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STIGMA AND SOCIAL ISOLATION:

Self-perceived Problems of a
Group of Multiple Sclerosis
Sufferers

by

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SUMMARY

Despite the numerous surveys of disabled people, there remains at present a number of gaps in our knowledge and understanding of the problems and needs of physically disabled people. This study explored some of the problems and needs as perceived by the physically disabled themselves. It was a qualitative study of a small group of 16 MS sufferers aged between 18 and 60 years; each respondent was interviewed in depth on up to three occasions.

One of the major problems from the MS sufferer's point of view was the delay in the disclosure of diagnosis. The significance of the clinical label for the respondents was that it gave back to them their credibility and enabled them to initiate the process of adjustment to disability. It would appear that there were some discrepancies between the medical and lay understanding of multiple sclerosis, in that, according to the respondents, the medical profession seems to view it as a tragedy and a medical failure whereas the MS sufferers expressed relief that "it was only MS and not cancer!"

The study found that a number of the problems experienced by the MS sufferers result from the public's lack of information or misunderstanding about multiple sclerosis. The respondents expressed a general feeling that there is a need to educate the general public by providing information and portraying a public image of multiple sclerosis in a more positive light. The expressions of sympathy and pity that a disclosure of MS elicits from normals, although welcome in the early stages of adjustment to disability, were found to be limiting and oppressive when the respondents were attempting to "come to terms with it".

The process of adjustment requires the MS sufferer to redefine his or her life style and status within the family. From the verbal accounts of the respondents, the inadequacy of supportive services has meant that many had undergone tensions and strains in their family relationships that might have been avoided if all had been informed about the effects of the disease. Respondents found themselves being encouraged by the family and in some cases coerced into an acceptance of a disabled role or status. There was general criticism of all of the 'caring agencies'. The medical profession was criticised on a number of counts: first the unnecessary delay in the doctor disclosing the diagnosis to the patient and second their abandonment and failure to face up to the problems of the long term chronic sick. The lack of medical back-up and encouragement for the MS sufferers and their families was regretted. The respondents seemed

to have had only limited contact with the community nursing services
and did not feel that it was appropriate for the nurse to offer advice or
medical information about handling multiple sclerosis.   The other agency
to produce criticism was the social workers who, from the respondent's accounts
seemed to be ill-equipped to assess the social and psychological needs of the
disabled.   A major problem that arose was the conflict between the
professional's and the client's definition of the situation, and significance
of such terms as 'disabled' which the client viewed as meaningful only in
dealing with administrative bureaucracy and not in their everyday lives.

The process of becoming disabled was closely associated with the
development of the respondents' awareness of the social meaning and significance
of disability, in that they found themselves being stigmatised and devalued.
A number of coping strategies such as 'passing', 'normalisation', 'pacing'
or 'withdrawal' were used by the respondents to manage their presentation of
self depending on the audience in the social setting.   However, the MS
sufferers did find that, in the later or severer stages of the illness, they
were unable to conceal their disability and were left with the options of
normalisation or withdrawal from social life.   The patient's ability to
adopt coping strategies and attempt to redefine his or her life was only
possible after they had been provided with a diagnosis.

Many of the respondents commented on the fact that their problem stemmed
from the visibility of their disability, which they felt had been intensified
and made obtrusive by the various aids and gadgets provided by the medical
and social services, in particular the wheelchair.   Some had found ways of
controlling their body image and avoiding the use of such stigma symbols
as wheelchairs, but naturally this was dependent on the stage and severity
of the disease.

The importance of friends and neighbours as social contacts and support
networks were shown in the study.   However, only in one case was there
evidence of a close neighbourhood network.   Many of the respodents had found
that their friends had withdrawn from then at the very time when they most
needed them, i.e. immediately after the person had discovered that he or
she was an MS sufferer.   Most of the respondents had found that their
friendship circle had changed after the onset of the disability.

The difficulty of "filling the day" with activities was revealed
in the leisure patterns of the respondents.   The majority regularly attended

a local branch of the MS Society which formed their main social contact and entertainment centre. However, it seemed that the Society failed to provide enough supportive information and activities for the younger members who would have liked the Society to act as a self-help group. Apart from the disease specific society, many attended clubs for the disabled, and a few went on various other activities organised for the disabled, such as swimming or horse-riding. One of the main occasions of their annual calendar for most of the respondents was their holiday, which both provided the MS sufferer with a different environment and new people to meet and also relieved the family of the burden of caring for an MS sufferer.

The study has thus found a number of problems identified by the MS sufferers which, on further research, may prove to be common to many other physically disabled people. If this were shown to be the case, it would suggest ways that doctors, social workers and voluntary workers might improve their services to their clients.

INTRODUCTION

There has been increasing interest in the identification of and provision for people suffering from chronic illness and disabling conditions since the passing of the Chronically Sick and Disabled Persons' Act 1970.

Surveys of impaired and handicapped people (for example, see Harris, 1971; Bennett, 1970; Warren and Knight, 1977) have shown that sul ,tantial numbers of these people could be helped by the provision of services, but for many reasons such people have not or cannot take the initiative to seek help and so increase the quality of their lives. In addition, a significant number of people have been provided with aids and gadgets, but have either failed or refused to use them (Jay, 1974). Although these studies have identified the possible number of disabled people within the community, there remains a significant number of questions to be answered in order to fill the gaps in our present understanding and knowledge of disabled people and their needs. For example, the following kinds of questions: Are there alterations in the patient's conception of himself and the composition of his reference group as a realisation of disability occurs? Are these alterations precipited, shaped and perpetuated by the attitudes, behaviour and "treatment" given by "helpers", family and friends? Do some of the social problems of disabled people such as social isolation, result from a stigma associated with their condition? What techniques or strategies do disabled people develop to cope with social situations in which they find themselves stigmatised? Can these techniques be more generally developed and be incorporated in rehabilitation programmes?

Most of the studies used survey techniques to gather quantifiable data about the most immediate and practical consequences of functionable disability, for example, the problems of self care, mobility and finding employment. The aim of the present study was to gather qualitative data to complement the existing body of knowledge about disabled people and their needs, by focusing on the meaning and social consequences to the disabled person of his impairment, in particular the problems of social isolation and stigma. It is important to note that this study differs from previous studies, firstly in the focus of the project, and secondly in the methods to be used, i.e. unstructured interviews to gather qualitative data. The study was concerned to examine the self-perceived problems and attitudes of disabled people by exploring three main areas:

(1) Disabled people's accounts of the impact and effect of
their impairment on their social interaction and relations
with significant others.

