1950

A study of the social factors in patients with a diagnosis of multiple sclerosis referred to the social service department, Massachusetts General Hospital 1945-1949

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Boston University

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Boston University
A STUDY OF THE SOCIAL FACTORS IN PATIENTS WITH A DIAGNOSIS OF MULTIPLE SCLEROSIS REFERRED TO THE SOCIAL SERVICE DEPARTMENT, MASSACHUSETTS GENERAL HOSPITAL 1946 - 1949

A Thesis

Submitted by
Annette Fisher
(A.S., Hunter College of the City of New York, 1946)

In Partial Fulfillment of Requirements for
the Degree of Master of Science in Social Service 1950

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with a diagnosis of multiple sclerosis who were known to the Massachusetts General Hospital, either as hospital patients, clinic patients, or both between January 1, 1945 and December 31, 1949 and who were referred to the Social Service Department, Neurological Service at some time during this period. Some of these patients were known to the hospital or clinic prior to 1945, either because of the multiple sclerosis or for the treatment of
with a diagnosis of multiple sclerosis who were known to the Massachusetts General Hospital, either as hospital patients, clinic patients, or both between January 1, 1945 and December 31, 1949 and who were referred to the Social Service Department, Neurological Service at some time during this period. Some of these patients were known to the hospital or clinic prior to 1945, either because of the multiple sclerosis or for the treatment of other conditions but were not referred to the Social Service Department until 1945 or later. Between 1945 and 1949 seventy patients in all with a diagnosis of multiple sclerosis, were referred to the Social Service Department. Of these thirty-four were classified as intake cases and have been completely omitted from the study, as only the very briefest of social information was recorded for them. On some of the thirty-six cases selected for presentation in this study, sufficient material is available for case illustration, while information available regarding some of the other cases will lend itself only to specific statistical use.

The years 1945 to 1949 were chosen as a basis of case selection for two reasons: (1) since multiple sclerosis is a relatively rare disease (when compared to all diseases in general), a period of several years was found to be necessary in order to present a sufficient number of cases from which some conclusions can be drawn; (2) these years are recent enough to reflect the current use of the Social Service Department.

Sources of Information

The sources of the material used in this study were medical records, the social service sheets ("pink sheets") which are attached to the medical records, carbon copies of the letters written and referral forms used by the Social Service Department and pamphlets and other published material relating to multiple sclerosis. Since it is the practice of the Social
Service Department to have complete case histories written on only selected cases and those carried by students, the material in the majority of cases studied represents a compilation of material largely from the other sources mentioned above. The medical records, all thirty-six of which were read, were used as a source of identifying factual information and material related to medical aspects including diagnosis and treatment.

A schedule listing the items considered to be relevant to this study, including social and medical factors and social needs of the individual patients, was devised and filled out for each of the thirty-six patients studied; the data thus secured was classified and evaluated.

Limitations

The limitations of the study and of the method adopted became more apparent as the work progressed. Almost nothing has been written about multiple sclerosis, other than the material available on the medical aspects of the disease; except for the article by Longworthy, social implications, emotional and psychiatric factors have apparently not yet been studied to any great extent or at least no such material has been published.

Another limitation was found in the nature and content of the records from which data were obtained. In only four of the cases studied were comprehensive social case histories available; in the remainder of the cases studied the bulk of the social information was recorded on the social service sheets attached to the medical records, and in many instances these

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1 For copy of schedule, see pages 66-67
3 Leo Alexander, M.D. and Rosalind Hermann, Social Worker, Lecture
were comparatively brief; much intensive case work service extending over a long period of time was thus summarized rather than recorded in detail. The social service records are written to serve the practical purposes of this Department and the hospital of which it is a part, and consequently, they often do not contain details which would be useful in a study such as this. Information (as for example, amount of income, composition of household, etc.) might be available for some cases and not for the remainder; therefore, many times comparable information for all cases was not obtainable. Often final disposition of cases or time at which service was rendered was not clear. Likewise medical records, which were the sources of certain data, were written by physicians for their specific purposes and use and do not record much material that would be relevant for and valuable to this study.

The selectivity of the cases both from the point of view of their having been referred to the Social Service Department (usually by physicians) and their having been accepted by this Department for fairly extensive study, would seemingly predispose this group to be composed of persons with the more obvious problems, many of these closely related to medical care and treatment. However, the degree of bias thus resulting and its relation to the representativeness of these patients as typical of other multiple sclerosis patients cannot be determined within this thesis.

given at a meeting of the American Association of Medical Social Workers at the Pratt Diagnostic Clinic, Boston, Massachusetts, on research on multiple sclerosis being conducted at Beth Israel Hospital and the Boston State Hospital.
CHAPTER II
BACKGROUND OF STUDY

History of the Massachusetts General Hospital

The Massachusetts General Hospital has been engaged in giving medical
care to sick people for well over one hundred years. In 1811 a corporation
was formed in Boston "for the erection, support, and maintenance of a gen-
eral hospital for sick and insane persons." McLean Hospital, the psychi-
atriic division, now located in Waverley, was first opened in Somerville in
the year 1818. "When the doors of the Massachusetts General Hospital were
opened three years later, in 1821, it was the third general hospital in the
United States and the first in New England."¹

Medical services began in the old Bulfinch Building which at the
present time is still in use; in the old days deliveries of patients, foods,
and supplies could be made by the water route of the Charles River almost
at the doors of this building.

Massachusetts General Hospital is a non-sectarian, voluntary hospital,
supported by private contributions and United Community Services in addition
to the fees of those patients who are able to pay.

Number of People Treated Each Year

The Massachusetts General Hospital has the capacity to care for
approximately a thousand in-patients. A recent yearly record shows that
15,056 bed patients were admitted in one year. These patients received

¹ Massachusetts General Hospital, For Employees, p. 7.
262,297 days of care and 719 was the daily average of patients in hospital beds. In addition to these in-patients, 164,333 visits were made by people to the Out-Patient Department, and of these 11,641 were new patients.

Teaching

The Massachusetts General Hospital is one of the most famous medical training and research institutions in the United States. From the original affiliation with the Harvard Medical School the educational activities and facilities have expanded greatly. Training is provided for medical students, doctors, nursing students, dieticians, school of social work students, and students of occupational and physical therapy. A course of training is also available for medical record librarians and medical illustrators; field experience is provided for young ministers.

Hospital Buildings

Activities of the hospital are carried on in ten major buildings in the hospital area and several residences and maintenance shops on adjacent property. Following is a list of the six major units of the hospital: the General Hospital for patients who are furnished physicians services by the resident staff and visiting staff without charge and who pay for hospitalization in accordance with their financial means; the Out-Patient Department for clinic patients, the Baker Memorial for private hospital patients of moderate financial means, Phillips House for private patients, the Emergency Ward which offers medical treatment to all classes of patients requiring emergency attention, Vincent Memorial Hospital-Burnham Memorial, the former provides gynecological surgery, medicine, radiology, endocrinology and investigation, the latter provides hospital care for children.2

2 Ibid., pp. 7 - 11.
History of the Social Service Department

Medical social service had its beginnings in Massachusetts General Hospital in the year 1905. "Prior to this time such service was unknown; now no hospital in the United States, of any size and of high standard, is without such a department and in many other countries the example has been followed." Doctor Richard C. Cabot, then Out-Patient Department Physician, initiated medical social service, with two social workers being employed to attempt to make medical care more efficient by working with factors in the patient's social environment or personal life that interfered with the carrying out of medical recommendations. In 1948 there was a staff of thirty-five professional social workers covering every clinical service of the hospital, both ward and out-patient, including the two private units.

In 1948 the department gave service to approximately ten thousand patients. Referrals to the Social Service Department were made for a variety of reasons: additional social study and review, discharge planning, rehabilitation planning so that the patient could function on a more adequate and satisfying level, chronic and terminal care, arrangements for transportation to and from the hospital, and other social and emotional problems in the area of family and community living and relationships. Teamwork in the care of the patient, in his diagnosis and treatment by the physician, social worker, and other professional hospital personnel, is an integral part of the hospital setting. "The work of the department has shared the goals and aims of the hospital in its three functions: complete

3 Josephine C. Barbour, Social Service Affairs, p. 3.
care of the patient, teaching, and research to improve that care."

History of the Neurological Service

The Department of Neurology had its beginning in 1872, when the Board of Trustees established the office of Electrician and specified that his "duties shall be to take charge and proper care of all magnetic and electrical apparatus . . . , and administer magnetism and electricity to patients, whenever called upon by the Physicians and Surgeons." The next year the title of Electrician was changed to Physician to Out-Patients with Diseases of the Nervous System. There was no house service for neurology until many years later although in 1903, neurology had been assigned the glorious total of two beds.

In 1926 a neurological and neuro-surgical ward was finally opened on the first floor of the Bulfinch Building; in 1934 the wards were moved to temporary quarters in the Baker Memorial, and in 1940 were assigned to their present location on the eleventh floor of the new White Building.

Soon after the establishment of the house service a weekly staff conference was initiated. At present these conferences are held in the Ether Dome every Thursday morning. Interesting cases of the neuromedical, neurosurgical and psychiatric services are demonstrated and discussed. The meetings are attended by the members of the department, medical students, visiting physicians, social service staff, and members of other departments of the hospital.

Description of the Nerve Clinic and the Neurological Service

Multiple sclerosis patients, along with patients having other

4 Ibid., p. 3.
5 The Massachusetts General Hospital News, pp. 1 - 2.
neurological diseases, are treated on an out-patient basis at the Nerve Clinic and if requiring hospitalization, are admitted on the Neurological Service. At the clinic no special division exists for multiple sclerosis patients, nor is any particular session reserved for them; they are seen during regular nerve clinic sessions at the same time as patients with many other diagnoses.

The Nerve Clinic meets every morning including Saturday, but Thursday morning is reserved for neurosurgical patients. Patients are referred to the clinic by local medical doctors, other clinics within the hospital, in-patient hospital services, other hospitals and outside clinics, social agencies and by themselves. The clinic admission fee is $2.25; the Admitting Nurse, however, must determine by discussion with the patient (or family) whether or not he is financially eligible for admission to the clinic, or if he needs hospital care, to the hospital, and establish a rate if he is unable to meet the regular fees. The Admitting Nurse also directs new clinic patients to the proper clinic as they describe their symptoms and complaints (if not accompanied by a physician's note). If a particularly complex or vague medical picture is presented and the nurse does not feel herself qualified to make a decision, the patient is referred to the Medical Clinic for screening and referral to the indicated clinic.

