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Some aspects of the social adjustment of patients with multiple sclerosis.

BOSTON UNIVERSITY
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SOME ASPECTS OF THE SOCIAL ADJUSTMENT OF PATIENTS WITH MULTIPLE SCLEROSIS

A Thesis

Submitted by

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CHAPTER I

INTRODUCTION

> Adjustment denotes a stage or degree of adaptation. Adjustment like any other social or psychological variable is measurable and may be measured in terms of man's ability to get along as a member of a family unit, the community and the larger world around him.[1]

In this study several areas - occupational, financial, social and personal - will be looked at to see the adjustment of a group of patients with multiple sclerosis. At present the neuropsychiatric clinic of the Veterans Administration Outpatient Clinic, Boston, Massachusetts, is engaged in a research project on multiple sclerosis. The project began in August, 1957, under the direction of Dr. Irving Levine and is expected to continue for another year. The social worker, as part of the team that includes a psychiatrist, psychologist and a technician, collected data on the social and environmental aspects of these patients. Over two hundred patients were interviewed. Out of these interviews grew some of the cases included in the study. Others were referred by the psychiatrist if he felt a patient was having problems that might be helped by casework treatment.

Other studies on the current adjustment of geriatric and tuberculosis patients have been the subjects of recent theses at the clinic. The interest of social workers in a medical setting in adjustment has been aptly

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[1] Marilyn E. Shephard, "The Social Adjustment of Veterans with Schizophrenic Disorders," p. 15.

expressed by Harriett Bartlett.

> In the medical setting, social workers are concerned with the problems of individuals and families in adjusting their social roles and functioning to the realities of illness, physical handicap and medical treatment.[2]

Purpose of the Study

This study will attempt to answer the following questions: What are the general characteristics of veterans in this sample - age, length of illness, degree of incapacitation - and how do they compare with other studies? What has been their adjustment to illness, work, family? What problem areas were focused on in casework treatment?

Justification for the Study

In the treatment of patients with multiple sclerosis there is a need to keep stress at a minimum because this aggravates their condition. If it seems indicated at the clinic the psychiatrist or the social worker attempts to help the patient through treatment to live as best he can within the limitations of his illness. The type of stressful situation and how he reacts to it determine who will treat him. This study will examine cases seen by the social worker.

To know what kinds of problems these patients are likely to face and if there are any particular patterns of stress in patients with this disease would facilitate psychosocial diagnosis and casework treatment. The more that is known about how these patients feel and react to their illness, the more effective will be the treatment. Since there is limited

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[2]Harriett Bartlett, Fifty Years of Social Work in the Medical Setting, p. 39.

medical treatment for the illness at this point, a means of help is casework or psychiatric treatment.

The writer has found two other studies on the social adjustment of multiple sclerotics by caseworkers. Both concentrated on the economic and emotional implications to the patient, of what it meant to continue to work or to have to give up work after the onset of the illness. There are articles by doctors and psychiatrists on social and emotional problems of patients with this disease and while helpful to social work, are not looked at as possible areas in which casework might be effective. This implication could be drawn from these articles but here the objective specifically is to examine the problems this sample of patients with multiple sclerosis have and if these problems are suitable for casework treatment.

Method and Scope

The data for this study came from questionnaires filled out by patients for the research project. These included information on work history, a description of symptoms, history of the illness, family history and personality descriptions. A second source of data were the social histories taken by caseworkers. These histories covered much the same material the questionnaires did with a greater emphasis on work history and family life. Casework interviews between the patients and workers were the third source of data. In these there was information on the patients' feelings and attitudes toward their illness and the workers' impressions of their functioning. Information also came from informal interviews with the two workers who had seen or were seeing this group of patients.

Twenty-six veterans were chosen as a sample out of a population of about two hundred who were interviewed for the research project. This

number had processed social service records. Some of these patients were seen in group therapy or individually by the psychiatrist so that more than twenty-six were being treated for emotional problems but only twenty-six by the social service department. It is likely that some of these patients, if they were presenting problems, were referred to the mental hygiene clinic of the Veterans Administration which is located in the same building. Referrals from the neuropsychiatric clinic to the mental hygiene clinic are frequent. There patients could receive casework treatment or psychotherapy. However, these records are separate and only those available in the General Medical section were used for purposes of this study.

Four of the twenty-six cases have not been seen in the past year (1958) by the social service department but continue their medical treatment at the clinic. If there had been a noticeable change in their social situation, presumably the patient would have come to the attention of the social service department again through the doctor's referral. Twenty-two patients have been seen in the past year (1958). Eleven are currently being seen and of the remaining eleven, one was last seen in January, three in March, one in May, two in July, one in August, two in October, and one in November.

The number of interviews per patient ranged from sixteen to one, with the highest number - five - having a total of eight interviews.

Limitations

The study is limited by the small size of the sample and by the fact that it is an all male sample. This disease affects women as well as men, but because of the type of agency, few women are treated here. The study

included only those patients referred to the social service department by the doctor or whose contact with social service started through the research interview and continued because both the patients and the workers agreed to further interviews. The sample, therefore, may not be representative of all multiple sclerosis patients seen at the clinic or of patients as a whole with this disease.

The unevenness of the source material further limited the study. All the records had questionnaires and social histories or casework interviews but some had more material than others due to variability in the purpose and detail of the recording, the number of times the patient was seen, and his ability to communicate his problems and feelings. There was limited material on the pre-morbid personality of the patients, not enough to be included here. The study would have more validity if more was known about how the patient functioned before he became ill. The study did not attempt to show the success or the lack of success of casework treatment in the problem areas described.

Setting

The Veterans Administration Boston Outpatient Clinic functions separately from a hospital but operates as any general outpatient department and works closely with V. A. hospitals in the area. Structurally the Social Work Service includes two main sections in the clinic - the General Medical Service and the Mental Hygiene Service. Twenty-eight clinical social workers are assigned to provide casework service to patients in the various clinics. The chief social worker coordinates and directs the social service program. Material for this thesis came from the social service records of patients treated in the neuropsychiatric

clinic where a social worker is assigned as a member of the clinic team. Here neurological diseases are treated and emotional problems that go along with these diseases may be treated also, or such patients may be referred to the mental hygiene clinic where psychiatric disorders are treated.

CHAPTER II

BACKGROUND FOR THE STUDY

A Description of the Disease

Although Charcot, the French neurologist and early teacher of Freud, first recognized the symptoms of multiple sclerosis eighty years ago, it is only in the past twenty or thirty years that medical research has concentrated attention on trying to discover its cause and treatment. Research has not yet found a cause or an effective cure for it. The literature on the disease describes findings with few definite conclusions. Its occurrence is more common than popularly believed. "In the United States about 250,000 people suffer from multiple sclerosis."[1]

This is a disease of relatively early onset affecting the central nervous system. After onset there may be a steady progression of symptoms without remissions or there may be recovery for awhile but gradually there is a steady progression of symptoms without remissions. "Prognosis on the whole is generally regarded as favorable for short-term, unfavorable for long-term."[2]

It is very difficult to make an early diagnosis or to know exactly the time of onset except in acute cases.

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[1] Molly Harrower and Rosalind Hermann, Psychological Factors in the Care of Patients with Multiple Sclerosis, p. 5.

[2] Jorge A. Lazarte, "Multiple Sclerosis: Prognosis for Ambulatory and Nonambulatory Patients" in Multiple Sclerosis and the Demyetinating Diseases, p. 512.

> Generally symptoms in the early stages are so slight and so transitory as to make little impression on the patient's recollection... They often subside without a trace returning later and evolving into a fully developed clinical picture of the disease.[3]

The patient often does not see a doctor at this time and if he does, the physician not having a deep acquaintance with the clinical picture of this disease often will fail to make a diagnosis or will make an incorrect one.

Because lesions can affect any part of the central nervous system the disease can literally affect any part of the body.