(2) Disabled people's accounts of how they coped with
interaction with strangers.

(3) Disabled people's retrospective accounts of the process
of becoming disabled.

Hence, the present study focuses on problems that arise and are coped
with in the everyday world of disabled people. Many of these problems
experienced by physically disabled people stem from the social construction
of disability rather than the physical impairment per se. For beneath
the physical disability is a social definition of the social and moral worth
of the disabled person. In other words, the significance of the disabling
condition is expressed in social terms. The significance of the condition
obtrudes into the social relationships and becomes the focal point by
which the persons are judged and evaluated. On top of the disability or
impairment is imposed the social and psychological consequences which may
alter his life style and, in some cases, produces a negative self-image.
Hence the stigma of physically disabled people is largely a social phenomenon
based on reciprocities. In other words, the disabled person is usually
made aware of his differentness and disadvantaged status by the reaction
of 'others'.

One of the major tasks for the physically disabled, in order to counter
the potentially stigmatising devalued status of self-conception that may
be attributed to them, is to be able to reveal their 'normality'. They
have to work to produce a mutually agreed and recognised acceptance of
their normality and this may require resources and training. Since
conceptions of social reality are socially distributed, people may have
difficulty in knowing how to conduct themselves in any given occasion.

The need and the ways in which people who are visibly different can
assert their ordinariness forms part of the social and psychological problems
experienced by the disabled. For them to achieve ordinariness or normality
requires their ability to tell others about their experiences in such a
way as to affirm their usual character and the fact that they are 'normals'
despite appearances. In the study, respondents are asked about how they

handle encounters with strangers in order to gain some information on this important topic.

Consequently it seems likely that major problems confronting physically disabled people and their families are those of 'managing' not only the physical effects of the impairment and disability but the social and emotional consequences of it. It was not just the 'know-aboutness' and obtrusiveness of their disability, but the stigma and social isolation resulting from it and this is the focus of the present study.

METHODOLOGY

Definition

Most of the research in Britain (Jefferys et al, 1969; Harris, 1971; Garrad, 1974; Sainsbury, 1973; Warren and Knight, 1977; Williams et al, 1976) has been concerned to develop operational definitions of the classifications of handicap and impairment with a view to aiding health and social service departments with the task of identifying and making provisions for handicapped and impaired people. The definitions of handicap used in the majority of surveys undertaken in Britain were those defined by Harris in her national survey of handicapped and impaired in Great Britain (1971). However, in this study, the broader term 'disabled' is used to 'refer collectively in a general way to a population of handicapped people as well as those with impairments which restrict activities, but who are not currently handicapped', (for discussion of this definition and the problems associated with such definitions, see Warren and Knight, 1977).

Selection of Cases

The study was established as a pilot descriptive study focusing on disabled individuals and their views. Although it was acknowledged that the family plays a significant and important part in managing problems associated with one of its members being disabled, family members were not included in the study. A number of problems arose in connection with selection and access to respondents. A variety of different approaches were considered in and attempt to collect a sample: for example, an attempt was made to use the directory of names from the Canterbury Handicap Survey, but it was decided that, as these people had been contacted on two occasions already, it would be unfair to interview them again; secondly, contact was made with some doctors in a rural health centre but there are many difficulties associated with sampling from general practitioners' records (Warren, 1976; Dawes, 1972) and again this proved unsuccessful; so that the decision was taken to restrict the sample to MS sufferers as contact had been made with local branches of the Multiple Sclerosis Society of Great Britain and Northern Ireland, who were very willing to assist in this study. All the names were taken from the membership list of the local branch of the MS Society. Naturally, there are a number of methodological problems of bias and a-typicality associated with such a selection procedure. However, in a small exploratory study it was thought that this should not be a significant factor as the aim was to explore methods and gather in-depth data from a small group and not to study a representative sample of all disabled people.

Although all the respondents had the same underlying medical condition, their accounts and problems discussed in the report relate to the social adaptation to impairment and disability and hopefully illustrate problems that may be common to all disabled people. Eventually a small sample of 20 people with multiple sclerosis and aged between 18 and 60 were identified, the upper age limit being imposed as it was felt that disablement in the elderly or those near retirement age may be regarded as qualitatively different from disablement afflicting those under retirement age. The decision to interview only young disabled people was to enable the research fellow to collect information on their recent recollections of the ways in which they had faced a number of crucial life events, such as marriage, child rearing and starting a career.

Contact with the respondents was made by two methods. First a telephone call in which the research fellow explained how she had got the respondent's name, briefly outlined the project and made an appointment to see the respondent; and second by letter to those members who were not on the telephone. Hence in some cases contact was made with the goodwill and personal introduction of the Chairman of the local branch of the Multiple Sclerosis Society. There were no refusals but two people died and two more were too ill to be interviewed. This left a group of sixteen people; eleven women and five men whom the research fellow attempted to interview on up to three occasions for each respondent.

CHARACTERISTICS OF THE RESPONDENTS

NAME[1]	SEX	AGE	MARITAL STATUS	NO. OF CHILDREN	EMPLOYMENT MAJOR JOB HELD IN OCCUP. CAREER[2]	SOCIAL CLASS	CURRENT MOBILITY
Mrs. Apple	Female	35	Married	One 5-year old daughter	Lecturer at College of Higher Education	Middle Class	Walks with a stick
Mrs. Ball	Female	59	Widowed	Married son living away from home	Skilled manual worker	Working Class	Wheelchair-bound Uses invalid car
Mr. Chain	Male	56	Separated	One son and one daughter not living with father	Purser on P. & O. Line	Middle Class	Uses sticks occasionally
Miss Dale	Female	60	Single	No children	Writer	Middle Class	Bed-bound
Mrs. Earl	Female	59	Married	No children	Shop-keeper	Working Class	Wheelchair-bound
Mr. Field	Male	58	Married	No children	Railway clerk	Working Class	Wheelchair-bound
Mrs. Field	Female	42	Married	No children	Shop assistant	Working Class	Wheelchair-bound
Miss Guy	Female	40	Single	No children	Never worked	-	Wheelchair-bound
Mrs. Hale	Female	60	Married	Two sons living away from home	Husband post-office sorter	Working Class	Wheelchair-bound