In general, the patients at the Nerve Clinic are sixteen years of age and older, but children may also be referred by the Children's Medical Clinic for a specialist's opinions and recommendations.

Hospital and clinic staff constitute one organization; that is, the same physicians see the patients whether they are in or out patients. The patients are seen routinely by the resident, the assistant resident, and house officers of the Neurological Service, by clinical fellows, by visit-
ing physicians and by medical students.

Patients are referred for hospitalization on the Neurological Service by the clinic, their own physicians and other medical agencies. If an emergency does not exist, they are put on a waiting list and admitted as a bed becomes available. Many multiple sclerosis patients are not hospitalized; in general, they are admitted to the hospital primarily for study before a definite diagnosis has been established and if hospital care becomes necessary at the time of acute exacerbation of their symptoms.

Because of the nature of multiple sclerosis, its many remissions and exacerbations, the lack of specific treatment, multiple sclerosis patients are not seen at the clinic at definite routine time intervals but according to their individual needs. If they are in an acute phase of their disease, they may be seen every few weeks; if, in remission, they may not need to return for many months. Very often, because no cure exists for multiple sclerosis, patients become discouraged and discontinue treatment entirely. No routine follow-up of patients who have lapsed from treatment is attempted, again, because actually no definite treatment or medical recommendation that will markedly alleviate the course of their disease can be given to these patients.

Social Service

One social worker carries the responsibility for both the Nerve Clinic and the Neurological Ward Service. Patients are referred to her by any of the hospital physicians, other hospital personnel, social agencies, or patients, themselves. There is no one hundred per cent coverage of any particular group of patients. Problems may range from the rather routine procedure of arranging for transportation to a complex problem of social relationships.
Special problems confronting the worker on the Neurological Service are the chronic nature of many of the diseases, lack of medical knowledge of cause and specific treatment of the illness, the fact that many patients because of their mental status are unable to assume responsibility for working out plans for their future care.
CHAPTER III
MULTIPLE SCLEROSIS, A CHRONIC DISEASE

Definition

Multiple sclerosis, also known as disseminated sclerosis, is a chronic, progressive disease syndrome of the central nervous system. In the normal, healthy individual the nerve fibers are covered throughout their entire length with a fatty sheath called myelin, whether they be in the spinal cord, brain or in the body proper. In multiple sclerosis, one finds many areas in the brain and spinal cord, scattered indiscriminately throughout the central nervous system, in which this myelin has been dissolved or destroyed. The method by which this dissolution or destruction is accomplished is unknown. The dissolved myelin is replaced by scar (sclerotic tissue), from which the disease derives its name.

The myelin sheath acts like the insulation on an electric wire and, when this insulation is wholly or partially gone, the nerves are so affected that nerve impulses are unable to pass through them properly. The nerve impulses either are completely stopped, producing paralysis of the parts of the body innervated by these nerves, or the impulses come through the affected nerves altered or enfeebled, so that those parts of the body innervated by such nerves perform their functions in a disturbed manner.

Types

Four clinical types of multiple sclerosis have been defined. "The

1 Nine Basic Projects - Seeking the Way to Stamp out Multiple Sclerosis.
commonest and most characteristic type is (1) that with outbursts (attacks) and remissions, and (2) the chronic progressive type ranks next in frequency, followed by (3) the stationary type, and (4) the acute type (acuteness of onset of a massive array of disturbances). The four categories are useful although they are not entirely distinct from each other; for instance, acuteness of onset has no relation to the future course in terms of type one or type two.\(^2\) Or quite commonly, a case which for a long period has been characterized by exacerbations and remissions may ultimately become chronically and steadily, although slowly progressive.

**Symptoms**

Since multiple sclerosis is a disease of the central nervous system, its symptoms may be present in almost every part of the body resulting in widespread discomfort and suffering to the victim. It is characterized essentially by a variety and multiplicity of signs and symptoms which do not fit into any one entity, but vary with the part of the nervous system involved. Most common symptoms are: disturbances of vision such as double vision; tremors of parts of the body (involuntary quivering); bladder trouble; weakness; difficulty in walking and balancing; numbness of parts of the body; speech difficulties; emotional disturbances.

To elaborate on some of the above symptoms: in addition to double vision other disturbances of vision may include impairment of the visual fields, especially central scotoma, retrobulbar neuritis, strabismus, and nystagmus (involuntary movement of the eyeballs). Persistent blindness

occurs very rarely but vision may be permanently markedly diminished. Tremor is another very characteristic sign of multiple sclerosis. Although the actual mechanism of the tremor is not yet clear, there is a cerebellar possibly a rubral component to it. There is an intention element, an aggravation by purposive effort. The tremor comes on gradually, usually in the upper extremities, frequently becomes violent. It may indeed, ultimately become so violent as to interfere with writing, dressing, feeding or other manual activity. Even an attempt to speak may create or intensify the tremor. The speech disturbance is usually characterized by scanning or explosive utterances, slowing, and halting; it may become slurred and monotonous. Irregular pauses make the speech difficult to follow, so that patience is required of the listener. Although some patients are seemingly unaware of this difficulty, others, in whom it occurs early, are sensitive and need to be given time to express themselves fully. Three of the above signs, nystagmus, tremor and scanning speech, constitute the classical triad of Charcot and used to be considered as the syndrome of multiple sclerosis. But, while this triad is frequently present, especially in the later stages, it does not by any means constitute the whole clinical picture.

The patient may have weakness in one or both legs or arms. He may have a slight limp or impaired grip or he may have paralysis with inability to move one or more of his extremities. At first there may be gradual difficulty in walking; the gait becomes spastic, there is increasing hypertonicity or stiffness of the lower limbs. Finally he may become unable to walk, or if he can walk, may stagger so much that it is dangerous for him to walk on busy streets or in places where staggering may result in injury.
Mild disturbances in the function of the bladder, such as partial retention, slight incontinence or frequency are common transitory complaints during the course of the illness. Later complete urinary, and much more rarely, rectal incontinence indicate severe sacral cord involvement. Sexual impotence in the male and anesthesia in the female are not uncommon.

Emotional disturbance as manifested in multiple sclerosis will be discussed later.

Diagnosis

Diagnosing multiple sclerosis in the early stages is a problem for the doctor. Its course is episodic in nature; that is, there is gradual progression with temporary remission, followed by further progress and other remissions until there is steady aggravation of all symptoms. Occasionally an acute attack will move rapidly to a fatal outcome. Usually the symptoms are slowly progressive and the patient becomes increasingly helpless. At times the patient may have a remission of the disease and appear to improve. Then he suffers a relapse, his former symptoms recur and new symptoms develop. Multiple sclerosis patients have been known to get well spontaneously. Again, the reason is unknown. As has been said, multiple sclerosis in its early phases is difficult to diagnose. It cannot always be safely recognized by the physical signs alone but by its behavior in time, that is, by the sequence of events which have led to the condition found on examination. Because of frequently mild and fleeting symptoms

4 National Multiple Sclerosis Society, You Can Help to Find the Secret!
(blurred vision, weakness and heaviness of legs, etc.), a diagnosis may not be made until several years after the onset of symptoms.

**Course and Prognosis**

"The course of the disease is chronic, progressive with numerous remissions and exacerbations. The remission generally is a functional one, the organic signs rarely showing actual regression." The duration of the disease varies, from one or two years to twenty or more years. It is, however, common for patients to continue in a state of reasonable function for as long as eight or ten years, and much longer periods are not rare. The prognosis depends upon the course of the disease and its underlying cause. The outlook as to life is not bad; as to recovery, not favorable. Many patients are incapacitated; they become bedridden and some intercurrent disease leads to a fatal termination.

**Etiology and Treatment**

"Practically nothing is known about the cause and control of multiple sclerosis and current methods of treatment are still in the stage of experimentation." Since the etiology is unknown, a specific treatment has not yet been found. There is at present no form of medication or other therapy that has any certain influence upon the course of the disease. The most common recommendations are for the patient to avoid fatigue, overwork, emotional disturbance, infections, and to keep as well nourished as possible. Medications to "build the patient up" are often prescribed.

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5 F.M.R. Walshe, *Disease of the Nervous System*, p. 163.
6 Wechsler, op.cit., p. 556.
7 Ibid., p. 558.
8 National Multiple Sclerosis Society, *Light ... On a Medical Mystery*, p. 5.
At the present time research projects relating to various aspects of multiple sclerosis are being conducted in many sections of the United States.

Prevalence of Multiple Sclerosis

Multiple sclerosis was first identified nearly eighty years ago by the eminent French neurologist, Jean Martin Charcot. At first considered a rare disease, modern diagnostic methods have established multiple sclerosis as a common nerve disorder. Reports from various parts of this country seem to indicate that multiple sclerosis is on the increase; this is also true of European countries. It is a disease that appears to be most common in cold, damp climates; in the United States it occurs most frequently on the North Atlantic Coast, in the Great Lakes region and the Northern Plains; it occurs most rarely in the Southern States.

Wechsler states that heredity plays no role in multiple sclerosis although isolated cases have been reported in mothers and children. It is extremely doubtful whether the disease is congenital.

Emotional Factors

"A certain group of patients with multiple sclerosis show personality problems at the onset or during the course of the disease. In some cases the symptoms develop or increase during periods of turmoil in interpersonal relationships... Even after the organic damages are clearly manifest, the patient may complain of symptoms which are largely or purely functional.

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9 National Multiple Sclerosis Society, Light... On A Medical Mystery, p. 5.
10 Wechsler, op. cit., p. 561.
It has long been known that patients with well developed symptoms of multiple sclerosis show emotional instability. This has been attributed to organic changes in the brain, releasing more labile emotional patterns. It is thought that euphoria is highly characteristic of multiple sclerosis. Forced crying or forced laughter may occur without relationship to the emotions which usually evoke these reactions. Such outbursts may be precipitated by drinking hot liquids; or by a variety of odors, sounds or sights. Many patients are neither sad, depressed nor dejected, as might be expected under the circumstances; in that case they exhibit what one might term a relative euphoria. On the other hand, many patients are relieved to have all responsibility taken away from them by an outside agent, and to be sure of having their basic needs fulfilled. Many patients can therefore adjust to such a situation easily, and this may account for lack of depression in some cases.