> The disease is characterized by a variety of signs and symptoms which will fit into any one entity, but vary with the part of the nervous system involved. . . Symptoms include difficulty in walking as the gait becomes spastic. Braces are worn to control spasticity. The gait if not spastic may be ataxic. If so there is stumbling and falling . . . Poor hand coordination and hand tremors are common . . . There are disturbances of speech. It may be halting, slurred or come out as explosive utterances . . . Sensory disturbances include numbness and tingling in the hands and feet . . . Optic atrophy rarely leads to total blindness but does cause blurred vision, sometimes quite marked . . . Bowel and bladder incontinence are frequent complaints . . . Sexual impotence in the male is not uncommon.[4]

"From the physiological point of view all the symptoms of multiple sclerosis indicate a regression to a state of helpless infancy".[5]

This is a disease that occurs most often in cold, damp climates so that New England where the population of this study lives would have a higher incidence of the disease than the southern part of the United States,

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[3] Walter Timme, "Multiple Sclerosis - Historical Retrospect" in Multiple Sclerosis and Demyelinating Diseases, p. 9.

[4] Israel S. Wechsler, A Textbook of Clinical Neurology, pp. 573, 575-576.

[5] Roy R. Grinker and Fred Robbins, Psychosomatic Casebook, p. 120.

for example. What is quite generally accepted about this disease is that heredity plays no role, and it is extremely doubtful whether the disease is congenital.[6]

Emotional Factors in Multiple Sclerosis

There are many varying opinions on the relationship of emotional factors to the cause and course of this illness. What seems to be the most common conclusion is that the importance of psychological factors in producing this disease has not been demonstrated but that emotional stress can have an effect on remissions and exacerbations during the course of it. Because the symptoms are such that the patients become more or less dependent on those around them, feelings of frustration are common. These in turn may result in anger, expressed or repressed, and guilt feelings, either way that the anger is handled. Psychological as well as physical regression to a more infantile level of development are often observed.

Most of the studies found a diversity of personalities in patients with this disease. Some found a passive-dependent component in their personalities.[7] Personality traits may be organically determined or psychologically determined, particularly in neurological illnesses. In the first class patients with multiple sclerosis may be observed to have personality traits that are caused by their organic lesions. An example of this would

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[6] Wechsler, op. cit., p. 579.

[7] Konstantin Geocaris, "Psychotic Episodes Heralding the Diagnosis of Multiple Sclerosis" in Menninger Clinic Bulletin, vol. 21 (May, 1957) p. 113.

be the "unpredictable outbursts of laughter and crying which are largely motor manifestations and do not represent emotional instability per se".[8] "Impulsive laughter, some rarely crying, occur in multiple sclerosis, and if present early, lead to the mistaken diagnosis of hysteria".[9] Here organically determined affect is wrongly interpreted as psychological disturbance. Although there are contradictions in the literature, euphoria appears to be the most commonly mentioned affect, considered in part especially in the late stages of the disease, to be organically determined. An example of the second type of emotional disturbance - a psychological reaction to be a stressful situation - may be commonly seen in "anxiety increasing the tremors, in-coordination or weakness of the patient".[10] "There are some patients who become aware themselves that periods of exceptional turmoil tend to bring on attacks".[11] Physicians treating the disease, although the specific relationship of stress and exacerbations of symptoms is not known will often tell the patient to avoid stress and tension as much as possible.

> The individual as a whole reacts to the disease in a manner which to some degree depends upon his personality make-up. The reaction

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[8] Edward A. Gordon, M.S. - Application of Rehabilitation Techniques, p. 15.

[9] Wechsler, op. cit., p. 578.

[10] Grinker and Robbins, op. cit., p. 119.

[11] O. R. Langworthy, "Relation of Personality Problems to Onset and Progress of Multiple Sclerosis", in Archives of Neurology and Psychology, vol. 59, 1948, p. 14.

> is modified by such factors as the extent . . . of the neuropathologic lesions, the social importance of the incapacity of the individual and the economic, marital and environmental significance of these to him.[12]

The following is a summary of a recent pilot study:

> From a sample of forty patients, twenty-two males and eighteen females in an age range from twenty to forty-five, compared with a control group of one hundred twelve, the following findings were reported:
>
> 1. Multiple sclerotic patients have a more active fantasy life. This appears a logical consequence of the motor restraint under which they live;
>
> 2. They have a greater tendency to withdraw;
>
> 3. Their anxiety was more bound up with bodily preoccupations;
>
> 4. They had more passive and regressive features in their personality than the control group.[13]

These findings seem to illustrate a quite realistic reaction to an overwhelming physical situation. The fantasy, withdrawal and regression need not be looked at as completely negative reactions. They could help the patient live with his illness and not cause him undue stress. The anxiety it seems would be the most harmful affect. If allowed to become too intense, it could only exaggerate the symptoms.

Casework Techniques

The veterans in this study were referred to the social worker for help

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[12] Francis J. Braceland, Mary Griffin, "The Mental Changes Associated with Multiple Sclerosis", Multiple Sclerosis and the Demyelinating Diseases, p. 454.

[13] G. S. Philippoulous, E. D. Wittkower, A. Cousineau, "The Etiologic Significances of Emotional Factors in Onset and Exacerbations of Multiple Sclerosis", Psychosomatic Medicine, vol. 20 (November-December, 1958) p. 461.

with a variety of problems as will be seen in Chapter V. Problems referred to a social worker may be of an inner psychic nature or related to external reality factors, or more often a combination of the two. Whatever the problem, the social worker deals with conscious material. Unconscious material may be brought up in interviews, especially in long term treatment cases but it is not handled directly, only in derivative form. "In general, . . . the aim of casework is to help the client find a satisfactory form of social adjustment."[14] Casework involves looking at the client, his psychological make-up and his social environment. It is in the latter area that casework concentrates, although a knowledge of the dynamics of personality is necessary to work effectively and to know what a particular experience may mean to an individual client. The social reality for the patients in this sample was their illness, the changes in their environment caused by the illness and their reactions to these changes.

The caseworker can help the client to adjust to his social reality by a number of techniques or in a number of different ways depending on the psychosocial diagnosis. These techniques include: modification, psychological support, clarification and interpretation.

> Environmental modification include the steps taken by the caseworker to change the environment by the worker's direct action. It is undertaken only when . . . pressures upon the client are beyond his control, or when such pressures are much more likely to yield to change when handled by the worker rather than by the client himself.[15]

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[14] Grete Bibring, "Psychiatry and Social Work" in Principles and Techniques in Social Casework - Selected Articles, 1940 - 1950, p. 309.

[15] Florence Hollis, "The Technique of Casework" in Principles and Techniques in Social Casework - Selected Articles, 1940 - 1950, pp. 414-414.

This technique would be used with children, the aged and others who could not act for themselves.

> Psychological support, clarification and insight development all differ from environmental modification and have common ground in that they take place through contact directly with the client.[16]

"In psychological support there is an emphasis not on understanding by the client but on reinforcing ego strengths through guidance and release of tension and through reassurance.[17] This technique would be used with seriously disturbed patients - psychotics or severe neurotics or with basically healthy individuals who are in a period of severe stress. This technique would also be used with clients who were very anxious or threatened by their reality problems, especially in the beginning of the treatment. The veterans in this sample, often overwhelmed by the frightening aspects of their symptoms and the progressive course of the disease would need this type of help at one or another point in their treatment.

> The dominant role in clarification, sometimes called counseling, is the client's understanding of himself, his environment and/or the people with whom he is associated. It may be an intellectual or an emotional process.[18]

> Insight therapy unlike clarification is concerned with past as well as current experiences and the connection between the two. Also, unlike clarification, there cannot be just an intellectual connection made but emotional affect that went along with these experiences must be relived.[19]

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[16] Hollis, op. cit., p. 415.

[17] Ibid., p. 416.

[18] Ibid., p. 418.

[19] Ibid., p. 422.

With this group of patients the techniques used were psychological support and some clarification. Environmental modification or direct action was not used. Change was always effected through and within the worker-client relationship. Insight therapy was not appropriate for these patients as much of their energy was directed toward maintaining a status quo in relation to the quite overpowering fact of their illness rather than with effecting some deeper psychic change.

> Clarification and psychological support usually go hand in hand, one or the other predominating and giving its characteristic emphasis to the total treatment process. These two methods taken together might be considered the central core of the casework method.[20]

The patients in this sample were not deeply disturbed psychotic or neurotic patients but did have varying degrees of personality problems, some more, some less severe always looked at here in relation to the reality problems of their illness.