Mr. Irwin	Male	40	Married	No children	Architect	Middle Class	Wheelchair-bound
Mr. Jolly	Male	59	Widowed	One married daughter with whom he lives	Manual worker	Working Class	Wheelchair-bound
Mrs. Kay	Female	35	Married	One 5-year old daughter	Husband civil servant	Middle Class	Uses sticks
Mr. Lee	Male	50	Married	No children	Business executive	Middle Class	Wheelchair-bound
Mrs. Morgan	Female	31	Married	Three sons aged 10, 8 and 5	Husband - school master	Middle Class	Uses stick
Mrs. Owen	Female	36	Married	Two daughters aged 14 and 12, one son aged 16.	Husband - skilled manual worker	Working Class	Uses sticks
Mrs. Pack	Female	53	Married	One daughter aged 18, one son aged 20	Husband - manual worker at Paper Mill	Working Class	Wheelchair-bound
Mrs. Reed	Female	29	Married	No children	Husband - salesman	Middle Class	Wheelchair-bound

[1] These are all fictious names.

[2] Currently none of the respondents are employed so that, for the men, the occupation listed above was their major job held in their working life and, for the married women, it was the job currently being held by their husbands who are not handicapped.

Data Collection

Three methods of data collection were used, in-depth interviews, non-participant observations, and the Kelly Repertory Grid Test, so that each method would complement the other.

In-Depth Interviews

At the outset, it had been decided that it would be inappropriate to use structured questionnaires or schedules to gather qualitative data on topics which were both potentially sensitive and personal to the disabled person. The adoption of the in-depth interview allows the interviewer to formulate her own questions and the respondent to formulate his or her own replies, so that, in the course of the interview, attitudes, opinions and information about underlying motives are elicited by means of the interpersonal reaction between the interviewer and the respondents (McFarland Smith, 1972; Fletcher, 1974; Converse and Schuman, 1974).

The adoption of non-structured in-depth interview technique enabled the research fellow to develop a good 'rapport' with the respondent and then to explore areas which have not been covered in the previous surveys of disabled people undertaken in recent years. The strategy used in this project was to explore a number of topic areas with the respondent:

(i) **Onset of Disabling Condition**
When and what symptoms made the person feel that something was wrong. The timing of the decision to seek medical advice, the experience with medical agencies leading to the eventual diagnosis and prognosis. Whether they felt more could have been done.

(ii) **The Disabling Condition**
Knowledge of causation and prognosis, and alternative therapy.

(iii) **State of Health**
Self-perceived feelings of present state of health (irrespective of their disabling condition).

(iv) Self Perception
      Feelings and attitudes about the way the person felt he or
      she had changed.

(v)   Effects on own Life
      Work, leisure, housing, friends.

(vi) Family Life
      The effects of disability on the distribution of roles
      within the family and the decision-making process.
      Family plans - holidays, leisure pursuits. Family social
      contact. Husband and wife relations, effect on their
      marriage.

(vii) Social Contact
      Who they see and how regularly, including friends and
      helpers etc. Quality of contact. Discussion of
      illness and disability with them.

The aim was to make the interview similar to a conversation between
two people, although one participant, a multiple sclerosis sufferer, was
involved largely in answering the questions. The pattern and the order
in which the topics were discussed was not standardised, so that a model
of everyday conversation could be followed. The readiness with which
respondents were prepared to talk to the research fellow on topics known to
be sensitive areas, for example, problems of incontinence and marital difficulties,
illustrate the value of such a method.

Problems Associated with In-Depth Interviewing

The methodological problems encountered in dealing with data which
are reconstructed from everyday conversational and non-verbal activity are
common to all fields of survey technique. However, by the adoption of the
method of non-structured in-depth interviewing, the problem becomes more
acute. The respondents' statements are taken at 'face value' as they are
in any study, nevertheless, it is important to try to ascertain the
interviewer effect or bias on the respondent with respect to the provision
of information in that context.

When the interviewer and the respondent encounter one another, they
begin to talk, to respond to various social stimuli, with each inferring from

the behaviour of the other (whether speech, gestures, posture or whatever) what ideas or feelings the other person is trying to convey.

"When one individual enters the presence of others, he will want to discover the facts of the situation. Were he to possess this information, he could know, and make allowances for, what will come to happen and he could give the others present as much of their due as is consistent with his enlightened self-interest .... Full information of this order is rarely available; in its absence, the individual tends to employ substitutes - cues, tests, hints, expressive gestures, status symbols, etc. - as predictive devices. In short, since the reality that the individual is concerned with is unpredictable at the moment, appearances must be relied upon in its stead."[1]

Goffman defines as 'predictive devices' such social attributes as sex, race and education, physical qualities like height, weight, facial appearance and posture, and a variety of vocal characteristics which influence the two actors in the interview situation. Hence, physical disability is potentially problematic in the situation in which the interviewer is a non-disabled person and the respondent is a visibly disabled person and the topics to be discussed cover the concept of disability.

Nevertheless, it appeared that in the present study, the difference in the visible status of the two actors in the interview situation did not prevent the establishment of a good rapport between the two participants and respondents were prepared to discuss with the interviewer topics which are socially recognised to be sensitive and taboo areas, particularly in the context of a social survey interview. The respondents did not challenge the purpose of the interview - which had been made intentionally vague. For example, "discuss with you some of the problems and difficulties associated with your illness or disability".

However, the way and the kinds of replies they give is to a large extent dependent on their concept of the research worker. In this project, the research worker presented herself as an interested person and stressed her interest in people and possible improvements to the services for the disabled. In all the cases, the respondents welcomed her, perhaps because she was a social contact and a person to talk to and unburden their problems and sorrows

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[1] Goffman, E. (1959) The Presentation of Self in Everyday Life. p. 249.

without the fear of losing face, or they may have seen her as a representative
of an official agency. By the end of the first interview, the research
worker seemed to be accepted by all the respondents as a person with whom they
could discuss their problems and needs.