The physician is frequently confused at the time of the onset of the first symptoms as to whether they have an organic or functional basis. It has been apparent to physicians that poor emotional adjustment was a problem in many cases of multiple sclerosis, even before the onset of organic symptoms. In these cases patients may be emotionally immature and exhibit their immaturity in all areas of interpersonal relationships. It is often seen, especially in the area of sexual adjustment, which can be evaluated at a pre-adolescent level of emotional growth.

The diagnosis of hysteria is frequently made at the onset of symptoms

not only because of the complex nature of the complaints but especially because of a personality structure consistent with the diagnosis. Later, when organic signs appear the diagnosis is changed to multiple sclerosis.

It would be logical to consider what the functional and organic factors are in the disease, and what relationship there may be between the two factors. The old concept that a patient is either hysterical or has a definite organic disease should be abandoned. Often symptoms of hysterical conversion develop in patients who have already been diagnosed as having multiple sclerosis.

"Multiple sclerosis is an outstanding social problem which has been sorely neglected. It is a disease of the young adult, stricken during the most productive period of life when he should make his greatest contribution to society and has become the young parent of children who look to him for guidance and support."

Age and Sex

There is no agreement among various authorities consulted as to whether multiple sclerosis occurs more frequently in men than in women or in women than in men. Of the thirty-six multiple sclerosis patients whose records were used as a basis for this study, nineteen were men and seventeen were women, an almost equal division. No conclusions can be drawn from this sample, however, both because of the selectivity factors involved and the relatively small number of cases involved.

Multiple sclerosis is essentially a disease of early adult life, most cases occurring between twenty and forty years of age. It is considered to be very rare in children. The ages of the patients in this study range from fifteen to sixty-seven. The age range for the males is from twenty-five to fifty-nine, whereas, for the females it is from fifteen to sixty-seven. The study of distribution according to sex is recorded in Table I.

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1 National Multiple Sclerosis Society, Join AARMS Against Multiple Sclerosis.
### TABLE I

**AGE AND SEX DISTRIBUTION OF PATIENT GROUP**

<table>
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<th>Males</th>
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<tr>
<td><strong>Total</strong></td>
<td>19</td>
<td>17</td>
<td>36</td>
</tr>
</tbody>
</table>

According to Richard M. Brecker, M.D., multiple sclerosis occurs frequently in the second decade, begins very commonly in the third, often in the fourth, sparsely in the fifth and sporadically thereafter. This observation seems to be borne out somewhat in the above statistics where it is noted that two patients ranged in age from fifteen to nineteen, six patients from twenty to twenty-nine, fifteen from thirty to thirty-nine, eight from forty to forty-nine, four from fifty to fifty-nine, and one from sixty to sixty-nine. Fifty-eight per cent of the patients studied are found in the age range from twenty to forty which agrees with other studies that have determined that most cases occur between twenty and forty. It should be noted, however, that many of the patients studied have been victims of

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2 Brecker, *op. cit.*, 745.
multiple sclerosis for several years and the ages recorded in Table I indicate not the age at onset of the disease but age at the time of referral to the Social Service Department. This aspect (duration of symptoms) will be discussed later in this chapter.

As with any other chronic disease, the age at which the person is affected is an important determinant in the meaning the illness will have to the patient, both socially and emotionally. Unfortunately, in multiple sclerosis, it is found that the victims are primarily young people who are handicapped during what should be the most productive period of their lives; men who are the breadwinners for young families, women who have the responsibility and care of households and young children.

Color, Religion and National Background

The color, religion and national background of the individual all affect his personality structure and may affect how he will react to a chronic illness, what it will mean to him, how he will cope with the many problems it will entail, the changes it will necessitate from his former mode of living. The color and religion of the patient will affect the community resources available for him.

Wechsler, in *A Textbook of Clinical Neurology*, has stated that multiple sclerosis is extremely rare in the Negro. It is interesting to note that none of the patients in this study were Negroes; of course, the reasons for this cannot be determined by the writer, whether caused by the rareness of the disease among Negroes or the fact that Negroes suffering from this disease might resort elsewhere for treatment. All thirty-six patients studied were of the white race.

In making plans for convalescent or chronic care for the patient, his religion as well as his color, are important factors in the type and
availability of care that will be accessible. In referring the patient to family and other community agencies for case work service his religion is again an important factor. Of the patients in this study group eleven were Protestants, twenty-two Catholic, two Hebrew, and one Greek Orthodox.

Twenty-eight or slightly more than seventy-seven per cent of the thirty-six patients were of native birth. The remaining eight patients were born in six different foreign lands; several of these had come to the United States as adults and were consequently handicapped by language difficulties. Their fears would tend to be intensified by their difficulty in understanding or in making themselves understood, and interpretation of their illness would be that much more of a problem.

Geographic Location

An important question, in reference to availability of expert medical opinion, treatment, community resources for care of the patient, is his place of residence. With a disease as baffling and obscure as multiple sclerosis, it is to be expected that persons having the disease or displaying the multiplicity of symptoms inherent in it, would be referred from various parts of the state to as famous a medical institution as the Massachusetts General Hospital. In Table II it is noted that of the thirty-six patients in the study group only three resided in Boston, the remainder being located in twenty-six communities at small or great distance from Boston.
### Table II
GEOGRAPHIC LOCATION OF PATIENT GROUP

<table>
<thead>
<tr>
<th>City or Town</th>
<th>Number of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arlington Heights</td>
<td>1</td>
</tr>
<tr>
<td>Ayer</td>
<td>1</td>
</tr>
<tr>
<td>Boston</td>
<td>3</td>
</tr>
<tr>
<td>Brockton</td>
<td>2</td>
</tr>
<tr>
<td>Cambridge</td>
<td>2</td>
</tr>
<tr>
<td>Chelsea</td>
<td>1</td>
</tr>
<tr>
<td>Cochituate</td>
<td>1</td>
</tr>
<tr>
<td>East Walpole</td>
<td>1</td>
</tr>
<tr>
<td>Everett</td>
<td>2</td>
</tr>
<tr>
<td>Fitchburg</td>
<td>1</td>
</tr>
<tr>
<td>Green Harbor</td>
<td>1</td>
</tr>
<tr>
<td>Holyoke</td>
<td>1</td>
</tr>
<tr>
<td>Lowell</td>
<td>1</td>
</tr>
<tr>
<td>Lynn</td>
<td>2</td>
</tr>
<tr>
<td>Malden</td>
<td>1</td>
</tr>
<tr>
<td>Manchester</td>
<td>2</td>
</tr>
<tr>
<td>Milton</td>
<td>1</td>
</tr>
<tr>
<td>Newton Center</td>
<td>1</td>
</tr>
<tr>
<td>Somerville</td>
<td>2</td>
</tr>
<tr>
<td>Springfield</td>
<td>2</td>
</tr>
<tr>
<td>Taunton</td>
<td>2</td>
</tr>
<tr>
<td>Uxbridge</td>
<td>1</td>
</tr>
<tr>
<td>Webster</td>
<td>1</td>
</tr>
<tr>
<td>Winchester</td>
<td>1</td>
</tr>
<tr>
<td>Winthrop</td>
<td>1</td>
</tr>
<tr>
<td>Woburn</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>36</strong></td>
</tr>
</tbody>
</table>

Many of these patients live at such a great distance from Boston that it would be a hardship for them to attend clinic regularly if this were recommended. This would be especially true of the severely handicapped patient, who might find it difficult to report to clinic from even a relatively short distance. Most of the local communities, however, are too small and isolated to afford the facilities and resources needed in the medical and social care of the patient group.
It is comforting to observe that physicians have an awareness that patients displaying the symptoms of multiple sclerosis may have a serious organic disease and should be referred for expert medical advice or diagnosis if this has not been established. Table III shows that of the thirty-six patients studied twenty-eight or over 77 per cent were referred to the hospital or clinic by their local medical doctors, three or over 9 per cent were referred by outside hospitals or clinics, three were referred by themselves. The source of referral for two or over 5 per cent is unknown.

**TABLE III**

**SOURCE OF REFERRAL TO HOSPITAL OR CLINIC**

<table>
<thead>
<tr>
<th>Source of Referral</th>
<th>Number of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Local medical doctor</td>
<td>23</td>
</tr>
<tr>
<td>Other hospital or clinic</td>
<td>3</td>
</tr>
<tr>
<td>Self</td>
<td>3</td>
</tr>
<tr>
<td>Unknown</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>36</td>
</tr>
</tbody>
</table>

**Onset of Symptoms**

Varying degrees of time elapsed for the thirty-six patients, between the time of onset of symptoms and the date on which they became known to the Massachusetts General Hospital. This can be attributed to various factors. In many cases, the first symptoms were fleeting in nature and the patient recovered spontaneously after a relatively short period of time. He may have consequently ignored these signs and not sought medical advice; additional symptoms may not have appeared for a number of years. In some cases, the patients were under treatment elsewhere before being referred to the
Massachusetts General Hospital for diagnosis or for medical recommendations when the diagnosis had already been established. At times, when the diagnosis could not be determined patients went from doctor to doctor always seeking the explanation for their disability. Not only was the disease itself disturbing to them, but the fact that no doctor could seem to discover what was wrong with them aggravated the concern they felt.

The precise reasons in each case, for the length of time elapsing between onset of symptoms and date on which the patient appeared at Massachusetts General Hospital, could not be determined by the writer's reading of medical records. In addition, it is often difficult for the physician to evaluate what were actually the first symptoms of multiple sclerosis, both because of the previously described momentary and fleeting nature of the symptoms and because other illness of the patient often confused and obscured the medical picture; sometimes only by very careful questioning could the physician elicit a description of symptoms that the patient had ignored and almost forgotten. Consequently, the lapse of time can only be estimated, not determined exactly.