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[20] Hollis, op. cit., p. 415.

CHAPTER III

A DESCRIPTION OF THE TWENTY-SIX VETERANS

General Characteristics

This disease has its highest incidence rate in the young adult years. "The age at onset in many studies has been shown to be in young adulthood, between twenty and forty."[1] "Multiple sclerosis is essentially a disease of early adult life, most cases occurring between twenty and forty."[2] "The ages of persons suffering from multiple sclerosis ranges chiefly from twenty to forty, but may occur as early as the tenth or as late as the sixtieth year."[3]

TABLE 1

AGE AT ONSET OF SYMPTOMS

Age at Onset	Number of Veterans
15-20	4
21-25	8
26-30	7
21-35	5
36-40	2
Total	26

[1] George A. Schumacher, "Multiple Sclerosis," Journal of Chronic Diseases, vol. 8 (October, 1958) p. 464.

[2] Wechsler, op. cit., p. 579.

[3] Timme, op. cit., p. 9.

An earlier age than twenty had to be provided in this sample because two veterans incurred the disease at nineteen and one at eighteen. The oldest reported age of onset was thirty-six. The average age at onset was twenty-eight.

This is not the age at which the illness was diagnosed in the majority of cases but the age at which the patients first remembered having symptoms. In the early stages of the disease symptoms are often fleeting and pass unnoticed so that the patient does not seek medical care. However, since this is only rarely a disease of childhood, it is not likely that symptoms began before age fifteen in this group.

TABLE 2

DURATION OF THE DISEASE

Years	Number of Veterans
0-5	3
6-10	4
11-15	16
16-20	1
21-25	1
26-30	1
Total	26

Twenty cases or 77 per cent of the veterans in this sample have had their illness from six to fifteen years. Three have had it five years or less and three have had it from sixteen to thirty years. The longest number of years a patient had his illness in this sample was twenty-nine years. The average duration was thirteen years. This study did not consider duration of disease related to death as all of these patients are living.

" . . . these patients do have a life expectancy greater than is commonly believed."[4] "The duration of the disease is from one or two to twenty years or more, the average being seven to nine."[5] "It is common for patients to continue in a state of reasonable function for as long as eight or ten years."[6] "Duration of the disease is from a year to more than thirty years."[7] The length of time patients have had the disease will have implications for the rest of the study. Most have had to live with their illness for some time and its effect on their work, personalities, and family life will have had time to take hold.

Twenty-one or 81 per cent of the veterans in this study are married. Five or 19 per cent are single. Of the twenty-one married, seventeen have children and four have no children. Two have one child, nine have two children, four have three children and two have four children. This has been the first and only marriage for these veterans, though one wife was married before. The length of time married ranged from twenty-six years to four months with the average being twelve years.

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[4] Lawrence C. Kolb, "The Social Significance of Multiple Sclerosis," in Multiple Sclerosis and the Demyelinating Diseases, p. 35.

[5] Wechsler, op. cit., p. 578.

[6] Richard M. Brickner, "Multiple Sclerosis," Medical Clinics of North America, May, 1948, p. 748.

[7] Timme, op. cit., p. 8.

TABLE 3

LIVING ARRANGEMENTS

Mode of Living	Number of Veterans
Alone	0
With wife	3
With wife and children	16
With both parents	2
With mother	2
With mother and other relative	1
With father	0
Other	2
Total	26

The "other relative" with whom one of the single veterans lived, together with his mother, was a widowed sister. The two patients included in the category "Other" were in the hospital at the time the data was collected. One had been in only a few weeks. He had attempted suicide. The stage of his illness would not have necessitated hospitalization at this time. The second patient included in this category was the most seriously ill of the group and could not be cared for at home at this point. He had been in the hospital about six months.

It is interesting that no veteran lived alone or with a father. This is explained partly by the large number married. But four out of five single veterans were at an age where, if they were not leaving home by marriage, would probably be making some step toward independent living. Though there is no way of telling from this table who cared for the patient in the home or the willingness on the part of the family to do this, all the veterans are in a position to be cared for by a wife or mother.

The living arrangements point up a similarity with a study of twenty-five veterans with multiple sclerosis at the Worcester V.A. clinic. "Contrary to the experience of other severely disabled groups, for example, tuberculosis, these cases have not required extensive, repeated and long term hospitalization with its subsequent separation from the family."[8] The veterans in this group usually were in the hospital for diagnosis but have been treated on an outpatient basis since for the most part. However, as other studies have shown " . . . family disruption occurs when a parent is chronically ill and remains in the home".[9] The patient living at home creates problems for himself and the family. Some of these problems will be discussed in Chapter V.

TABLE 4

EDUCATIONAL ACHIEVEMENT

School	Grade or Year Completed	Number of Veterans
Grammar	6	1
	7	1
	8	0
High	9	1
	10	3
	11	1
	12	5
College	1	3
	2	2
	3	0
	4	5
Graduate	-	4
	Total	26

[8]Narrative Report for Period Ending March 31, 1958 for Area Covered by the Boston VA Outpatient Clinic.

[9]Sara Arnaud, "Some Psychological Characteristics of Children of Multiple Sclerotics," Psychosomatic Medicine, vol. 21 (January-February, 1959), p. 8.

The four veterans who went to graduate school completed the course. One of the veterans placed in this category was a priest. He completed college, then seminary training. Nineteen of the veterans graduated from high school and had further study. Five veterans had had some vocational training in addition to the education recorded in the table. One who completed two years of high school had special training in repairing business machines. The second left school at the same point and took courses later in radio and T. V. repairing. The third graduated from high school and had special training in watch and jewelry repair. The fourth left school in the sixth grade, then went to baker's school in the Navy which he had made his career, and the last veteran in this grouping left high school after his third year and later took courses in a college of pharmacy.

The veterans in this sample seemed well motivated to get an education, but several factors may explain their level of educational attainment, one of them being the fact that eighteen of the twenty-six veterans were eligible for benefits under either the World War II or Korean bills providing money for education. These bills brought a chance for an education within the reach of more of these veterans than ordinarily might have been so if they had to rely on their own financial resources. This would be unlike another sample where these kinds of benefits would not be available. Three had college training before they entered service, two were career men and three were not eligible for these benefits because they did not serve in periods covered by the bills.

Employment

All were employed before the onset of illness.

Table 5

EMPLOYMENT BEFORE THE ONSET OF THE ILLNESS

Job	Number of Veterans
Professional	6
White collar	3
Small business	1
Service	2
Blue collar	16
Total	26

Among professional occupations were included teacher, civil engineer, artist, priest, chemist. The classification "white collar" was the least precise grouping. It included a post office clerk, a drug clerk, and a traveling salesman. The "blue collar" group included truck driver, mechanic, sheet metal worker, machinist, etc. The one small business man owned a jewelry and watch repair shop. Of the fourteen who had some college or graduate training only six were employed in the professions. It seemed that they did not particularly utilize their education in choosing a job. There is not enough information in the material to indicate what factors in the environment or in the individual personality influenced this kind of a job choice. From the literature there is an often mentioned speculation that patients with multiple sclerosis have a tendency to passive-dependent types of personalities.[10] "In male patients with multiple sclerosis it is quite clear that there is often marked immaturity in the emotional sphere."[11] "Psychologically, the pre-morbid state of the

[10]Konstantin Geocaris, "Psychotic Episodes Heralding the Diagnosis of Multiple Sclerosis," Menninger Clinic Bulletin, vol. 21 (May, 1957), p.113.

[11]Grinker and Robbins, op. cit., p. 121.

multiple sclerosis patient is that of great immaturity."[12] This group of veterans seemed to show more drive in gaining an education, though the G. I. bills were an added incentive, than they did in getting a job suited to their training. But school is a more protective environment than the job market. Some passive-dependent features may be in this group but there is not enough evidence to prove this. In only one case did the onset of illness change job plans. This was with a veteran whose completion of graduate school and onset of symptoms came at once. He had an M. A. in art but continued working as a post office clerk where he had been working part-time while going to school.

