic heart disease

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2. Blood diseases

Hemophilia

Leukemia

Sickle cell anemia

#### CENTRAL NERVOUS SYSTEM

Glaucoma Cerebral vascular accident

### LOCOMOTOR SYSTEM

Practured hip Polyarthritis Varicose ulcer Arthritis

### PULMONARY DISEASES

Asthma Bronchiectasis Pulmonary oedema Lung abscess

#### METABOLIC DISEASES

Addison's disease Diabetes

#### OTHERS

Cancer
Tuberculosis
Cellulitis
Leukoplakia (skin)
Lupus erythematosis

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