As can be seen in Table IV periods of time ranging from less than one year (at times several days when symptoms were very acute) to over ten years elapsed before patients with multiple sclerosis were known to the Massachusetts General Hospital. Ten or over 27 per cent of the patients studied, turned to the Massachusetts General Hospital for care after having symptoms for less than one year, and at the other range of the scale, for six or over 16 per cent of the patient group over ten years had elapsed.
TABLE IV
AMOUNT OF TIME ELAPSING BETWEEN ONSET OF SYMPTOMS AND PATIENTS BECOMING KNOWN TO THE MASSACHUSETTS GENERAL HOSPITAL

<table>
<thead>
<tr>
<th>Time Elapsed</th>
<th>Number of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than one year</td>
<td>10</td>
</tr>
<tr>
<td>One year</td>
<td>5</td>
</tr>
<tr>
<td>Two years</td>
<td>4</td>
</tr>
<tr>
<td>Three years</td>
<td>3</td>
</tr>
<tr>
<td>Four years</td>
<td>2</td>
</tr>
<tr>
<td>Five years</td>
<td>2</td>
</tr>
<tr>
<td>Six years</td>
<td>1</td>
</tr>
<tr>
<td>Seven years</td>
<td>1</td>
</tr>
<tr>
<td>Eight years</td>
<td>0</td>
</tr>
<tr>
<td>Nine years</td>
<td>0</td>
</tr>
<tr>
<td>Ten years</td>
<td>1</td>
</tr>
<tr>
<td>Over ten years</td>
<td>6</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>35</strong></td>
</tr>
</tbody>
</table>

* In the case of one patient the lapse of time could not be estimated since the patient had been hospitalized several times for other illnesses; there was a definite hysterical component in his illness, he was known to a number of clinics for a variety of symptoms. Therefore, the time of onset of symptoms of multiple sclerosis would be most difficult to judge.

Type of Contact with Hospital

Of the thirty-six patients studied, twelve were known only to the clinic, that is, were never hospitalized at the Massachusetts General Hospital, five were known only to the hospital, that is, were never clinic patients, and nineteen were known both to the clinic and the hospital. Hospitalization was usually recommended for a period of study when a definite diagnosis had not been established, to consider future method of treatment for patient, or at the time of acute exacerbation of symptoms.

The number of Nerve Clinic visits for the individual patient ranged
from two to over thirty; at times of remission of symptoms patients often did not keep their appointments, and might not return to the clinic for several years. At time of exacerbation, they might attend every few weeks. Usually if a patient did not keep his appointment no follow-up was attempted; this can be attributed to lack of specific treatment for the disease. There seems to be little relationship between severity of symptoms and number of clinic visits or length of time known to the clinic.

Marital Status

The patient's marital status and mode of living will have a profound effect upon plans made for his care and upon physical and mental adjustment to his illness. Patients with a relatively minor handicap who need comparatively simple care but who live alone and have no relative with whom they can stay, must frequently go to a nursing home or institution for chronic care. In other cases, the patient may be severely incapacitated and require quite extensive care, but because of the household arrangements may be able to remain at home and receive adequate attention. An older woman having few household responsibilities may be able to continue to manage alone at home, while a young mother with several small children may need outside help in the management of her home.

As is to be expected, since most of the patients affected with multiple sclerosis are between twenty and fifty years of age, the great majority are married.
TABLE V
MARITAL STATUS

<table>
<thead>
<tr>
<th>Marital Status</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>14</td>
<td>10</td>
<td>24</td>
</tr>
<tr>
<td>Single</td>
<td>3</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Widowed</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Divorced</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>19</td>
<td>17</td>
<td>36</td>
</tr>
</tbody>
</table>

The above Table shows that out of a patient group of thirty-six, twenty-four are married, seven are single, two are divorced, and three are widowed. Since two of the girls are under eighteen, they are probably not expected to be married.

TABLE VI
MODE OF LIVING

<table>
<thead>
<tr>
<th>Mode of Living</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse</td>
<td>4</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Spouse and children</td>
<td>10</td>
<td>6</td>
<td>16</td>
</tr>
<tr>
<td>Children without spouse</td>
<td>0</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Parent(s)</td>
<td>2</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Other relatives</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Alone</td>
<td>3</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>19</td>
<td>17</td>
<td>36</td>
</tr>
</tbody>
</table>

Table VI shows that of the thirty-six patients, twenty-four of whom are married, six were living with their spouses, sixteen with spouse and children, three with children without spouse, six with parent or parents, two with other relatives, and three alone. Two of the women were living alone with
their young children as their husbands were in the Service (known to the Social Service Department in 1945); both husbands later received dependency discharges. A widow lived alone with her son. One male patient, who was divorced from his wife, was together with his two children living with his parents. One of the women patients, who was a widow was together with her four children, living with her parents.

The statistics on the tables do not reveal the capacity of the members of the patient's household to care for him, nor what members of the household may have been dependent upon the patient. Many of the younger married patients had several small children.

Material was not available on a sufficient number of the thirty-six patients to show statistically in what type of dwelling they lived.
CHAPTER V
SOCIAL CHARACTERISTICS OF PATIENTS WITH A DIAGNOSIS OF MULTIPLE SCLEROSIS

Sources of Referral of Patients to the Social Service Department

The social worker on the Neurological Service of the Massachusetts General Hospital does not automatically review the situation of all patients with a diagnosis of multiple sclerosis, but considers the needs and problems of those patients referred to the department. The sources of referral to the Social Service Department of the thirty-six cases used as the basis for this study are presented in Table VII. These thirty-six cases are that portion of the seventy multiple sclerosis patients who were referred to the Social Service Department between 1945 and 1949 regarding whom sufficient information for the purposes of this study was available.

TABLE VII
SOURCE OF REFERRAL OF PATIENTS TO THE SOCIAL SERVICE DEPARTMENT

<table>
<thead>
<tr>
<th>Source of Referral</th>
<th>Number of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician</td>
<td>30</td>
</tr>
<tr>
<td>Other social agencies</td>
<td>3</td>
</tr>
<tr>
<td>Relatives</td>
<td>2</td>
</tr>
<tr>
<td>Visiting nurse</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>36</strong></td>
</tr>
</tbody>
</table>

The writer believes that the fact that thirty of the patient group of thirty-six, or over 83 per cent, were referred by physicians speaks well for the cooperative relationship between the medical and social service staff, and their emphasis on the "total patient". In these cases the physician, aware of the interplay of medical, social and emotional factors in the...
patient's illness, took the initiative in getting the patient to the social worker.

In the remaining six cases, referred by sources other than the physician, there is no indication whether or not the physician was also aware of the patient's needs and too brought them to the attention of the social worker.

Of the thirty-six cases referred to the Social Service Department between 1945 and 1949, fifteen were referred in 1945, six in 1946, six in 1947, four in 1948, and five in 1949. The writer is unable to interpret the difference in number of referrals in these years because of lack of factual material as to total number of multiple sclerosis patients known to the Massachusetts General Hospital in each of these years.

Physical Status of Patients

For the purposes of this study the thirty-six patients studied were classified as to the severity of their physical handicaps or limitations. In this way, it was hoped to determine how the varying degrees of the severity of the disease might affect and limit the patient in regard to his mode of living, occupation, etc., and how it might affect his medical-social problems and the type of social service assistance he required. The degree of physical handicap at the time of referral to the Social Service Department was used as the basis of classification, since in view of the nature of multiple sclerosis the patient's condition might vary from time to time and thus his problems and needs would also be different.

The classifications used by the writer were ambulatory, semi-ambulatory and bed and wheelchair existence. It must be emphasized that the above are not necessarily medical classifications (since no such specific divisions were to be found on the medical records), but rather the writer's own,
based on her understanding of the degree of the patient's handicap from the reading of the medical and social records. Since all of the patients known to the Social Service Department were handicapped to some extent, the three classifications will be defined in the following manner.

**Ambulatory** will be considered to be those patients who have the least amount of handicap, who are still able to get about though they may function at a lower level of activity than before they became ill. Example: (1) Male patient who was employed at strenuous labor previously and who now can work only at sedentary employment. (2) Female patient who is still able to look after her household and care for her children but needs some assistance with these tasks.

**Semi-ambulatory** will be considered to be those patients who are no longer able to work or have responsibility for the care of others, but are able to assume the responsibility for their own care and needs to some extent.

**Bed and wheelchair existence** is self-explanatory.

It should be observed, of course, that the patient's ability to work, care for others, etc., will depend on not only upon his physical limitations, but also on his desire to do those things, conditioned by his feelings about his illness, his social situation, his emotional development. Consequently, two patients with approximately the same degree of handicap may function on entirely different levels of activity.

The physical status of the thirty-six patients studied, at the time of their referral to the Social Service Department, is presented in relationship to sex and age in Table VIII.
### TABLE VIII

**PHYSICAL STATUS OF PATIENTS IN RELATION TO AGE AND SEX**

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Ambulatory</th>
<th>Physical Status</th>
<th>Bed &amp; wheelchair</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Semi-ambulatory</td>
<td>Male Female</td>
<td></td>
</tr>
<tr>
<td>15 - 19</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>20 - 24</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>25 - 29</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>30 - 34</td>
<td>1</td>
<td>4</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>35 - 39</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>40 - 44</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>45 - 49</td>
<td>1</td>
<td>3</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>50 - 54</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>55 - 59</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>60 - 64</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>65 - 69</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>7</td>
<td>9</td>
<td>6</td>
<td>36</td>
</tr>
</tbody>
</table>

The physical status of the patient and the prognosis regarding the future course of the disease with which he is afflicted will determine to a large extent the future course of his life, and will be factors also in determining and limiting the role of the medical social worker in working with the individual. For many of the patients, prognosis was not noted in the medical record, but in those medical records in which it was, prognosis was considered either guarded or poor.

Twelve of the thirty-six patients studied were considered to be ambulatory, fifteen semi-ambulatory and nine confined to a bed and wheelchair existence.

Physical status cannot be considered alone but one must also take into account the sex and age of the patient in conjunction with the physical status as important determinants of the effect of the disease upon the patient and his family and in the services to be offered by the medical worker.
social worker. As stated previously, the patient's marital status will have an important effect upon plans made for his care, upon services he needs, upon his adjustment to his illness. In many instances, marital status plus the patient's mode of living would be just as great a factor in the types of problems he evidences and assistance he requires as his physical status; actually both must be considered in conjunction. Of the twelve ambulatory patients, ten were married, one single, one widowed; of the fifteen semi-ambulatory patients, eight were married, five single, one divorced, one widowed. Of the nine confined to bed and wheelchair, seven were married, one single, and one widowed.