To gather the data required for this type of study, it was essential
to interview and see the respondents on more than one occasion, as, "It
is impossible to try to understand the social context of the respondent at
the time of the first contact." (Cicourel, 1964). In the majority of
the cases, the respondents were interviewed on three occasions. However, in
two cases it was impossible to interview them a third time as one person had
become seriously ill at home and another person had been hospitalised.

It took between four and five hours in total to collect the data from
each respondent. It is possible that the information could have been
collected on two rather than three interview occasions. However, it must
be remembered that the subjects in the study were multiple sclerosis sufferers
who had to cope with the problem of fatigue and it would have been
inappropriate to carry out long (i.e. of two or more hours' duration)
interviews with them. The interviews were exhausting and sometimes anxiety
provoking for both participants and it would have been impossible for the
interviewer and the respondent to have sustained a long interview in which
such difficult and problematic areas as marital difficulties were explored.
The frequency of seeing the respondents was regulated to intervals of approximately
two to three months as this period proved 'manageable' in data collection
terms and the respondent remembered the interviewer. The method also requires
the interviewer to be able to distance him or herself from the respondent.
Frequently, the respondents attempted to draw the interviewer into a special
relationship with them, other times they wanted her to take sides with them
against an official agency or against their spouse; sometimes they attempted
to develop a more personal relationship with the interviewer and these were
particularly problematic to handle.

Despite the problems of interviewer/respondent relationships, the
advantages of the nature and the quality of the data gathered by such methods
were evident in the respondents' answers in which they discussed a whole range
of problems from depression, fear for the future, incontinence, to marital
difficulties. In this study, the method of using transcripts of tape recorded
interviews provided insightful and interesting data.

In the analysis of the data, there do appear to be differences in the content of the interview, depending on whether the data was from the first or subsequent interview. The differences were evident in the topics discussed and the amount of critisism and disquiet voiced by the respondents. There did not appear to be such marked differences between the contents of the second and third interviews. It is impossible to state whether this was an outcome of the timing of the interview in which the topics arose in that the interviewer tended to not mention topics which she suspected would be problematic or anxiety-provoking until the second interview. The transcripts provide some material to suggest that in fact this was the case and that in the first interviews the researcher was more concerned to establish a good rapport between the respondent and herself and so focused the discussion to exploring general topics.

However, it must be remembered that this method is expensive in that one hour's interview takes on average three to four hours to transcribe and type. The method also produces a 'mountain' of data which have to be organised into topics for the purposes of analysis. The researcher attempted to pick up common patterns in the transcripts and produced a number of assumptions which were then checked against all the data. The analysis of qualitative data is very time-consuming. Nevertheless, the value of being able to play back the tape and listen to it and evaluate the varying inflections, intonations, bewilderment and tensions and other audible clues is a major advantage in that the researcher was able to 'make sense' of the respondents' utterences within the context of the discussion and to hear the feelings of the actor elicited by such a topic. The researcher was also able to see how the respondent led up to a discussion of a topic such as their feelings of depression.

The use of tapes and transcripts enabled research workers to hear the voices of their respondents and the ways in which they discussed their own perceived problems. As this project was concerned to explore the potential problems of stigma and social discrimination, it was essential to be able to use such tools as tape recorded interviews. Clearly, it would have been meaningless to go in with a schedule and discuss such sensitive and emotional topics. The use of the interview (in the sense of a conversation) is as part of the real world and it is easier and more relevant to extrapolate from the data produced by such a method about the everyday problems of disabled people. In addition, it enables the researcher to check for any evidence of interviewer bias or attempts to 'lead' respondents to give a 'right' answer.

Non-Participant Observation

It had been anticipated that the research worker would be able to observe disabled people in a number of social settings. The project had only limited success with this method in that it was impossible to find sufficient social settings in which normal and disabled people came together and where the research worker's presence would not intrude into the situation and change it. Two or three very cold days were spent hanging around public libraries, cinemas and community centres without success. Eventually, the research worker arranged to go shopping with a number of disabled people. Shopping was considered to be an everyday activity and carried out in the social setting in which the disabled person was interacting with strangers. The research worker adopted the role of a shopper and equipped herself with a shopping basket. She walked at some distance behind the disabled person and noted down the reactions of the other shoppers and shop assistants to the wheelchair-bound disabled people and this provided some interesting data.

Kelly Repertory Grid

The Repertory Grid technique was devised by Kelly (1955) and had been modified by Bannister (1962; 1966). Kelly described a new theory of human behaviour, the 'personal construct theory', and related it to a new method of carrying out clinical interviews and classifying the data obtained form them. The method is designed to explore how people see themselves, how they order their experiences, how they appraise and reappraise their experiences and give meaning to them, or in Kelly's words how they construct their environment. The fundamental postulate of construct theory is that "a person's processes are psychologically channelised by the way in which he anticipates events" (Kelly, 1955). This makes man an interpreter, not merely a reactor. It makes him an anticipator, not merely a responder. Thus each man interprets in terms of constructs, i.e. bi-polar discriminations, which may be verbal labels or operative discriminations. The technique is very simple: the person is asked to list a number of important people relating to given categories (in the case of the present study, these included yourself, family members, friends, like person, dislike person, disabled person I know), there are the elements. The person is then asked to compare three elements at a time finding a way or ways which are important and meaningful to the subject in which two of them are similar and different from the third. These descriptive terms elicited in this way are called the constructs.

Once the constructs have been elicited the person is asked to rank all the elements chosen on each of the constructs providing a grid. What is measured is the relationship for the subject between sorting categories, the elements and the constructs.

This method was tried out on a number of the respondents in the study but without success. Firstly it was a very time-consuming procedure, taking up to three hours to administer and the respondents became bored with the process. Bender (1974) also found, using the Kelly Repertory Grid to test medical students, that the testing time took three hours. This length of time to administer the Grid had to be weighed against the problems of the Grid alienating the respondent and making it impossible to carry out an in-depth interview at the same session. Secondly, the respondents found the test inappropriate and in some cases threatening to compare such elements as ideal self, person I would most like to be like etc. and for the research worker to attempt to explain the reasons behind using the method would have invalidated the whole method. Thirdly, respondents found it upsetting when they were asked about their past, present and future with respect to people they knew.