Presently ten veterans were employed and sixteen were unemployed. Only three of the sixteen patients unemployed had to leave work at the onset of their symptoms. The remaining twelve had to leave at varying times after the onset, from one year to fifteen years later with the range as follows: three, four, six, seven, nine, eleven, and twelve years. The largest number of those presently unemployed - thirteen - were not incapacitated immediately. The average duration of illness for this group of veterans was found to be thirteen years. The average length of time after onset of the illness that the patient became unemployed was seven years.

The Employed

Of the ten who are employed only two are in their original jobs, one a teacher and one a fire alarm operator. Both have had multiple sclerosis for fourteen years. Another patient, already mentioned, who had an advanced

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[12] Langworthy, op. cit., p. 24.

degree in art and was presently a letter sorter in the post office should be included here because he did not change his job either, although his case is somewhat different because he was not employed in the type of job he would probably have chosen except for the illness.

Seven of those presently employed have changed from a more active to a less active type of work:

a. from traveling salesman to telephone operator in his home;

b. from telephone lineman to clerk;

c. from rigger to bench worker;

d. from mechanic to clerk;

e. from mechanic to clerk;

f. from chemist to clerk;

g. from free lance artist to teacher.

Of the ten employed two had had their illness fifteen years; four, fourteen years; one, twelve years; one, eleven years; one, six years; and one, four years. This group was working an average of twelve years after the onset of illness.

Thirty-eight per cent of the population of this sample were employed four to fifteen years after the onset of symptoms. In a study by Kolb of one hundred seventy-six patients,

> . . . 80 per cent were unable to hold a job within five years following the onset of initial symptoms. Actually 75 per cent had to relinquish their jobs within a year of the initial symptoms of the disease . . . Only twenty-eight could work and twenty of these had been ill for less than five years.[13]

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[13] Kolb, op. cit., p. 32.

In a study by MacLean of multiple sclerotic patients in a rural community around the question of the progression of the disease in terms of disability ". . . in eighteen cases, twelve were able to work and six unable to work. Those working had the disease an average of eleven years, those not an average of thirteen years".[14]

A study by Thygesen of one hundred Norwegian multiple sclerotic patients showed one-fourth were able to work eight to fifteen years after onset of the illness.[15]

Kolb's sample was drawn from the lower class of an urban community and MacLean's from a rural farming community. The type of community from which the Norwegian sample was taken was not known. Economic problems influencing housing, diet, care given to the patient, could have accounted for the sharp decline in Kolb's sample. The rural community may not have been up against such hardships.

The work record of this sample - 38 per cent working with an average length of illness, twelve years - stands between Kolb's, 16 per cent working, all of whom had the illness five years or less, Thygesen's, 25 per cent working and MacLean's sample where 67 per cent were working with an average length of illness of eleven years. The veterans working in this sample had their illness the longest average number of years of the other

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[14] Alexander R. MacLean, Joseph Berkson, Henry W. Woltman and Louise Schionneman, "Multiple Sclerosis in a Rural Community," in Multiple Sclerosis and the Demyelinating Diseases, p. 27.

[15] Kolb, op. cit., p. 32.

three studies. But this becomes significant only when compared with Kolb's study as Thygesen's and MacLean's samples also showed long work records after the onset of symptoms.

Because of the wide range of work years seen in these studies, one can presume that factors other than length of time one has had the illness must influence ability to work. Since it does not have to be a steadily progressive, but may be a remitting type of illness for some years in the beginning stages of the disease, there are physical factors to think of in the length of time a patient is able to work. Also here we have speculated that there might be something in the stress of urban life and the relative calm of rural life that might influence the patient's physical condition and so his ability to work. This sample is drawn from a metropolitan area, yet there is not the sharp decline as in Kolb's sample which is drawn from the city of Baltimore. As will be seen in a discussion of the income of these veterans later in the chapter, such adverse economic factors did not impinge on them as they might have in Kolb's sample and may have relieved pressure and enabled them to function on the job longer. There are many reasons for differing lengths of time in working in these studies that are not known.

The Unemployed

Of the thirteen unemployed some time after the onset of the illness, ten stayed in the same job until illness forced them to leave. Three changed jobs before retiring and in these, too, there was a shift from a more active to a less active and demanding type of work:

a. from truck driving to taxi driving;

b. from a plasterer to a radio and television repair man;

c. from a smelter operator to working in a lab for the same company

Sixty-two per cent of the population of this sample was unemployed. This compares closely with 69 per cent unemployed found in a study at the Massachusetts General Hospital of thirty-six patients.[16]

The occupational readjustment as well as retirement from active work were factors in this group of patients. "In a certain sense the most fundamental basis of the family's status is the occupational status of the husband and father."[17] Because this illness allows for a long life in many cases but imposes quite extensive physical limitations on patients as it runs its course, they often have to make a number of these adjustments. They can be out and about in the community but often cannot do the job they want to do and this adds to the frustrations the illness imposes. Of the seven in the employed group and the three in the presently unemployed group who changed jobs to keep working longer, six out of these ten spoke of difficulty in adjusting to a job they did not like in comparison with one they had before they became ill, or, felt they were doing work below their intellectual capabilities. For example, one patient who had been a mechanic and boss of a number of men in a large plant now was a clerk in a civil service job. He went from a "blue collar" to a "white collar" job and while one might quickly say this was a step upward, in the former he had more responsibility, while the latter was a

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[16] Annette Fisher, "A Study of the Social Factors in Patients with a Diagnosis of Multiple Sclerosis Referred to Social Service, Massachusetts General Hospital, 1945-1949," p. 37.

[17] Talcott Parsons, "Age and Sex in the Social Structure of the United States," in Personality in Nature, Society and Culture, p. 368.

more routine job and was much less rewarding to him. The free lance artist who turned to teaching because it required less activity (he needed to contact people, make sales when he was on his own) looked on teaching as a restrictive job compared to the more independent, creative life he led before his illness.

TABLE 6

PHYSICAL STATUS RELATED TO ABILITY TO WORK

Status	Number of Veterans
Ambulatory - working	5
Ambulatory - not working	1
Semi-ambulatory - working	5
Semi-ambulatory - not working	10
Wheelchair	4
Bedridden	1
Total	26

In the ambulatory category were classified those patients who reported a minimum of symptoms and who needed no aids in walking, such as braces, crutches or canes. Two reported their walk was sometimes slightly off balance, three that their walk was good. The one classified ambulatory and not walking reported symptoms that could only place him in this category. He had an emotional problem along with his multiple sclerosis that was interfering with his work as well as with his total adjustment.

The semi-ambulatory group included those patients who needed some help in walking - braces with crutches or cane or only a cane and who reported more serious involvement in other areas - vision, hand coordination, spasticity, stiffness. In all in this grouping the number of

symptoms showed a marked increase over the ambulatory group where only one or two were mentioned. In those classified as semi-ambulatory, gait was a universal problem and some aid was needed to keep balance. There was a constellation of symptoms rather than one or two as in the ambulatory group.

Of the five who were working and the ten who were not in the semi-ambulatory group there was a similar degree of disability reported. But the striking symptom occurring more often in the non-working group was impaired vision. Eight out of ten in the non-working group reported visual symptoms. One said this was his most disabling symptom and he might well have been speaking for the others in this group with the same symptom. One of the working group reported this symptom but it only was an occasional blurring.

One might have assumed that all patients who were ambulatory worked and the more seriously involved patients would not work. From Table 6 this was not found to be strictly true because five patients who had quite a high degree of involvement did work.

Of the four wheelchair patients, all were unemployed. One of these veterans was the oldest in the sample - sixty-five. His illness came on twenty-nine years ago. A second was forty and two were in their thirties. All four reported extensive involvement.

The one bedridden case had been ill for seven years and was, of course, unemployed. He had grown rapidly worse. The onset of his symptons came quickly and he was incapacitated within a year afterwards. The other three patients who had a rapid initial onset have not grown as ill as this patient.

Because this sample has shown itself to be composed of patients who have had their illness an average of thirteen years, it is not surprising that there are six in the ambulatory group and eighteen in the other three more involved groups. What is surprising is the number of patients who are fully employed in this sample of men with symptoms for the most part of many years' duration. Visual impairment seems the most disabling symptom as far as work goes.