Economic Implications

Multiple sclerosis, as other chronic illnesses, frequently necessitates many changes in housing, occupation and manner of living. The individual 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 load of anxiety. Often his capacities vary with the course of the disease. Aside from the emotional and mental adjustments engendered by chronic illness, far reaching economic problems inevitably ensue. When the wage earner is stricken, destitution for the whole family may follow. When the wife is ill, someone may have to be employed to care for the household, or another member of the family may have to remain at home from school or from work. Even when the sick person is not a wage earner, the constantly recurring, never ceasing expenditure for physicians, medicine, special foodstuffs, and the like quickly wreak havoc with the family budget. So it is not surprising to find a close link between poverty and chronic illness. However, multiple

sclerosis may be found in all strata of society and in persons of widely varying occupations.

In Table IX is noted the various occupations of the patient group of thirty-six before onset of multiple sclerosis or before the multiple sclerosis became to any extent incapacitating.

**TABLE IX**

**OCCUPATION BEFORE ONSET OF MULTIPLE SCLEROSIS**

<table>
<thead>
<tr>
<th>Occupation</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Housewife</td>
<td>0</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>Factory</td>
<td>4</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Mechanic</td>
<td>5</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Truck driver, trolley operator</td>
<td>3</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Attended school</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Advertising manager</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Clerk</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Dental assistant</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Laundry worker</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Plumber</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Speech teacher</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Variety of jobs</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>19</td>
<td>17</td>
<td>36</td>
</tr>
</tbody>
</table>

According to the above table, other than the predominance of factory work for males and females, and housewives in females, there seems to have been no outstanding occupation.

At the time of referral to the Social Service Department, the employment picture had changed dramatically as can be seen in Table X.
As is evident from Table X, at time of referral to the Social Service Department twenty-five or over 69 per cent of the thirty-six patients with multiple sclerosis were unemployed. The duration of the period of unemployment varied from several weeks to several years. There will be further discussion of need for employment later in this chapter. Three housewives, who were completely incapacitated (confined to bed and wheelchair) were in Table X considered to be unemployed. All the employed patients (and the female attending school) were in the ambulatory classification. One male patient, listed as being employed as a trolley car operator, soon after referral to the Social Service Department decided to change his occupation to that of a salesman in view of his physical condition. One female patient was unemployed temporarily, and received unemployment compensation, but was able to return to work after a relatively short period in which there was exacerbation of symptoms. If housewives and the young girl attending school are omitted, only four or slightly over 11 per cent of the thirty-six patients were gainfully employed at the time of referral to the Social Service Department; this in contrast to twenty-five or over 69 per
cent of the patients who had been gainfully employed before the onset of
multiple sclerosis.

It would seem from Table X that housewives were more often able to
continue with their household tasks than were employed men able to continue
working. This can probably be attributed to the differing nature and
demands of work at home as compared to the business world; that is, the
housewife would be more readily able to adjust her schedule to her capaci-
ties than would the workingman in competition with other workingmen in a
profit system of economy. Even semi-ambulatory women who have no small
children might manage to perform some household duties of a light nature,
and thus, still be considered housewives.

In view of the fact that so large a percentage of the patients were
unemployed it would be of interest to note their source of income, for
the support of the patient himself and very often the support also of his
family. The amount of the income in many of the cases studied is not
known. However, as is evident from the amount of unemployment, financially
many of the patients were having a difficult time managing, which fact
was often brought out in talking with the social worker. This will be
discussed in greater detail later.

TABLE XI

PRINCIPAL SOURCE OF INCOME

<table>
<thead>
<tr>
<th>Source of Income</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse</td>
<td>5</td>
<td>10</td>
<td>15</td>
</tr>
<tr>
<td>Other member of family</td>
<td>2</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Wages</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Savings</td>
<td>4</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Public assistance</td>
<td>6</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>Unemployment compensation</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>19</td>
<td>17</td>
<td>36</td>
</tr>
</tbody>
</table>
From Table XI it can be seen that of the patient group of thirty-six the source of support for fifteen was the spouse, for five other members of the family, for three their own wages, for six savings, for six public assistance and for one unemployment compensation. In addition to an allotment from her husband in service, one patient was receiving supplementary support from a private social agency. Two patients were receiving supplementation from public welfare. Four patients, supported mainly by their spouses, were also receiving financial contributions from their children. One female patient's savings were supplemented by some assistance from her family. One male patient was receiving unemployment compensation, although his wife was the main source of support.

Needs for Which Patients Were Referred to Social Service Department

As stated previously, no specific medical treatment exists at present that will cure or materially alter the course of multiple sclerosis. It has been observed, however, that improvement may be fostered by favorable social and personal factors, while negative ones operate to limit the individual's functioning capacity. In planning care, therefore, the patient's emotional vulnerability, his ego strengths, and social satisfactions and strains should be part of the evaluation on which medical and social treatment is based. It is consequently important to observe the reasons for a patient's referral to the Social Service Department.

The needs or reasons for which the referrals were made to the Social Service Department are presented in relation to the patient's physical status in Table XII.

2 Frances Upham, A Dynamic Approach to Illness, p. 90.
TABLE XII

REASONS FOR REFERRAL OF PATIENTS TO THE SOCIAL SERVICE DEPARTMENT
AS RELATED TO PHYSICAL STATUS

<table>
<thead>
<tr>
<th>Reasons for Referral</th>
<th>Ambulatory</th>
<th>Physical Status and Sex</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male Female</td>
<td>Semi-ambulatory</td>
<td>Bed &amp; Wheelchair</td>
</tr>
<tr>
<td>Discharge planning*</td>
<td>5</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Social review in view of chronic disease</td>
<td>1</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Employment planning</td>
<td>5</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Interpretation to patient, patient's family or agency</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Convalescent or nursing home care</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Home planning</td>
<td>0</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Social review</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Transportation</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Chronic care</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>School and family adjustment</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Miscellaneous</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>7</strong></td>
<td><strong>5</strong></td>
<td><strong>9</strong></td>
</tr>
</tbody>
</table>

* All patients who had been hospitalized.

It should be noted that social review was a more frequent reason for referral than is evident from Table XII. This is due to the fact that social review was included as part of the reason for referral in some of the other categories listed on Table XII. Thus, of the five patients referred for employment planning, two were referred for social review and employment planning. This type of referral also applied to three of the patients referred for discharge planning, one referred for interpretation, one referred for transportation and one referred for home planning.

In all, social review was the reason for referral for ten patients if one includes the category, "social review in view of chronic disease", and in part the reason for referral of eight patients (social review and
employment planning, social review and discharge planning, etc.). There seems to be little or no relationship between this particular reason for referral and the patient's physical status. This can be explained on the basis of the fact that social review might be equally indicated for any patient, no matter what his physical status, since by social review the social worker should determine the social situation in relation to the medical needs and also clarify the need of service to the patient.

Employment planning was requested for five patients, all male and all ambulatory; four of these patients were unemployed, one employed but it was felt that his job as a street car operator might be unsuitable. In the writer's classification, ambulatory patients were considered able to work. However, as stated before, they might no longer be able to continue with their previous occupations which might be too strenuous, require too much motor coordination, etc., and would hence require assistance in obtaining more appropriate employment.

Discharge planning was the reason for referral for eight patients, four semi-ambulatory and four confined to bed and wheelchair. All eight patients had been hospitalized and in all eight cases the physician requested this service so that an evaluation could be made of the resources, either in the home or outside, for the care of the patient after hospital discharge. A higher proportion of semi-ambulatory and bed and wheelchair patients required hospitalization than did ambulatory patients: thirty-three per cent of the ambulatory patients, 60 per cent of the semi-ambulatory patients and 89 per cent of the bed and wheelchair patients. The statistics (Table XII) would seem to indicate that the proportion of patients referred for discharge planning would increase as the patients' handicap increased.
The total number of referrals in the other categories in Table XII is too small in each category to permit any conclusions to be drawn as to the relationship of these reasons for referral to physical status.

**Services Required by Patients**

The social worker on the Neurological Service does not, as previously stated, interview all patients with a diagnosis of multiple sclerosis, or members of their families. Multiple sclerosis patients become known to her when a doctor, another agency, or a member of the patient's family requests her services. When a referral is made, it is expected that the medical social worker will not only endeavor, whenever possible, to meet the needs for which the patient has been referred, but also in individualizing the patient become aware of other needs he may have and attempt to meet them. The social worker will be interested not only in specific needs but more important in gaining understanding of the patient, what having multiple sclerosis means to him and what problems it presents to him. She then tries to help the patient understand his situation and to do something constructive about it. This may involve making the patient aware of the particular resources that exist to meet his needs, or may involve helping him to accept the need for these resources and to use them as effectively as possible.

In addition to the factor of the multiple sclerosis itself, problems presented by the patient may be arbitrarily classified as those related to arrangements for physical care, those related to finances (usually need for employment or referral to public welfare agencies) and those of an emotional nature. Many patients would, of course, present more than one problem (actually the problems are interrelated and often cannot be separated) and consequently require social service in more than one area or several services.
might be employed to meet one need.

To present examples of varying problems of patients afflicted with multiple sclerosis and the means by which the Social Service Department endeavors to meet these problems, six cases of the thirty-six studied have been selected for illustration. A basis of the selection was the physical status of the patient, since it was felt that the degree of handicap was an important factor in the problems presented by the patient and therefore in the services required to alleviate these problems. It was also thought that by choosing cases from each of the three classifications of physical status a more complete and comprehensive picture would be given of the social factors found in patients with multiple sclerosis and the implications of these social factors. Two patients were selected from each classification—ambulatory, semi-ambulatory, and bed and wheelchair -- and will be discussed in the following pages.

The first two case illustrations are those of ambulatory patients with multiple sclerosis.