The problems the research worker in this study had in attempting to administer the Kelly Repertory Grid may have been associated with the nature of the disease such as multiple sclerosis in that the patient suffers from fatigue and in some cases appeared to be depressed at the point at which she attempted to administer the test. In addition, a greater perusal of the literature on the Kelly Repertory Grid showed that a number of researchers had experienced difficulty with the process of the selection of constructs and elements, some had resorted to modifying the method by provision of some of the elements but it was felt that this would invalidate the method in Kellian terms. In the literature, there seems to have been insufficient attention paid to standardising the methodology and training researchers to use the method, although there has been a great deal of attention to the statistical analysis of the data. The researcher felt that it would require a separate study to explore the ways in which the method could be used with disabled people interviewed in their homes, but that within the context of the present study it was not useful and it would possibly jeopardise the collection of data from the interview situation. Hence it was decided to abandon this method at the pilot stage as it was felt that, to attempt to continue to use it, would bias the in-depth interviews and might have resulted in respondents refusing to be seen again.

MULTIPLE SCLEROSIS[1]

Multiple sclerosis, sometimes called disseminated sclerosis, is today one of the main chronic disorders of the nervous system. It is a disease of early and middle adulthood and one which occurs more frequently in females. The disablement consequent upon the complaint varies considerably: from severe paralysis in a few cases to no visually apparent incapacity.

The unequal geographical distribution of multiple sclerosis is one of its most striking and potentially significant characteristics. The disease occurs with much greater frequency in temperate latitudes and it is particularly prevalent on the Island of Orkney where the prevalence rate is about six times greater than the world average of 30 per 100,000 population (Donnelly, 1974). In Great Britain as a whole, it is estimated that between 40,000 and 50,000 individuals suffer from the illness, implying a rate of more than twice the world average figure.

Multiple sclerosis is a disease of unknown causation characterised by episodes of disfunction in the brain and spinal chord which have a tendency to remit, leaving the patient with no obvious signs of disability. With the passage of time, however, the severity of these attacks may increase, resulting in a less complete recovery of function after each exacerbation. The areas of damage are apparently scattered in a random manner and the symptoms experienced by the individual depend on the location of the point of attack. However, there is evidence to suggest that there are distinct sites of predilection (the optic pathways, for example, are frequently involved) and the lesions may present a symetrical pattern, which is encountered sufficiently often to necessitate a more convincing explanation than chance alone (Lumsden, 1970). The process of demyelination (the removal of the protective myelin sheath) is known to both accelerate and decelerate and these changes are associated with the relapses and remissions which characterise the illness.

Many theories have been advanced regarding the causes of multiple sclerosis and the mechanisms by which the disease is produced. There is a growing body of knowledge concerning the theory that multiple sclerosis may be an auto-immune disease. Auto-immune diseases are thought to be caused by something misleading the normal protective immune mechanisms of

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[1] Paraphrase of OHE pamphlet.

the body into producing antibodies against some of its own tissue. A
viral theory which is closely tied in with the auto-immune theory suggests
that a specific virus latent within the nervous system becomes activated
through trauma or infection and in turn generates the process of demyelination.
There may be some familial factor and multiple cases of multiple sclerosis
in a family have been described in the medical literature.

There is at present no generally accepted specific laboratory test
for multiple sclerosis. This means that the diagnosis is based upon an
initial suspicion, provoked by a case history of remission and relapse and
a wide variety of signs and symptoms, which is then strengthened by performing
tests to exclude other possible diagnoses. The diagnosis can be further
obscured by the failure of an individual to report any symptoms, e.g. an
episode of tingling or numbness, or blurring of vision, until a definite
disability occurs.

The prognosis of multiple sclerosis is notoriously uncertain and
covers a whole spectrum from the chronic stage of being bed-bound, this is
one extreme of the spectrum which relatively few people experience, to a
more benign form of the disease, in which relapses are mild and infrequent,
permitting active life for many years. It is extremely difficult to construct
a typical picture of the general course of the disease.

Multiple sclerosis, therefore, poses special problems to doctors
which in part derives from the unique medical aspect of the aetiology and
symptomology of the disease. The inability to make a firm diagnosis at
an early stage creates problems in informing the patient of the diagnosis
of their complaint and, even after informing the patient of the diagnosis, the
doctor cannot give a clear indication of the likely course of events.

There is no known method of treatment that has had any convincing
effect on the disease. Admission to hospital for rest is often advised
during an exacerbation of weakness of the limbs and where there has been
multiple cranial nerve lesions. Nevertheless, many modes of therapy have
been advocated, claims for success from the various forms of therapy being
based on the assumption that the therapy produced a remission of the symptoms.
However, as the symptoms of multiple sclerosis may remit spontaneously,
there is difficulty in being able to prove that the remission was
produced by the therapy and not spontaneously. Drug therapy in multiple
sclerosis is directed towards the control and amelioration of symptoms.

This symptomatic therapy is used to reduce and control spasticity and reflex spasm, to relieve bladder and bowel disfunction, ameliorate visual disturbances and help patients cope with emotional stress, depression and apprehension. Physiotherapy is most often used for patients who have residual motor disabilities and are in a relatively static phase of the disease. Through specific exercises, physiotherapy aims to counteract spasticity and maintain functioning in unaffected limb and trunk muscles. This mode of therapy should not be used in the acute phase of the disease.

RESULTS

The Public Image of Multiple Sclerosis

Although this study was not designed to explore the general public's knowledge and attitude towards multiple sclerosis, it did gather some information on the topic. First the non-participant observation study of some multiple sclerosis sufferers going shopping, although only relating to a small number of observational sessions, did provide some examples of 'normals'' attitudes to MS sufferers.

One example occurred at the exit of a supermarket where it was impossible for a wheelchair to pass through by the cash desk, so that the disabled person was required to go to the back of the shop and out in another direction. Whilst the disabled person was doing this, the researcher paid for her own purchases and was able to hear comments by the shop assistants, for example, "Oh, that poor lady. It's such a shame, she's got that terrible disease, multiple sclerosis, you know. It affects their head," while the other shop assistant commented, "Yes, but she makes the most of it doesn't she, she gets us to do everything for her, she doesn't try you know. She just makes you do it."