> It should be observed, of course, that the patient's ability to work will depend not only . . . upon his physical limitations but also on 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.[18]

This was seen in one case in this sample, a man who was ambulatory but not able to work. Though it may have been true in others the material was not clear enough to determine this.

Income

Of the twenty-six veterans, eighteen are 100 per cent service-connected for multiple sclerosis which means they receive a monthly pension from the government. In these cases the maximum received was $337.00 monthly and the minimum $260.00 for married veterans. There are provisions made for wives and children and in addition the State gives $50.00 to veterans 100 per cent service connected. The above figures included this allotment. With single veterans in this class the highest amount received was $260.00 and the lowest $160.00. There is some difference in

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[18] Fisher, op. cit., p. 33.

the amount if service was during wartime or peacetime. If it was during the latter the amount is somewhat less.

Two veterans were 80 per cent service connected and received $128.00 and $210.00 respectively, because of varying reasons for the differing amounts - married or single, war or peacetime, children or no children.

Two veterans were 60 per cent service connected. Both received $120.00.

One was 50 per cent and received $110.00.

Three were 30 per cent. Two received $55.00 and one $44.00 monthly. Under 50 per cent there are no provisions for wives and children.

Of the eighteen who were 100 per cent service connected, three worked full time and so had wages to supplement pensions. Working did not affect these payments.

Both veterans with 80 per cent and 60 per cent ratings, and the three rated 30 per cent, worked. The one rated 50 per cent did not work but his wife did. In addition there are seven other wives who worked. Besides money payments all medical care is free including hospitalization. Three of the 100 per cent service connected veterans who were most severely involved own homes equipped for paraplegics. The government pays $10,000 toward the purchase of a house like this. The government in addition pays $1600.00 toward the purchase of the first automobile for a paraplegic patient.

Unlike other studies - Kolb's and Fisher's, for example - where loss of work often meant financial ruin and turning to others - people or institutions - for support with accompanying feelings of loss of prestige and status, these veterans were in a rather unique position financially because of their compensation payments. In no case was the income found

to be sub-marginal. The patient was getting an income sufficient to maintain his family and the income was in his name.

CHAPTER IV

EMOTIONAL ADJUSTMENT

Up to this point external factors of the patient's life have been described. Here some attempt will be made at a presentation of his feelings about himself and his illness. Admittedly, this is open to less precise description than the information presented up to now but an attempt has to be made at such a description in order to get a more complete picture of the individuals who make up this sample.

The information for this chapter came from a section of the questionnaire in which the patient was asked to describe himself and from the worker's recorded observations in the case record. First, the patient's description of himself will be looked at. For this description of his personality the following words were used as hints on the questionnaire - disposition, sociability, nervousness. These hints gave a definite slant to the descriptions. This was helpful for categorizing as there would have been a myriad of responses otherwise, but the patient's freedom and imagination in describing himself was limited. Also it has to be considered that one or all of these words had frightening or unfavorable connotations in the individual patient's mind and so colored his responses. With all these factors in mind, it seems there still might be some value in examining how the patient saw himself.

Descriptions by patients of emotional adjustment (multiple coded) are shown in Table 7.

TABLE 7

DESCRIPTIONS BY PATIENTS OF EMOTIONAL ADJUSTMENT
(MULTIPLE CODED)

Self-Characterizations	Number of Responses
A. Satisfactory	16
Sociable (8)[a]	
Pleasant (4)	
Calm (2)	
Usually calm (1)	
Feels great (1)	
B. Questionable	31
Easily irritated (7)	
Nervous (7)	
Not very sociable (5)	
Easily irritated at times (4)	
Depressed at times (3)	
Gets upset at times (3)	
Tense (2)	

[a] Number of patients given in parentheses.

Some patients gave only one response, some several. These were the types of responses occurring most often. Responses which indicated a satisfactory adjustment numbered sixteen. Two of these seemed unrelated to the reality of the patient's situation. "Feels great" came from a patient who was severely involved and unemployed. Another patient who described himself as calm and pleasant with an even disposition was a wheelchair patient who seldom went out of the house and was not well accepted by his wife.

In Table 7 responses which indicated some discomfort in adjustment numbered thirty one. In this group the term "nervous" is an ambiguous one.

It is not precise and can mean many things to the individual who uses it to describe himself. In its broadest meaning here it would seem to imply a generalized anxiety. However, one patient who described himself as "generally nervous" and further as "recently becoming less sociable, not wanting to see old friends" attempted suicide and was hospitalized because of this at the time these data were collected.

The general mood from these self-characterizations seemed to be a certain amount of irritability, "nervousness", lack of sociability and depression. These kinds of responses outnumbered about two to one responses like a fair degree of sociability, pleasantness, calmness.

"It is thought that euphoria is highly characteristic of multiple sclerosis. I have found only about 10 per cent who are frankly euphoric."[1] One response could be categorized euphoric - feels great - when viewed in the light of the case material. "Relative euphoria could seem to describe a larger portion of the patients seen. Most of them are neither sad, depressed nor dejected as might be expected under the circumstances."[2] In this sample this latter description might be applied to the one patient describing himself as calm and pleasant amid rather trying circumstances.

In an article, "The Mental Changes Associated with Multiple Sclerosis" the authors found in a sample of seventy-five patients that

> . . . 10 per cent were euphoric, 20 per cent depressed, 18 per cent showed lability of mood, 12 per cent showed unusual irritability and 40 per cent reacted with moods commensurate with their conception of the probable outlook for the future of their disease.[3]

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[1] Brickner, op. cit., p. 746.

[2] Ibid.

[3] Braceland and Griffin, op. cit., p. 451.

> . . . euphoria or a benign, cheerful outlook with apparent disregard of physical disability has been found only in a minority of patients. It is the experience of most clinicians that irritability, querulousness, lack of stamina, emotional instability and depressive moods are as characteristic as is euphoria.[4]

In this sample the majority of patients saw themselves in a variety of moods rather than the two at each end of a scale - euphoria and depression. Only three could be placed in these extreme points on such an imagined scale.

TABLE 8

EMOTIONAL RESPONSE TO THE ILLNESS AS SEEN BY WORKER
(MULTIPLE CODED)

Response	Number of Times Appearing
A. Favorable	3
Accepting of limitations, trying to work realistically within them (2)[a]	
Underlying anxiety handled well by friendly, outgoing manner (1)	
B. Questionable	36
Fearful (8)	
Resentful (6)	
Denial of dependency (5)	
Somewhat rigidly controlled (4)	
Hostile (3)	
Tense (2)	
Dependent (2)	
Feelings of inadequacy (2)	
Depressed (2)	
Feelings of insecurity (1)	
Bland (1)	

[a] Number of patients given in parentheses

[4] Schumacher, op. cit., p. 467.

Three responses interpreted by the worker indicated an adequate adjustment. The patient described as "bland" was the one previously pointed out as being mildly euphoric. The remaining thirty-five observations showed some difficulty in adjustment. These observations had to do with the patient's feelings about himself and his interpersonal relationships. If this study ended with a look at these patients' adjustment in the work situation, there would be a different impression than what is gained at this point. Their work record is good and would indicate an ability to work within the limitations of their illness. It still may mean this. It is beyond the scope of this study to decide. However, what is known to a degree at this point is that many are functioning with many underlying fears and tensions. In a recent pilot study of forty multiple sclerosis patients six out of the forty were regarded as emotionally well.[5]

Among the eight patients who were described as fearful, their fears seemed to center around increasing loss of vision, loss of independence, fear of being bound to a wheelchair, a heightened fear of failure. In general, these patients were fearful of the progressiveness of their illness and the limitations it placed upon them. One patient feared seeing others bound to a wheelchair. He was in a wheelchair and it was felt other patients mirrored what he did not want to accept in himself. He had a strong need to deny the implications of his illness.

Patients described as resentful were so mainly because of their sense of helplessness and reduced status from having to give up work or having to move to another job not in keeping with their abilities. One patient

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[5]Philippopoulous, Wittkower and Cousineau, op. cit., p. 465.

was resentful about his brother now having the job he would have if he were well, another at his having to be an art teacher rather than a free lance artist.

Patients denied their dependency in two cases by leading very vigorous lives, doing strenuous work and engaging in an active social life, not in keeping with the physical limitations this illness imposes. Others denied by minimizing their illness or feeling it would soon be cured.