Case Illustration 1 *

Case of Mrs. Barbara Gold

Mrs. Gold was referred to the Social Service Department by a Boston family agency in January, 1949 for assistance in home planning. Patient's symptoms of multiple sclerosis had apparently had their onset during her first pregnancy in 1945. She had been known to the clinic at Massachusetts General Hospital since 1948 and was admitted to the hospital in 1949, when she was referred to the Social Service Department. In August of 1949 she was again hospitalized and underwent a therapeutic abortion.

Mrs. Gold was a twenty-four year old, white, Jewish woman who lived with her husband and two small children in a multiple dwelling in Boston. Prior to patient's hospitalization, weakness and incontinence kept patient and therefore the children, confined to the house. A housekeeper was supplied by the family agency.

* Names of patients in this and following case illustrations are disguised.
referring patient at the time of her hospitalization and was kept
in the home for a length of time thereafter.
The patient had a variety of problems and was seen regularly
both in the clinic and by the medical social worker. The problems
were patient's attitude toward her illness, financial difficulties,
emotional immaturity of patient and husband, patient's inability
to care for her household and manage the children who were quite
uncontrollable. Two family agencies cooperated on this case in
the area of financial assistance and placement of children for a
period of time. Mr. and Mrs. Gold then requested that the children
be returned home and this was done. The role of the medical social
worker was to attempt to help the patient achieve a more realistic
attitude toward her illness, and also to keep the other agencies
informed of any changes in patient's condition, and what these
changes might imply in their planning for patient.
At present Mrs. Gold is still being followed by the Social
Service Department; she now finds that she is unable to continue
caring for the children and is again requesting placement for
them which the doctor thinks advisable.

Comment

Case Illustration 1 was typical in many ways of two other cases of
young ambulatory women, mothers of small children who required some
assistance in the management of their homes and care of their children.
In this sort of planning, cooperation with other agencies was of paramount
importance; in one of the other cases, a family agency which had known the
patient for some time before she was referred to the medical social worker
assumed the major responsibility in planning with the patient, requesting
mainly medical interpretation from the medical social worker.

In this case the medical-social problems related to the patient's
illness are superimposed upon probably pre-existing social problems. The
devastating emotional impact of a chronic, mystifying illness accentuated
difficulties that in a relatively favorable environment patient and husband
had been able to handle. In addition to the emotional aspects of this
case, regarding which comparatively little material is recorded, it
illustrates a continuous process of adjusting the environment to meet the
current situation. The social worker helps Mr. and Mrs. Gold make plans for the care of the children that will meet Mrs. Gold's physical and emotional needs.

Because of the chronic long term nature of multiple sclerosis Mrs. Gold will no doubt be a community responsibility and require community assistance for many years to come.

Case Illustration 2

Case of Mr. Patrick O'Shea

Mr. O'Shea was referred to the Social Service Department in November, 1949 by a visiting physician in the Nerve Clinic for discussion of employment plans. Patient had been known to the Nerve Clinic since 1945, attending rather irregularly and had never been hospitalized; his first symptoms of multiple sclerosis had appeared approximately thirteen years before he was known to the clinic. Patient's major physical difficulty was weakness of legs. Doctors believed that patient was able to work, preferably at sedentary employment.

Mr. O'Shea was a thirty-four year old, white, married Catholic man who lived with his wife and mother-in-law in a city outside of Boston. He had worked on varying jobs, but was unemployed since he had been laid off eight months before. Mr. O'Shea was being supported by unemployment compensation and by his wife who worked. Patient felt that his problem was not so much obtaining employment as having the initiative to start looking. He felt that part of his confidence was gone and at the same time was not quite ready to admit that there were any limitations to the amount of work he could do.

Worker in her interviews with patient received the impression that patient obviously felt that he needed some incentive to work and though he tended to depreciate his own abilities and qualities, was uncomfortable in the position of being supported by his wife. He also felt some resentment against her for being able to work when he could not. Mr. O'Shea had, however, considerable insight into his own problems and related well to doctor and worker who treated him as an adult person rather than as a dependent one.

The worker had contact with patient fairly often. He has now been referred to the Division of Vocational Rehabilitation for possibility of employment and the case is being followed by the Social Service Department at the present time.

Comment

As discussed before, ambulatory patients such as Mr. O'Shea are able
to continue working. The difficulty lies in the area of their being able to perform only limited types of work, the fact that they may have not had experience in, or training and skill for the tasks that they are physically equipped to undertake. Like Mr. O'Shea, such patients cannot easily accept the fact that their physical incapacities are permanent and are blocked in seeking the recommended type of sedentary employment, both by their own attitudes, fears and anxieties, and the difficulties that actually exist in finding such employment. They are further handicapped by the fact that periods of exacerbation, when they will be unable to work at all, will occur and by reality fears that their condition may be progressive.

Mr. O'Shea was in need of both indirect and direct social service; that is, he could benefit by casework therapy, his relationship to the worker and the fact that she treated him as an independent rather than a dependent person, as an enabling influence in making the effort to seek employment. He also needed to be referred to appropriate community resources for employment planning. In working with patients like Mr. O'Shea who need employment, an important part of the function of the medical social worker is to interpret the patient's medical condition, limitations, prognosis to such employment agencies.

The third and fourth case illustrations are those of semi-ambulatory patients with multiple sclerosis.

**Case Illustration 3**

**Case of Mr. Harold Collins**

Mr. Collins was referred to the Social Service Department in October, 1946 by the Neuromedical Assistant Resident for social review and transportation home. Patient had apparently had multiple sclerosis since 1942 but was not known to Massachusetts
General Hospital until 1944 when he was hospitalized. After that he was seen from time to time at the clinic but the diagnosis was not established until the advent of his second hospital admission in 1946, when he was referred to the Social Service Department.

Mr. Collins was a thirty-eight year old man of apparent intelligence and stability, married and with three young children. He had been employed in a machine shop but had been out of work for six weeks in view of his illness. He was concerned about his financial status, since he was living on savings and did not think that they could last much longer.

The doctors discussed with patient the nature of multiple sclerosis, its symptoms, remissions and exacerbations, without giving him the actual name. Mr. Collins seemed somewhat relieved that the doctors had at last understood the nature of his illness although he was concerned about the lack of definite therapy. He was worried about his dependence and anxious to return to work as soon as his physical condition permitted.

The social worker informed Mr. Collins of the possibility of Aid to Dependent Children, and a medical letter was sent to the local Department of Public Welfare in reference to his eligibility for aid. Patient's wife arranged transportation home.

Later the public health social worker in patient's district called the worker at the Massachusetts General Hospital as she had heard of the patient's problems and wanted to know if she could be of assistance. A medical report was sent to her with the hope that she could assist in interpreting Mr. Collins' difficulties to his wife and the Welfare Department.

Comment

With a semi-ambulatory patient like Mr. Collins who is unable to work, aside from the emotional aspects involved, the primary problem would seem to be of a financial nature. Mr. Collins has three young children for whom he is now unable to provide; referral to a Public Welfare agency for financial assistance is therefore indicated. There is no definite statement as to how Mr. Collins felt about accepting public support, but there are indications that this was a threat to him, reflecting on his independence and his ability to be the head of his family. Consequently before Mr. Collins could be referred for public assistance, his feeling about accepting it would have to be worked through.
This case illustrates also the fears a patient has in regard to a disease such as multiple sclerosis, both before the diagnosis has been established and once it is known.

Case Illustration 4

Case of Mr. William Larkin

Mr. Larkin was referred to the Social Service Department in October, 1948 by the Neuromedical Resident for post-hospital planning. Patient's diagnosis was multiple sclerosis, incontinence of urine, acute and chronic cystitis. Mr. Larkin had been ill for approximately fifteen years and unemployed for two years. He was hospitalized from September 13, 1948 to October 15, 1948.

Mr. Larkin was a fifty-nine year old, single, Catholic man who lived with his sister in a city at some distance from Boston. Both were supported by Public Welfare. It was learned that the sister was now in a nursing home and was mentally incompetent. She also had a heart condition and was in critical condition.

The patient was interviewed by the social worker and he refused to allow her to contact his sister. He also refused to go to a nursing home although it was explained to him that there would be no one to take care of him at home. The patient insisted that he could manage by himself in his own home. The doctors were consulted and the Public Welfare Department in patient's community contacted. It was decided to send patient to his own home with the Public Welfare assuming the responsibility of having him followed medically by a doctor and placing him in a nursing home if he was not able to take care of himself. Public Welfare arranged his transportation home. The Social Service Department did not plan to follow this case as he was discharged for medical care in his own community.

Comment

Case Illustration 4 presents the problem of the chronically ill person who has no family who are able to or willing to assume the responsibility for his care and who is opposed to being cared for away from home.

In this case the best (and only) course of action would seem to be to go along with the plan the patient wishes, as long as this proves at all feasible, with casework services directed towards having the patient become
more accepting of other arrangements when these should prove necessary.

Mr. Larkin was a patient who lived at a great distance from Boston and therefore neither the clinic nor the Social Service Department could follow his case, but rather have the responsibility for his care assumed by local agencies.

The fifth and sixth case illustrations are those of bed and wheelchair patients with multiple sclerosis.

**Case Illustration 5**

**Case of Mr. John Henderson**

Mr. Henderson was referred to the Social Service Department in October, 1945 by the Neuromedical House Officer for social review. He had been hospitalized in 1939 and for a very short period at the time of referral.

Mr. Henderson was a very attractive and intelligent thirty-seven year old man, severely handicapped by multiple sclerosis. His vision was so poor that he could be considered legally blind; he was unable to walk and had other complications. His life had been a succession of frustrations. During high school he worked to pay his own board and room; and later worked his way through college and graduate school. He finally saved enough to be married; there were no children. Mrs. Henderson was also a college graduate and was, according to worker, a most understanding and sympathetic person. Mr. Henderson had located his first good position, as an executive in a large concern, when he had his first attack of multiple sclerosis in 1939. At the time of referral to the Social Service Department he was completely bedridden. He was cared for at home, with the help of his father, while his wife was employed as a secretary. Mr. Henderson was receiving weekly assistance from the Welfare Department to supplement his wife's earnings.