In the observational study, the researcher also heard two other people make similar comments to the above example and reveal the normal's lack of information about multiple sclerosis. These 'normals' appeared to be either misinformed or to equate multiple sclerosis with suffering from 'nerves' and 'being mental'. There was also some suggestion of a rather negative image of the tragedy of the MS sufferer, although one would not attempt to argue that being a multiple sclerosis sufferer was a pleasurable experience, it is unfortunate that the negative side of the disease seems to be the one that these shoppers were aware of rather than the more positive side of the advantages of the remission years.

There were differing views amongst the respondents with respect to what these shoppers were reacting to or discriminating against, whether it was the knowledge that the person had multiple sclerosis or whether it was the visible sign of a physically disabled person seated in a wheelchair. Many respondents thought it was their visible appearance of being wheelchair-bound that drew attention to their physical disability and it was the presence of this that 'normals' reacted to rather than any knowledge of the disease multiple sclerosis.

Mrs. Earl: "I don't think so. No, because MS is so wide isn't it? It strikes different people in so many different ways. You can't say, Oh that person is MS so therefore paralysed in one leg or two legs. I mean, it takes you so widely. I mean, people don't know you've got MS. I mean, very often they say to me, 'What is it, polio?' or, 'Why can't you get over it? Got arthritis or something?' You know, so unless you wear a card over you, sort of thing, people just don't know that you are MS. Obviously they know you're disabled because you're unable to walk but, otherwise, no, I don't think so."

Mr. Irwin: "As I said, if you say multiple sclerosis, that <u>doesn't</u>, in itself, answer any questions at all. Everyone's different. A person's different whether they've got multiple sclerosis or not ..... Well, they say, you know, 'What's up with you?' sort of thing. If you say multiple sclerosis, people are getting to know what that is or at least a bit about it, but normally it's a foreign language to them, you know. You might as well be saying something in Chinese to them. So I say, 'MS,' which covers a multitude of sins! MS - multitude of sins!"

Whether the general public are reacting to the disease label or to the visible sign of physical disability is an area requiring more research. There is a noticeable lack of research about public opinions on chronic diseases, although some authors do state what they think the public's reaction to multiple sclerosis is. For example, in a medical journal, there was a statement that, "the popular conception of multiple sclerosis appears to be too often one of a chronic, crippling disease, categorised in the early stages by relapses and remissions, followed by a chronic progression to a bed-bound, incontinent, paralysed state, after which death ensues as a result of pneumonia, urinary infection and/or bed sores."[1] Davis noted in her book "Living with Multiple Sclerosis" (1973) that the majority of the general public were completely unfamiliar with the name multiple sclerosis as well as many of the symptoms and she contrasted this with the general public's awareness and sometimes first-hand experience with one or more chronic diseases such as cancer or heart disease. She claimed that the general public were familiar with these names and had in some instances knowledge of the symptoms. Unfortunately, neither of these authors quote any references to substantiate their statements. So that there does appear to be a need for more research in the area of public attitudes to chronic diseases such as multiple sclerosis, particularly as the 'normals'' attitudes

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[1] British Medical Journal, 12.2 1972, page 392.

to sufferers of these diseases can greatly affect their quality and style of life. (This is discussed in greater detail in the section entitled "Stigma").

Respondents' Suggestions about the Public Image of Multiple Sclerosis

However, the respondents in the study did make the positive suggestion for more open discussion about multiple sclerosis and would welcome this for a number of reasons: first, they would like more information for themselves and for their families about the disease; second, at the present time they felt that the general public did not know or understand the impact of the disease on its victims and, therefore, frequently evaluated and judged them and their actions inappropriately and stigmatised them; third to destroy the negative image that is sometimes promoted by the publicity about the disease.

Mrs. Ball: "I really hate it. There was an article in one of the Sunday papers, 'I Know How I Will Die' written by an MS sufferer, and that doesn't help anyone does it? It doesn't help at all."

The general public's, but more particularly their friends' and relatives' lack of comprehension and understanding of the impact of the disease, left most of the respondents feeling lonely, misunderstood and isolated. One man commented, "You've got to have it to understand it, it's a terrible disease you know, really."

Mrs. Owen (an afflicted woman with three children): "No one talked to my family about it. Lawrence (the respondent's son) is haunted by it. He doesn't understand. His school master said, 'I told you your mother would not be able to do what she used to do.' But he doesn't understand. The one who understands most is the 12 year old, Julie. That's because she watches me. The others don't watch, they just accept me. We often have rows about it. They expect me to go on as before as though nothing had happened. I have to ask them to do things and they call me, 'Lady Muck'."

The respondents felt there was a need to educate the general public about multiple sclerosis, as frequently when they met normals and revealed that they had multiple sclerosis, the normals appeared to be embarrassed and sometimes the sufferers suspected that the normals feared the possibility

of catching the disease (this was mentioned by three of the respondents).
The respondents expressed the view that there was a need to uncover and reveal
the problems and the nature of multiple sclerosis, and that it should be
publicly discussed, so that many of the misconceptions about the disease
could be dispelled.

In the last few years, a number of changes have occurred in that there
has been an increase in the radio and television programmes discussing
multiple sclerosis and disabling conditions in general. The groups such
as the Multiple Sclerosis Action Group has also been actively engaged in
publicising information about multiple sclerosis. However, it seems that
the Multiple Sclerosis Society itself is in a quandary with respect to
the publicity about the disease. For example, in the report of the working
party of the Multiple Sclerosis Society of Great Britain and Northern Ireland,
"We concluded that aggressive lobbying and militant action would jeopardise
existing good relations the Society possesses, and indeed, if attracting
unfavourable publicity, such actions could well have the effect of diverting
possible legacies and donations away from the Society. Furthermore, while
we are only too conscious of the tragic consequences of the disease upon
its victims,* particularly the youthful ones, and their immediate circle
of relations, we believe that the use of the forceful PR tactics to achieve
publicity for the disease could well have the effect of alienating the
goodwill of the public and the media."[1] It is interesting that in this quote
the working party stress the tragic nature of the disease and also the necessity
to not become involved in publicity or pressure group action that would in
any way alienate the public, i.e. the normals or non-disabled population.
It seems that the view of the membership may be in conflict with that of the
Society in that all the respondents mentioned the failure of the various
publicity programmes to inform the general public about the disease and
reiterated the need for more publicity and open discussion of the disease.
Some made the point that there should be more publicity to show the disease
in positive rather than negative terms, for example, the advantage of the
remission years in which a person can be 'back to normal' or nearly. All
the respondents felt far more should be done to inform the public about
the nature of multiple sclerosis and its problems for its victims.