In patients who were described as rigidly self-controlled, there was a striving to maintain independence but at the risk of irritability and family conflict. As their loss of physical control became greater their accent on a rather perfectionistic performance from themselves and others around them increased.

Hostility was much like resentment. It described feeling of helplessness. However, the hostility in the cases in which it was cited was openly expressed whereas resentment was often veiled under a superficial acceptance of the illness.

The two patients described as dependent actually were so for quite different reasons. One was severely disabled. Realistically, he could be nothing else but dependent. He had returned to the state of "helpless infancy" described in the literature. The other patient was quite disabled but for many years past, even when he was less disabled, he had given into the helplessness of his position and demanded constant attention and waiting on from his family. In one the degree of incapacitation realistically caused dependency, in the other the attitude toward the illness.

One of the patients who was depressed was quite disabled, had few friends and was lonely. His chief pastime was going around to hospitals

visiting other multiple sclerotic patients. He was often preoccupied with thoughts of death.

Feelings of insecurity were particularly emphasized in the case record of one patient, but was an underlying theme in much of what patients said.

The three patients whom the worker saw as handling themselves well were among the more seriously disabled, but through a combination of strengths in their personalities, warm family relationships, work and outside interests, they were able to handle fear and tension so it did not interfere with functioning as much as in some other cases.

A psychologist reporting on her experience with group therapy sessions with multiple sclerosis patients said:

> Gradually they have been able to discuss their deeper feelings of being a burden on their relatives, their fear of the future and of dependency, the progress of the disease, their fear of getting worse and not being able to carry through on their commitments.[6]

The workers saw many of these same areas as concerns of patients in this present study. What Grinker and Robbins observed was also true of this group of patients.

> Some patients with brain lesions may respond to their disease in their habitual pattern of reaction to stress. Some patients may regress and give an appearance worse than that appropriate to their pathology. Others may attempt to deny their defects and minimize their disability.[7]

Comment

Though the defenses of denial, avoidance or suppression may have been operating in the two patients about whom there was some question as to the

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[6] Harrower and Hermann, op. cit., p. 25.

[7] Grinker and Robbins, op. cit., p. 119.

validity of their descriptions of themselves in Table 7. They also may have been reacting to their illness in an "organically determined" way, that is, their lesions might have been such that their moods were affected. One of these patients appeared "bland" to the worker. The other was seen as depressed but his superficial manner was euphoric. In the second case there was more of a question whether his affect was due to an organic lesion or to a psychological cause. One might speculate here both could have been operating. In the first case this patient's lack of concern about his situation seemed more clearly to be due to his physical condition.

This discussion assumes that only euphoria or relative euphoria may be due to an organic lesion. Whether or not irritability, depression, etc., may be or not is not considered here and they are presumed to be psychological reactions. In the literature it is euphoria that is spoken of as the "organically determined" affect most likely to go along with this disease, although it is no longer considered a necessary concomitant to it.

It is assumed then that the other responses are not organically but rather psychologically determined, though they may not assume the same significance that such reactions or responses would assume in a study of neurotic patients, for example, because these responses are bound to an overwhelming reality problem. For example, the response "somewhat rigidly controlled" might take on a different meaning if it were not considered in the whole context of the patient and his problem, specifically his illness.

CHAPTER V

CASEWORK TREATMENT

The social worker meets an individual who is experiencing some stress - a need for a job, for hospitalization or placement of children, for help in his social relationships. The worker ". . . faced with having to do something with his client about a problem . . . must ask and answer the question as to what part of the problem should be placed in the center of attention".[1] The problem ". . . becomes more manageable to him who bears it and to his helper when some part of it is carved out for a working center at a given time".[2] The following discussion illustrates the problems that were presented by the patients in this sample and selected by the worker as the most upsetting to the patients. The types of casework help used in these problem areas were psychological support and clarification or counseling as defined by Florence Hollis in Chapter I.

It is not surprising that these two casework techniques were used. From the evidence in Chapter IV on how the patient saw himself and how the worker observed him, it seemed that the casework help that would be most appropriate would be a supportive type rather than an insight type. These patients were threatened by their illness, anxious and fearful for the most part. In a recent article there was the following statement:

> The worker will not burden these clients with early interpretations, nor will he present the reality situation to them as long

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[1] Helen Harris Perlman, Social Casework, p. 29.

[2] Ibid., p. 39.

> as they are not ready to look at it. Rather he will ally himself with them psychologically, looking at the world from their viewpoint.[3]

With patients in this sample evidence presented up to this point around their feelings about themselves and their illness would seem to indicate that this would be the only ground on which the worker and patient could initially and for some time afterwards meet.

TABLE 9

FOCI OF TREATMENT
(MULTIPLE CODED)

Problem Area		Number of Times Appearing
A. Psychological support		6
Patients' acceptance of illness	(2)[a]	
Encouragement of more realistic attitudes	(2)	
Family's acceptance of illness	(1)	
Help toward employment	(1)	
B. Counseling		20
Conflict with wife	(7)	
Conflict with son	(6)	
Conflict with children	(4)	
Conflict with daughter	(1)	
Conflict with mother and father	(1)	
Conflict with mother	(1)	

[a] Number of patients given in parentheses

There was information on twenty-one of the twenty-six veterans about

[3] Sidney Love and Herta Mayer, "Going Along with Defenses in Resistive Families," Social Casework, vol. 40, (Feb., 1959), p. 72.

foci of treatment. Five veterans were seen only once. They were not interested in continuing and no treatment plan was made. Of the twenty-one veterans included here, seventeen were married and four single.

In the areas of conflict with child or children and with wives there was some overlapping. In five cases there was focus in both areas. Eleven out of fourteen married veterans with children reported conflict with children. Seven out of seventeen married veterans reported conflicts with wives. Forty-two per cent of the married veterans reported conflicts with wives. Seventy-eight per cent of married veterans with children reported conflicts in this area or almost twice as many as reported conflicts with wives.

In the single patient reporting conflict with his mother only, the father was dead and this was the only parent he was living with.

In the two patients who needed help in accepting their illness, an attempt was made to help them adjust to a position they perceived as utterly dependent.

In the two cases where support was used to encourage more realistic attitudes, the first involved a patient who was neglected by his wife, and to whom the relationship was offered with the goal of increasing his self-esteem. He was in a dilapidated condition not wholly warranted by his physical condition. Part of this was thought to be a reflection of his poor image of himself. The second patient was single and fearful of his mother's failing health and what would happen to him without her. He needed casework support to think about his future more realistically.

In helping a patient find employment, some time had to be spent in reassuring and supporting him because his poor image of himself was inter-

fering with his presenting himself to employers.

Since 81 per cent of the veterans in this group were married and both married and single lived in a family group, except for two who were presently in the hospital, it was not surprising that the foci of treatment in so many cases was on family relationships. "Chronic illness causes loss of place in the family whether the patient is father, mother or child; it frequently entails a permanent readjustment for each person in the home."[4]

> Illness, and particularly prolonged illness, does not lessen the patient's need to play the role he feels society imposes on him. There is an irreconcilable discrepancy between what he considers his duties and goals to be and the realization of his utter inability to meet them.[5]

> To understand treatment we must remind ourselves what a social case is. Our individuation or particularization must cover not only the person himself but the environment with which he is interacting. Our case always envisages person, behavior and social setting, which includes other persons. . . . Casework under favorable circumstances can mitigate or even prevent some . . . crippling effects . . . especially in family life.[6]

Case Illustrations

For the problem areas requiring counseling it will be necessary to give more detailed examples from the cases in order to understand what was involved.

A. Relationship with children:

1. Conflict with sons;

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[4]Frances Upham, A Dynamic Approach to Illness, p. 48.

[5]Minna Field, Patients are People, p. 135.