Mr. Henderson had read all the current literature about multiple sclerosis and was naturally disappointed that no treatment was available. He was willing to consider a period of care in a chronic hospital, according to his wife's plans. It is interesting to note that in 1947, patient wrote to the social worker, inquiring about a new treatment he had heard was being tried at Massachusetts General Hospital for multiple sclerosis; the doctors knew nothing of the treatment patient had inquired about.

The possibility of care at a chronic hospital was reviewed with Mrs. Henderson who was already familiar with these resources. She planned to discuss patient's problems with her local welfare
board, and then make her decision. Medical information was sent to the local welfare board.

Comment

Most of the patients in this study confined to a bed and wheelchair were able to remain at home, and the case of Mr. Henderson illustrates some of the problems involved and the resources available. The social worker's contact in this case was quite brief giving her only the opportunity to review the situation and discuss the most outstanding problem, that of the facilities available for the patient's care.

Case Illustration 5 also points out the reaction of many patients who are aware of their diagnosis; their assiduous perusal of all the literature available on the disease, their frantic hope that at last a cure has been discovered, their bitter disappointment when this hope proves unfounded.

Mrs. Henderson, in the face of many defeats, apparently still remains an adequate person, able to plan for her husband's care with a minimum amount of assistance, but also able to accept help from social agencies when there is a need for doing so.

Case Illustration 6

Case of Mrs. Betty Carson

Mrs. Betty Carson was referred to the Social Service Department in November, 1947, by the Neuromedical Resident for assistance in planning for nursing home care. It was decided, however, by the doctors to have the patient remain in the hospital for a period of study and treatment; in all, she was hospitalized for a period of two months. Patient was then referred to the Social Service Department again in January, 1948 for long term nursing care. Patient's diagnosis was multiple sclerosis with spastic paraplegia, infection and urinary incontinence; she also had deep ulcerations on her legs and thighs. Patient had her first symptoms of multiple sclerosis.
at the age of sixteen but these had cleared up within a year. Three years prior to the hospital admission a diagnosis of multiple sclerosis had been made at a local hospital.

Mrs. Carson was a thirty-two year old, married, Catholic woman who lived in the town of ________ with her husband. Patient had never had any children and had worked until she became incapacitated three years prior to hospital admission. For the past two years, she had been bedridden. Mr. Carson worked as a laborer at a mill, earning fifty dollars a week.

Discharge plans were discussed by the worker with patient and husband. Mr. Carson had attempted on his own to work out various plans for the patient's care at home, but none of these had proved feasible. He himself had been caring for patient as best he could, before and after work, but in view of patient's physical condition it was not possible for him to continue with this arrangement. He could not afford nursing home care and, in any case, Mrs. Carson needed more care than could be given in a nursing home. Therefore, the State Infirmary at Tewksbury seemed the only resource for care. Husband accepted the plan although he realized that it would be difficult for him to see patient very often. Mrs. Carson accepted the plan of transfer very well, realizing that she would need long-term care. Arrangements were worked out for transfer to Tewksbury. Worker commented that "patient is a very remarkable young woman who accepts her illness with an amazing amount of courage."

Comment

Case Illustration 6 presents a situation in which the severely handicapped person must be referred to a state institution both because of the person's medical needs and the lack of facilities elsewhere to meet these needs. The illness is a burden not only upon the patient but upon the family who attempt to care for her while this is at all possible. It has social, emotional, and financial implications.

The role of the medical social worker in the case has seemed to be that of making Mr. and Mrs. Carson aware of the facilities for her care, and of giving casework support and therapy to both patient and husband in working through arrangements for the care decided upon.

Disposition of Patients

Of the thirty-six patients whose cases were studied, twenty-three
remained at home under care of the clinic, five remained at home under care of their local medical doctor or local hospital, five remained at home with no indication in the material studied as to where care was to be continued, one was referred for long-term convalescent care, one was institutionalized, and one applied for institutional care. The above arrangements seem to have little significance in relation to the patient's physical status since the great majority of patients remained at home—all of the twelve ambulatory patients, thirteen of the fifteen semi-ambulatory patients, eight of the nine bed and wheel-chair patients—and no conclusions can be drawn. It would seem, however, that factors other than physical status, as for example, resources in the home, would be the determinants in establishing the arrangements, both physical and medical, made for care of the patient.

As stated previously, all seven male ambulatory patients were able to remain at home with continuation of medical care at the clinic. All of these men were married and living at home with their wives or wives and children.

All the five ambulatory female patients were also able to remain at home, under care of the clinic or local hospital. Three of these patients were married and living at home; all three had young children and at one time or another required assistance in the care of their households. One patient was a young school girl living at home with her parents. The fifth female patient was an employed widow living at home with her teenage son; she was able to continue with her work.

Eight of the nine semi-ambulatory male patients were able to remain at home; one applied for admission to a state institution for chronic diseases. Four of eight patients able to remain at home were married and
living at home with their wives or their wives and children and were able
to receive the care needed at home. One patient was divorced, but was
living with his parents and able to receive any care indicated. Two
patients were single; one lived at home with his mother. The other, a man
of fifty-nine, lived alone and needed care outside the home. He, however,
refused to consider this and it was finally worked out that he would re-
main at home under care of a local doctor. If this plan proved not to be
feasible, nursing home care would be considered. (See Case Illustration 4,
page 48) One patient was a widower and lived alone; he had been referred
to the Social Service Department for question of nursing home care for a
short period, but this was unacceptable to him and he preferred to make his
own arrangements. He was discharged from the clinic to care of his local
medical doctor as he lived at a great distance from Boston and was unable
to attend clinic. The remaining semi-ambulatory male patient was single
and also lived alone. Resources for his care were discussed with him, and
when he felt unable to manage at home he applied for admission to a state
institution for chronic diseases. In addition to multiple sclerosis, this
patient had a number of other diseases, many psychological problems, and
had been under the care of a multitude of physicians, clinics, hospitals,
and a variety of other practitioners.

Five of the six female semi-ambulatory patients were able to remain
at home; one was referred for long-term convalescent care. Three of these
patients were married, two living with their husbands and children, one
having many marital problems fluctuating between her own home and that of
her sister. One patient was single and lived at home with her mother and
sibling. Another patient was divorced, and at the time of the exacerbation
of her symptoms, a sister moved in with her so that she did not remain
alone. The patient referred for convalescent care was a single person of thirty-seven who was living with relatives and was restless and unhappy in their home.

All three of the male patients confined to bed and wheelchair were able to remain at home; they were all married and living at home with their families. The wife of one planned to obtain a job and engage someone to look after the patient while she worked. The wife of the second patient wished to care for him at home. The father of the third patient assumed responsibility for him while his wife worked; the wife knew of the resources available for the care of the patient, planned to discuss some of these with the local welfare board and then make her own decision as to his ultimate disposition. (See Case Illustration 5, pages 49-50)

Five of the six female patients confined to a bed and wheelchair existence were able to remain at home. Three of these five patients were married, one single, and one widowed. In the case of one married patient, a paraplegic who had three small children, arrangements were worked out in her community for her care at home. Another patient could be looked after by a single daughter. The third married patient, when first known to the Social Service Department, was able to remain at home; later her family felt unable to continue to care for her as she had also developed carcinoma and she was referred to a hospital for terminal care where she died. The single patient lived at home with her mother and care could thus be adequately provided for her. The widowed patient lived with her parents who were anxious to have her with them. The sixth female patient confined to a bed and wheelchair existence was referred to a state institution for the care of the chronically ill. (See Case Illustration 6, pages 50-51)
Social Implications

Multiple sclerosis is a serious social problem that has brought tragedy to thousands of victims, particularly young people in the prime of life. It has implications that range all the way from occupational re-adjustment to complete helplessness and dependence upon the community. Few phases of life are left untouched—families that have always been independent and self-sustaining must now ask for help, with or without the realization that their dependence upon others will be not for a brief period, but will be a way of life that may endure for many years.

The young housewife and mother is not only no longer able to manage her household and care for her children, but must become increasingly dependent upon others for her own physical care and in many instances for financial aid. Similarly the workman, as his disease progresses, finds himself less able to work, his physical limitations spreading and his activities gradually coming to a standstill. The physical and mental health of the families of those stricken with multiple sclerosis is also jeopardized. If the husband is the patient, the wife may be obliged to obtain employment and also care for the patient, the home, and the children. If the wife is ill, the husband may find it necessary to lose time from work in order to care for her and perhaps may be forced to place the children. Increased physical incapacity may necessitate long-term planning outside the home and many difficult adjustments that must be made.

Multiple sclerosis is a chronic disease aggravated by the fact that there is neither a cure nor a control for it. One unfortunate aspect to the lack of effective therapy is the appearance in non-scientific publications of articles describing new “miracle cures” which have no foundation in fact. The writer has seen pathetic letters written to the hospital by patients with multiple sclerosis who have read these articles and
desperately hope again that a remedy has indeed been found; they write that they wonder why the hospital has not used the new drug, or exercise, or whatever "cure" the latest article may advocate, to help them. Whatever adjustment they may have at last achieved to the realities of their disease is greatly disturbed by such articles.

The course of the disease is a long one, and aside from spontaneous remissions or exacerbations, there may be little fluctuation in the long years following the onset. In addition the fear of fatal termination is present in the background. Along with growing physical incapacity and discomfort come the attendant problems of increased inability to work and to care for oneself, difficulty in adjustments, and increase of dependence.

In most cases used in this study, it could not be determined whether or not the patient was aware of his actual diagnosis or what his understanding of the disease was. There is apparently no definite policy at the Massachusetts General Hospital as to whether or not a patient with multiple sclerosis should be informed of his diagnosis. His attitude toward the disease, however, would not be based only on his knowledge of the disease and its medical implications but also on such factors as personality structure, emotional maturity, previous life experiences, and environmental situation. Dr. Alexander has observed that multiple sclerosis patients often drop out of Nerve Clinic since they are very demanding patients and the physician is usually unable to give them as much time as they desire.  

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3 Leo Alexander, M.D. and Rosalind Herrmann, Social Worker, Lecture.
Favorable and Unfavorable Factors in Multiple Sclerosis

Tentative findings in the study being conducted at Beth Israel and Boston State Hospitals indicate that favorable factors leading to remissions in the course of multiple sclerosis are: favorable psychological influences, an allergen free regime, repeated blood transfusions, vitamins, potassium chloride, hormones, physiotherapy and activation, and oddly enough, psychoses (possibly because certain body hormones are activated). There is no agreement as to whether pregnancy constitutes a favorable or unfavorable factor. In the medical records studied by the writer, medical recommendations for multiple sclerosis patients have been of a palliative nature, such as vitamin pills, yeast, general hygiene, amyral, tonic, nicotine acid, and wheat germ. Reassurance was a medical recommendation noted in several medical records.