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* my underlining.

[1] Report of the working party of the Multiple Sclerosis Society of
Great Britain and Northern Ireland, 1974, page 9.

The Process of Becoming Disabled

First Symptoms - Decision to Seek Medical Attention

One major problem with multiple sclerosis is the unclear and changing pattern of the early symptoms. Frequently, the respondents could see with hindsight that a number of the unexplained symptoms or pains that they had experienced were, in fact, the early signs of the disease. It is very difficult for both the patient and the doctor to ascertain when the symptoms started.

In the early stages, the subjects tended to normalise the symptoms by use of common sense explanations, for example, tingling in the legs was explained as "been sitting down too long", or "my foot fell asleep"; the development of an unsteady gait was explained as "can't take my drink as I used to"; feelings of extreme fatigue were seen as the effects of "having recently had a baby"; stiff joints and limbs were thought to be arthritis. These common sense explanations of the symptoms are the main reason given by a number of the respondents for the delay in seeking medical attention and advice. They commented that the vacillating nature and appearance of the symptoms made them think that nothing was wrong or that it had got better. One woman who complained of blurred vision for a few days was on the point of going to see her doctor when her vision appeared to clear up, so she did not bother. Rarely was there any sense of urgency or severity about the early symptoms. It was usually when the symptoms returned or became socially unacceptable, for example, a 19 year old girl finding herself incontinent, that the advice of the medical profession was sought.

The credibility of many of the early symptoms was questioned by members of the family and their immediate friends. One woman whose early symptoms had been an unsteady gait and general lethargy had been criticised by her children and friends as 'lazy' or 'putting it on'.

Mrs. Pack: "I suppose going back over 17 years, I can see when it happened, I kept falling down. My husband thought I was putting it on. He kept saying, 'It's typical of you. You can't even walk properly now.'"

Information on the early stages prior to the respondents seeking medical advice was difficult to gather, although it did appear that all the respondents had failed to seek medical advice for the "early symptoms". This was not surprising in the light of the findings of Dunnell and Cartwright (1972)

who found that in a survey of a random sample of adults, they reported on average 3.9 symptoms each during the two weeks prior to interview. Although 91 per cent of the adults reported symptoms in the two week period, only 16 per cent had consulted a doctor during that period, so that there is a general reluctance on the part of the public to interpret the symptoms as requiring medical attention. However, one reaction to the early symptoms reported by about half the respondents was to seek self medication or advice from significant others about possible treatment, for example, aspirin was taken to aleviate "their odd aches and pains". Nevertheless, the respondents appeared to be reluctant to define themselves as sick and in need of medical attention at that stage in their illness career. It was usually at the point at which their various coping and accommodating strategies broke down that they turned to the medical profession.

In the present study, it was impossible with such a small sample and varying lengths of time since the onset of the disease to explore fully the pattern of illness behaviour of multiple sclerosis sufferers. Nevertheless, there appeared to be some indication of this behaviour in that there were some similarities in the respondents' accounts of their health-seeking behaviour. For example, the failure of the common-sense explanations to account for symptoms, the re-occurrence of the symptoms, the occurrence of symptoms which were socially unacceptable such as incontinence and the need to legitimise their sick status at the point at which they recognised the potential severity of the symptoms were all 'triggers' to the MS sufferers seeking medical advice. Naturally there are problems associated with retrospective accounts of health-seeking behaviour, as discussed by McKinlay (1972) such as the fallibility of memory and the question of the extent to which any respondents' accounts of past events is a reconstruction adjusted to suit the present circumstances and audience. However, the respondents' accounts of the reason for seeking medical advice are in line with the current body of medical sociological knowledge.

A few subjects had visited a doctor and had been told that there was no physical basis for their symptoms. In fact, one man who complained that he was frequently falling down and was very stiff had been told by a consultant that he was malingering and ought to pull himself together. The treatment by members of the family and the doctor of the early symptoms as 'imaginary' or 'in the mind' resulted in a threat to the multiple sclerosis sufferer's whole self conception.

Process of being Referred to Consultant - The "Medical Merry-go-round"

All the respondents considered that they had experienced "unnecessary" delay in the process from the time of the symptoms being deemed in need of medical attention to the time of the final diagnosis. The first phase between the patients experiencing symptoms and identifying them as requiring medical attention varied from days to years according to severity and nature of the symptoms. After having sought medical attention from the general practitioners, there were often delays of months and sometimes years before the patients were referred to a consultant. One man had been told by his general practitioner to "go away and relax, you'll find it probably cures itself". From the accounts of many of the patients, it would appear that it was their persistent attendance at the general practitioner's surgery that eventually made the doctor decide to refer them to the consultant rather than from the general practitioner's own initiative. In two cases, it was the decision of a locum rather than their general practitioner to send patients to see the consultant.

Eventually the respondents had their sick status legitimised by their general practitioner (although no diagnosis was given at this stage), but for several respondents it had taken a number of surgery visits before the general practitioner had recognised and accepted that they were not malingering. The general practitioner referred the patient to the consultant and so began the "medical merry-go-round" as one respondent put it.

Once having been referred to the consultant, most patients had attended at least three out-patient visits spaced-out between months or years before they had been given a lumbar puncture test and before they had been told the truth about the disease. From the patient's point of view, the whole process was very time consuming and anxiety-provoking.

A fairly typical example of the process is illustrated in Miss Dale's case.