[6]Gordon Hamilton, Theory and Practice of Social Casework, pp. 167-168.

a. This conflict was with a six year old son. The patient said his son showed disappointment when patient could not participate in games with him. This irritated the patient to a considerable degree so as to interfere with his getting along with his son.

b. The conflict was with a teen-age son who had been followed in a child guidance clinic for some years. The patient said his son was unable to adapt to things that the patient would like him to do. The son's adolescent rebellion aggravated his illness, according to the patient. On the other hand, this patient described his daughter as "a dream".

c. Conflict was with an eleven year old son. He too was seen over a period of time in a child guidance clinic. The patient demanded much academically from his son. He had two years of graduate school but could not pursue the career he prepared for because of illness. The patient focused so much of his energy on his son's achieving academically that the son rebelled.

d. Conflict was with a six year old son. The son tended to be demanding and too active for patient. He spoke more fondly of his daughter. His son remarked about patient's unsteady, spastic gait.

e. The conflict was with a nine year old son. Patient said in contrast that his daughter presented no problem. His son was described as stubborn and insolent. The son was being seen in a child guidance clinic. Patient got so upset with him he had difficulty breathing and often had to leave the table and eat by himself. He expressed some feeling about not being able to participate in sports with his son.

f. This conflict was with a teen-age son. Patient demanded much attention from the family. This son rebelled at this. He had been seen at a child guidance clinic.

2. Conflict with daughter;

a. There was friction with patient's twelve year old daughter around her attempt to assert independence.

3. Conflict with children;

a. Patient found it difficult to put up with his children's activity. Their "running around" made him irritable.

b. Patient said his children took up too much of his wife's time. He felt she should have been spending more with him.

c. In this case patient was the step-father. His wife was quite dominanting. He never was able to play the father role with these children. He was handicapped when he married his wife. This

coupled with her dominance had prevented him from assuming his proper role and caused resulting frustration and resentment on his part.

d. Patient said he was irritable with his children and had a need to have them obey.

B. Relationship with wives:

1. Patient objected to his wife working.

2. Conflict with a son had led to some tension with wife who tended to side with the son.

3. Patient complained that his wife was too concerned with her house and children and did not pay enough attention to him. He felt his wife was not interested in him. He had separated from her once during the past year. This was the patient who attempted suicide.

4. The wife works. This couple had been on the brink of separation for some time. Patient did the housework and some cooking. His wife was seen in casework also. She had said she worked because she did not like to take money from her husband because she was the older one in the family, implying she was the boss.

5. Patient's demanding ways and emotional as well as physical regression had tended to alienate his wife and children both so that any kind of a warm family atmosphere had been destroyed in their home and there was constant bickering and fighting.

6. Patient felt his wife rejected him because of his disability. She left home because of the attention her mother paid to a brother with cerebral palsy. She probably identified patient with her brother. She felt patient kept his diagnosis from her when they got married. Patient was not aware of his diagnosis at the time. Patient, on the other hand, kept his sense of adequacy by bringing up his intellectual superiority over his wife. He had an I.Q. of 135 and his wife of 80. This was a topic of many arguments between them.

C. Conflict with mother and father:

1. Mother was the dominant figure in the home where the veteran was living with both parents. His mother worked though there were four incomes other than her own coming into the home. Patient resented the fact that she worked. He said she did not need to and could spend more time at home. Veteran's father was alcoholic. He had no relationship with him. Symptoms of the illness, especially staggering gait reminded him of someone drunk. He felt an identification with his father which he did not want and which was upsetting him.

D. Conflict with mother:

1. Patient had lived alone with his mother since he was seven.

His father died then and he was an only child. His mother was possessive. She still bought him all his clothes. She had broken up plans for his marriage, yet patient was hostilely dependent on her.

Comment

In conflicts with children, irritation at their activity and a need to have them obey seemed to be the principal patterns in this problem area. The activity of the children seemed to point up to the patients the passivity illness had forced on them. Sons' demands on the patients, for example, to engage in sports, seemed to heighten their feelings of resentment at their own physical inadequacy which they then projected in anger onto the sons in whom they found some fault to criticize.

Patients seemed to be trying to emphasize the authoritative aspects of the father role, probably in an effort to compensate for the threat to their adequacy caused by their illness. Several conflicts were reported in adolescent rebellion of children when the latter's assertion of independence and the father's efforts to control would come into open conflict. One patient's dependency made him seek a son-mother relationship with his wife and it seemed he looked on his children as rival siblings for her attention. With one patient who had a conflict with his daughter it centered around her assertion of independence.

In conflicts with children, conflict with sons seemed to be the most serious. Only in this group had some of the children been seen at a child guidance clinic. It is interesting that three of the veterans who had difficulty with sons emphasized that they were more fond of their daughters.

Nine wives worked. Another was actively seeking work and one mother worked. Four patients disapproved of their wives working. In addition,

the single patient disapproved of his mother's working and the husband of the wife seeking work disapproved of her plan. Five approved. In all cases where the patient disapproved the problems included conflict with children, as well as with wives, and with the single veteran conflict with both parents. Only one of the patients who disapproved worked and his was a home-bound job.

In conflicts with wives feelings of rejection seemed to be a theme running through their problems in this area. Lack of money was not a major concern in these families forcing wives to work, so that their going to work may show some rejection on their part of the patient. Feelings of being rejected in the patient at his wife's going to work may have been stronger here than in other groups where working was more of an economic necessity and for this reason patients might accept it better. It would seem that wives working would reenforce the reversal of roles that had already come in some cases and was threatening in others because of the patient's disability. The husband had lost status in the family in having to give up his job in some cases. His physical incapacity had made him dependent. These feelings of rejection seemed real in some cases; in others they could have been a projection of his feelings of loss of self-esteem.

Although wives working was an important reason for conflict in this area, there were other reasons for conflict. Among them were the following: tension with wife over a son's "acting out", rejection by a wife because of her identifying her husband with a hated brother.

The family relationships in many in this group of patients seemed to show quite severe strain and serious conflict. What would make information more meaningful in this area would be a knowledge of the pre-morbid personalities of the patients and their wives.

CHAPTER VI

SUMMARY AND CONCLUSIONS

This study was undertaken because of the interest in multiple sclerosis patients at the Veterans Administration Outpatient Clinic, Boston, Massachusetts, particularly since a research project has centered around this group since August, 1957. It is a continuing interest of the social service department to know the adjustment of patients with any disease so that they might make a workable treatment plan in keeping with the diagnosis.

This study attempted to find answers to the following questions:

What are the general characteristics of veterans in this sample - age, length of illness, degree of incapacitation - and how do they compare with other studies?

What has been their adjustment to illness, work, family?

What problem areas were focused on in casework treatment?

A sample of twenty-six veterans with multiple sclerosis who had social service as well as medical records was chosen. Questionnaires filled out by the patients for the research project, social histories, and casework interviews recorded by the worker and informal interviews with workers who had seen or were seeing patients were the sources of data.

The study was limited by the small, all male sample. Whether or not this group was representative of all the patients with this disease seen at the clinic is not known as these patients were the ones seen most often by social service and it might be presumed had more problems than

those not seen. Limited in the information available on the pre-morbid personality of these patients, this study did not attempt to look in this area. The effectiveness of casework treatment was not measured.

Symptoms of the disease and emotional factors associated with it were described. Following this came a discussion of casework techniques, particularly psychological support and clarification.

It was found that the majority of veterans had incurred their illness in the younger adult years between the ages of twenty and forty. They had had their illness an average of thirteen years. Even though this is a chronic, progressive disease without a cure and limited treatment, the patient can live a relatively long life though he may become quite handicapped. Acuteness of onset and rapid physical deterioration is not common for the disease and was not for this group. One patient who became ill seven years ago went downhill more rapidly than any of the others and was presently hospitalized. Other studies found the duration of illness to be from seven to thirty years with an average in one, seven to nine years, and in another eight to ten years.

Since the average age of onset was twenty-eight in this study, most of the veterans had married and were beginning to raise families when the illness struck. Twenty-one or 81 per cent were married and seventeen of the twenty-one had children.

Except for two veterans who were hospitalized, all lived at home and were in a position to be cared for by a wife or mother or some other relative. One was hospitalized temporarily and would return to his wife and family. The other was too ill to leave in the near future.

Their school history showed a high level of educational attainment.

Nineteen of the twenty-six graduated from high school and had further training - vocational, college or graduate school. Two did not complete grammar school. Five left high school before graduating. The G. I. Bills after World War II and the Korean War providing for tuition fees, books and living expenses presumably accounted in part for the educational training this group had. Eighteen of the twenty-six veterans were eligible for these benefits. This group probably differs from another sample because of these particular benefits.