Unfavorable factors leading to exacerbations in the course of multiple sclerosis are thought to be emotional upheavals which may precipitate the disease or make it worse, particularly after the loss of a loved person, infectious disease, injuries and accidents, severe allergic reactions, prolonged physical stress, undernutrition, poverty in general, and puerperium. The possible result of unfavorable factors can be illustrated with two cases used in this study, as follows. In one case, that of an adolescent girl, her first symptoms occurred at the time of her father's death. Another patient had an exacerbation of her symptoms at the time of her husband's death and became completely incapacitated.

4 Ibid.
5 Ibid.
CHAPTER VI
SUMMARY AND CONCLUSIONS

Summary

The purpose of this study was to: 1) attempt to present a general picture of patients with a diagnosis of multiple sclerosis known to the Social Service Department of the Massachusetts General Hospital, to determine the social factors inherent in their situation and the implication of these social factors; 2) learn why these patients were referred to the Social Service Department, what plans were made for them, and the relation, if any, of these plans to the extent of the patient's physical handicap.

The social and medical records regarding thirty-six patients with a diagnosis of multiple sclerosis were studied. This group represents the total of those patients treated for multiple sclerosis at Massachusetts General Hospital between January 1, 1945, and December 30, 1949, who were referred to the Social Service Department and on whom sufficient information for study was available. Limitations centered about the nature of the recordings, both social and medical, and the lack of published material on social and emotional factors connected with multiple sclerosis.

Multiple sclerosis is a chronic disease of the central nervous system which may affect any part of the body in a variety of ways and with a variety of symptoms. It is a disease primarily of the young adult and has many social and emotional implications for the patient, his family, and the community. Practically nothing is known about the cause and control of multiple sclerosis, though at present many studies are being conducted relating to the nature of and the treatment of this disease.

It was found that of the thirty-six patients studied nineteen were
men and seventeen women, an almost equal division. Their ages ranged from fifteen to sixty-seven years, although 58 per cent were between twenty and forty. As pointed out in Chapter III, these ages do not necessarily represent the age at onset of multiple sclerosis. In regard to marital status, twenty-four patients, or approximately 70 per cent of the patients over eighteen, were married, seven single, two divorced, and three widowed. 

Recording on the patient's mode of living indicated that twenty-two patients lived with spouse or spouse and children, three lived with their children without spouse, six lived with their parents, two with other relatives, and three alone.

All of the patients were of the white race; 77 per cent were native born; twenty-two were Catholic, eleven Protestant, two Hebrew, and one Greek Orthodox.

A great majority of the patients, 91 per cent, lived outside of Boston in twenty-six different communities; only three patients lived in Boston itself. Twenty-eight, or 77 per cent, of the patients were referred to Massachusetts General Hospital by their local medical doctors, the remainder by other hospitals or clinics, by themselves, or by an unknown source. The amount of time that had elapsed between the first onset of the symptoms of multiple sclerosis and when the patient became known to Massachusetts General Hospital varied from considerably less than a year to over ten years. Twelve of the thirty-six patients were known only to the clinic, five were known only to the hospital, and nineteen were known both to the hospital and the clinic.

The source of referral to the Social Service Department for thirty, or over 83 per cent, of the patients was the physician who saw them either in the hospital or in the clinic, the remainder being referred by other
social agencies, relatives, or a visiting nurse. Fifteen patients were referred in 1945, six in 1946, six in 1947, four in 1948, and five in 1949.

The thirty-six patients were divided by the writer into three classifications in relation to their physical status; they were considered as being ambulatory, semi-ambulatory, and confined to bed and wheelchair. Twelve of the patients were found to be ambulatory (seven male, five female), fifteen semi-ambulatory (nine male, six female), and nine confined to a bed and wheelchair existence (three male, six female).

In reference to the patient's occupation a dramatic difference was found in the amount of unemployment before and after onset of multiple sclerosis—before, 69 per cent were gainfully employed; after, only 11 per cent were gainfully employed. It is interesting to note that before onset of multiple sclerosis, twenty-five patients were employed, after onset the same number, twenty-five, unemployed. Source of income for the thirty-six patients was as follows: fifteen spouse, five other members of family, six savings, three wages, six public assistance, one unemployment compensation.

Needs for which patients were referred to the Social Service Department varied considerably: five for employment planning, eight for discharge planning, eight for social review in view of chronic disease, three for interpretation, two for convalescent or nursing home care, two for social review, one for school and family adjustment, two for transportation, one for chronic care, two for home planning, and two for miscellaneous reasons.

Services required by patients were to meet three primary problems, that of physical care, lack of financial resources, and emotional adjustment.
While known to the Social Service Department, thirty-three patients were able to remain at home, one was referred for a long period of convalescent care, one was institutionalized, and one applied for institutionalization.

Conclusions

Multiple sclerosis presents many of the characteristics and problems, social and emotional, of the chronic disease syndrome, but also has its own unique implications and complications. Patients with multiple sclerosis, as those with other chronic diseases, are frequently subject to many and intense physical, environmental, and emotional stresses during the course of the disease. Not only are they themselves affected by the disease, but their families and their communities are also greatly affected. The mystifying nature of multiple sclerosis, the lack of knowledge as to its cause and cure, add to the burden imposed by its presence, and contribute to the numerous and varied problems and needs experienced by patients with multiple sclerosis.

Certainly, the outstanding, the primary need in relation to multiple sclerosis is a medical discovery that will lead to its cure, or at least provide specific treatment to alleviate its symptoms and alter its course. In 1946 the National Multiple Sclerosis Society was formed to try to solve the problems of this disease, and has initiated many valuable research projects and provided funds for others; more work is being done at present in the field of multiple sclerosis than ever before and it is hoped that some valuable discoveries will be made in the near future.

It is important, however, to consider the implications of the disease at present, what it means to the patient and his family, and what services may be rendered by the social worker.
Multiple sclerosis is an incapacitating disease of long duration, and it is therefore not surprising that patients are often confronted with financial problems. Of the thirty-six patients in this study, twenty-five had been employed before onset of the disease or before its symptoms became severe, but only three were working at the time of referral to the Social Service Department. Only six patients were receiving public assistance, but in many cases this may have been due to the fact that a number of patients had been incapacitated for a relatively short period of time, and had not yet been obliged to apply for public aid. The social worker informed the patients who seemed to be having financial difficulties of the resources available and a proportion of them probably applied for and were granted aid when the Social Service Department was no longer in contact with them. The need for change in employment for patients with a relatively minor handicap is also an important consideration to be dealt with in multiple sclerosis patients, having both financial and emotional aspects.

Physical care for the patient with multiple sclerosis often presents numerous problems. Many patients are able to function at almost a normal level and so present no difficulty in this area but even for them there lurks the always present fear that they will become progressively worse and increasingly dependent. For other patients, incapacity may range from being able to look after their own needs but not being able to assume responsibility for others to being completely helpless and requiring intensive nursing care. Social Service planning in relation to physical care needed by the patient will, however, depend not only on his physical status but also on facilities available in his own home, attitude of the family, and resources in the community.

Emotional problems of multiple sclerosis patients warrant consideration from the viewpoint of their role in precipitating or aggravating the
disease, from the viewpoint of their arising as a result of the presence of the disease, and from the viewpoint of their preventing the patient from functioning at an adequate level as possible in spite of his handicap. Like other patients with a chronic disease, multiple sclerosis patients have fears and anxieties about the course of their disease, about their financial situation, about becoming dependent. But, in addition, they are concerned about the lack of knowledge concerning their disease and the reality that they may become progressively worse. The writer would have liked to include more material on the emotional problems and needs of the patient group studied but, because of the nature of the recording and the limitations of time, this was not feasible. It is felt, however, that intensive study should be made of the emotional and social factors in multiple sclerosis as well as of the medical aspects, so that treatment of the "whole patient" rather than treatment of the disease alone could be undertaken.

As stated before, many patients, for varying reasons, discontinue treatment at the clinic and usually no attempt at follow-up is made. In spite of the lack of specific medical treatment for multiple sclerosis, the writer believes that it might prove of value to follow the patient from the social work point of view (either the medical social worker or a social agency in the community) because of the nature of problems involved in this disease and the hope that social therapy may prove helpful in social and emotional areas while medicine seeks a treatment or a cure.

Approved

Richard K. Conant
Dean
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## SCHEDULE

### I. IDENTIFYING DATA
- **Name**
- **Address**
- **Sex**
- **Race**
- **Citizenship**
- **Unit #**
- **Age**
- **Religion**
- **Social Service #**
- **Marital Status**
- **Nationality**

### II. SOCIAL DATA
- **Living Conditions**
  - **a) Type**
    - own home
    - rooming house
  - **b) Members of Household**
    - spouse
    - spouse and children
    - parents
    - children
    - other members of family
    - alone
- **Occupation**
  - **a) Before illness**
  - **b) After onset of illness**
- **Occupation of Members of Household**
- **Education**
- **Income**
  - **a) Amount**
  - **b) Source**
    - wages
    - public assistance
    - family
    - pension or benefits
    - savings
    - other

### III. MEDICAL DATA
- **Sources of Referral to Clinic**
  - local medical doctor
  - other hospitals or clinics
  - social agency
  - self
- **Length of Time under Treatment at Clinic**
  - **a) First seen**
  - **b) How often seen**
- **Part of Body Affected**
- **How Incapacitating**
  - ambulatory
  - semi-ambulatory
  - bed and wheelchair
Other Illnesses and Medical Care

Prognosis

Medical Recommendations

Discharge Plans \{ at home
institution
other

Ability to Work

IV. SOCIAL SERVICE DATA

Reason for Referral

Source of Referral

Date of Referral

Social Problems Connected with Illness

Services Required by Patients

Type of Service Given

Other Agencies Contaced and Purpose

Disposition or Treatment Plan