All veterans in this sample were employed before the onset of their illness, principally in "blue collar" jobs. The level of their educational attainment did not point to this but rather toward "white collar" or professional work. Only one patient could be said to have been interrupted in pursuit of a professional career because of his illness. This was the patient whose leaving graduate school and onset of symptoms coincided.

Presently ten patients or 38 per cent of this group were employed. One study had a higher per cent working - 67 per cent - and two had a lower - 16 per cent and 25 per cent. In the employed group there was shift from a more active to a less active kind of work in seven out of ten cases.

Sixteen were unemployed but only three had to leave work at the onset of symptoms. Thirteen worked for a time afterwards. The average length of time after onset of symptoms that this group had to give up working was seven years. Three in this group changed from a more active to a less active job to continue working longer.

The degree of disability was not always related to work in the

ambulatory and semi-ambulatory groups. Some with quite severe involvement were still working. Impaired vision appeared to be the most disabling symptom as far as keeping a patient from work.

The income for this group was not sub-marginal. Compensation payments or a combination of these plus the veteran's or his wife's wages provided adequately for the family. This was in contrast to a study at the Massachusetts General Hospital where loss of job for that group of patients most often meant sharply reduced income in the home.

Descriptions by patients of their personalities roughly gave a two to one ratio to questionable adjustment over good adjustment. The general mood of these self-characterizations seemed to be a certain amount of irritability, "nervousness", lack of sociability and depression. A fair degree of sociability, pleasantness and calmness were the bases for classifying patients under "good adjustment". Responses that were probably "organically determined" were found in two cases.

The workers' observations of the patients' adjustment showed a higher degree of questionable adjustment than the patients' descriptions of themselves. Observations of questionable adjustment numbered thirty-five to three for adequate adjustment in the workers' opinion. Though there needs to be consideration for personal bias or opinion based on inadequate knowledge of the patient by the worker, the intellectual framework within which he operates should cut down on the possibility of bias.

Treatment for twenty-one out of the twenty-six patients was discussed. Treatment included psychological support in areas of acceptance of the illness, help toward employment and encouragement of more realistic attitudes. Counseling or clarification was the second technique used with

more involved problems of family relationships, for example, conflicts with children, wives and parents.

Some patterns were found in these problem areas; a need to control and irritability at their activity in conflicts with children, feelings of rejection in problems with wives. Forty-two per cent of married veterans had problems with wives, 78 per cent had problems with children. Wives working tended to heighten the reversal of roles brought about by the dependency illness forced on the patients.

The physical disability caused by this illness coupled with the lack of an effective treatment or cure poses a social as well as a medical problem for this group of chronically ill patients.

In answer to the first question asked in this study concerning the comparison of patients in this group with other studies in such areas as age at onset, duration of illness, marital status, living arrangements, the findings were quite similar. As has been commonly found, the patients in this sample became ill with this disease as young adults when they were in the process of setting up homes and raising families. Since this disease does not run its course quickly but is chronic and progressive these patients lived at home for the most part. Since there is no treatment these patients are in a hospital only for diagnosis in the beginning of the illness and for nursing care at the end when they are almost completely helpless.

Work was an interesting area of study in these patients. Although they were quite well educated, their jobs before the onset of illness did not reflect this in the majority of cases. This could not be explained by the illness alone because the onset of symptoms caused pursuit of a

professional career to be cut short in only one case. Their motivation for an education and what it meant to them may have had some influence on the kind of job they chose, even with training. If the G. I. Bills were not available perhaps some of them would not have added training and they may have used it without particular interest or purpose.

Although we may speculate that there might have been some passivity in this group of patients in the limited ambition they showed in seeking a job in keeping with their abilities since passivity is a component found in some studies of the pre-morbid personalities of these patients, after the onset of illness they were quite active in terms of work. This apparent lack of ambition was not reflected in the tenacity with which they held onto jobs once they got ill. The illness may have been an incentive to mobilize strength in some cases. Twenty-three out of twenty-six kept working after the onset of symptoms, and the average number of years after they were ill that they gave up work was seven. Eleven changed their jobs in order to keep working longer. Generally we might say the emphasis in our culture on a man's "work" equated with his "worth" would be an incentive to many patients to stay on the job as long as possible and implies a drive to keep status and a feeling of self-esteem that the symptoms of this disease particularly threaten.

Work was not particularly a financial necessity as might be true for other groups because of the compensation payments these veterans received. That is why the incentive to keep working seemed to have more a status value than a monetary value. One wonders if the medical and financial benefits this group is entitled to had contributed to their being active for a longer time because of having less worry and stress in these two

important areas. Though financially this group did not have to step down in their position in the community the compensation payments probably did not completely satisfy the patients' need for prestige and feelings of status. The payments apparently were not some thing the majority of patients relied on unless they had to.

At the outset of this study it was expected that ability to work would show graphically patients' level of functioning and adjustment to his illness. However, in the patients' own words, in the workers' observations of them and in problems brought up in the casework interviews, this was found not to be so. The place where these patients had to fight their greatest battle was in the home. The majority of patients in this sample was now middle aged, lived at home, except for occasional hospital stays and family living patterns revolving around the illness had time to be established.

In observations on patients' emotional responses to his illness more limitations developed than were first thought of in the beginning of the study. What defenses - denial, avoidance, suppression - were operating in the patients' observations of themselves could not be demonstrated and so the validity of their responses are questionable. The workers' observations because of the intellectual framework within which they work should cut down on bias, so that one can speculate that there were some defenses like denial, avoidance and suppression operating in the patient, defenses often accompanying chronic illness in an effort to flee from the painful reality situation the patient is faced with, since the number of questionable adjustments was higher than good adjustments in workers' opinion than in patients.

That these patients faced problems in occupational readjustment, with wives, children and parents was evident. These are problem areas in which casework and psychotherapy work. Because these patients seemed threatened by their illness, a supportive relationship would probably be more often indicated especially in the beginning of treatment than an insight type of treatment that might have to stir up more anxiety before problems could be resolved.

Another study might take up the effectiveness of casework treatment or motivation of these patients for casework, neither of which was studied here. Another aspect of the problem that has already been examined in other studies and needs to be further looked at for conclusions is a comparison of the pre-morbid personalities of these patients so that more valid conclusions about their present functioning might be made on a comparative basis. What this study brought up was the question about wives of patients with a chronically disabling disease and their personalities, both pre-morbid and after the illness comes. Often in this group they seemed to quickly take over the management of the household and there was some indication that they rejected the patient. Quite a number worked when there was no particular economic necessity to do so. This was only an indication and the feelings of rejection may have been projections on the patients' part because of their loss of self-esteem. Wives are a group who might also be included in casework since they are so emotionally tied up with the disrupting illness that is upsetting their family life.

Along with the medical treatment available at present for this disease it seems help for these patients with the many stresses their

illness imposes can come from casework or psychotherapy. The anxiety of knowing that they have a disease for which there is no cure in itself is enough to interfere seriously with a patient's functioning. To relieve this and other stresses would help the patient function better even though the limitations of his illness remain.

Accepted
David Landy
Research Advisor

APPENDIX

APPENDIX A

SCHEDULE

Identifying Data

1. Year of Birth _____
2. Present Age _____
3. Age of Onset of Illness _____
4. Duration of Illness _____
5. Marital Status _____
6. Length of Time Married _____
7. Number of Children _____
8. Living with Whom _____
9. Last Grade Completed _____
10. Disability Rating _____
11. Dates of Military Service _____
12. Source of Income _____

Occupational History

13. Job Before Onset of Illness _____
14. Job After Onset _____
15. Present Job _____

Degree of Disability

16. Ambulatory { Working _____ / Not Working _____
17. Semi-ambulatory { Working _____ / Not Working _____
18. Wheelchair _____
19. Bedridden _____

Personality Adjustment

20. Described by Patients in the Questionnaire _____
21. Described by Worker in the Social History or Casework Interview _____

Family Adjustment

22. Adjustment with Child or Children _____
23. Adjustment with Wife _____
24. Adjustment with Parent or Parents _____

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