Miss Dale: "I think that the multiple sclerosis was triggered off by my carrying something too heavy. I went to Hever Castle and saw everything and then suddenly I had an awful pain in my leg, but I waited for it to go off. It didn't and so I went to see the doctor. The pain dominated me. It started in June and then at Christmas time the pain suddenly went, one leg went like ice cold, even when I sat almost on the fire. Then my hands

went, then I went to the doctor and I said, 'I can't feel my hands,' and
I cried. The doctor just gave me some valium and I was furious and I
just tore up the prescription. He was treating me like a fool. So I
went privately and the doctor said, 'You have stocking and glove anaesthesia.'
Then I went on the medical Merry-go-round. First Kent and Canterbury Hospital,
then the Maudsley for a myelogram and lumbar puncture, and the doctor said
I had multiple dislocations and he would operate. They tried a surgical
collar for a number of weeks and I wore it day and night, but it didn't
get any better and then I got suspicious. I read an article by Professor
Field who is a researcher in the field of multiple sclerosis and he described
the symptoms, and I thought - they are my symptoms and I wondered about it
for ages. In the article he had mentioned Sunflower oil and I thought
what about Sunflower oil! I hadn't been near a doctor for three years, so
I wrote to my doctor that I had a strong suspicion that I had multiple sclerosis
and I wondered if I should have Sunflower oil. He came to see me and said
that I could have Sunflower oil but he did not acknowledge that I had
multiple sclerosis. But I developed diarrhoea. Then he sent me to the
Maudsley and I had a number of eye tests and electric tests. I knew that
if the eye clue fitted, that was it, and they asked about my waterworks.
It was like a jigsaw. I knew it was just my eyes. Finally, they came to
my bed and it was just like dictating a telegram. They stood one each side
of the bed and they said, 'Sorry, you have multiple sclerosis'. I thought
I might just have had a common cold, it was so callous to tell me that way.
They could have said, 'we're awfully sorry, but ......', not just like that!
They then left my bed, never asked how I could manage when I got home or
anything. I was lucky, I had a friend when I got home. I telephoned her
and she came to see me and organised a wheelchair and things, but not the
doctors."

The respondents were most hostile to the "medical merry-go-round"
that they felt they had been placed on, particularly where they felt they
had been fobbed off by the doctors or where they thought the doctors
were experimenting with them. This process of "being passed around"
from consultant to consultant increased the respondents' anxiety as they
suspected that the doctors were "keeping the truth from them - because it
was bad news!" The delays in the process of the respondents' patient careers
contributed to their uncertainty and frustrated their expectation of being
provided with a 'diagnosis'. One man thought the series of tests that he
was subjected to were a smoke screen to hide the inefficiency of the doctors.

Mr. Irwin: "They said I had flat feet and gave me rubber soled shoes, as if you ever did.   I saw one specialist after another.   It was pure buck-passing."

Others thought they had been given a "make-believe" or inappropriate label.

Mrs. Earl: "Oh yes, I asked them.   I said, 'Is it multiple sclerosis?' and they said, 'No.'   That's the senior neurologist at a London hospital. I asked him and he said, 'No, it's paraesthesia.'   Now that I worked it out, that meant paralysis of the nerves.   Well, surely if that isn't MS?.   You know ..... I mean, I just sort of thought it out for myself.   Rightly or wrongly, I mean, I'm not a doctor.   But it seemed to me ..... you know I mean I'm not the type to read medical books or anything like that.   I don't do that.   I try to work it out in my mind.   Just a common sense attitude. They would insist that it wasn't MS.   That it was paraesthesia but if I saw any different doctors, they said, 'What's wrong,' or something and I'd say, 'It's paraesthesia,' they used to look a bit old-fashioned at you, you know, as if, 'Oh well, somebody's fobbed her off with something.'   I knew it wasn't right."

Two more respondents claimed to have diagnosed themselves as suffering from multiple sclerosis but when confronting their doctors with it found that this had been denied.

"Eventually I was certain something was very wrong and I suspected multiple sclerosis.   I asked the consultant on several occasions to be told the truth but this was denied.   I had to wait three more years before I was officially told.   Only then did I begin to start accepting the fact that something was wrong and that I had to learn to live with it." (Female respondent who had previously nursed multiple sclerosis patients).

There was some suggestion in the data that the respondents were attempting to re-write their medical history and make a coherent and manageable account of it, in that they began to look with hindsight at earlier events and attempt to incorporate them as 'first' signs of their illness.   For example, one woman explained that it all started with a fall down stairs. Another woman commented that it was started by her carrying a heavy suitcase. A man commented that it probably started because of over work.   Blaxter (1976) found similar accounts in her study in that "a major feature of the

patients' accounts of their illness condition was their strenuous attempts
to see their medical conditions as a whole, to connect together everything
that had happened to them in an attempt to provide a coherent story in
which effect followed cause in a rational way." In the case of the multiple
sclerosis sufferers, in the present study, the medical profession was unable
to offer any causal explanation, so that some respondents attempted to
provide their own explanations and attribute cause to environmental and
behavioural conditions rather than to produce any physiological explanations.

Delay in Disclosure of Diagnosis

A major criticism of the medical profession levied by a number of
the respondents was that they felt that the doctors had known the diagnosis
months and sometimes years before telling them. McIntosh (1977) shows that
cancer patients, if not formally given a diagnosis, become more anxious
and uncertain, and seek information to reduce their uncertainty. Over half the
respondents complained that they had found out by accident or by deliberate
action on their part. For exmaple, one woman admitted to hospital for an
ectopic pregnancy said she heard the houseman talking to a nurse about her,
"Oh she's got MS has she?", and this was the first she knew of it. As
this particular patient had been a nurse, she knew what MS meant and its
significance. A few women, after leaving hospital, had opened the consultant's
letter to their general practitioner and found out in this way. Another woman
said that she had read an article about multiple sclerosis in a woman's
magazine and recognised her own symptoms. When she confronted her general
practitioner about it, he told her, "Yes, you've had it for five years!"

Although admittance to hospital was required by some of the respondents,
even at this point a number of them had not been told the diagnosis. The
reluctance of the medical profession to tell patients was illustrated by
the experience of Mrs. Owen.

Mrs. Owen: "They suspected it and they didn't tell me. I've been in
and out like a yoyo (reference to hospital). I saw the doctor at the
hospital and he said, 'Are you going to be upset if it's serious?' I was
very upset as I thought I had got arthritis, but I didn't seem to be getting
better. They discharged me and I was given a letter to the doctor. I
opened it and it said, 'MS confirmed'. When I was discharged they told me,
they didn't want to ..... I asked the doctor, 'Have I or have I not got
multiple sclerosis?' And he said, or rather replied with a question, 'What

do you know about it?' And I said, 'Only what I read in the book from the
hospital library.' But isn't it silly that the doctors won't tell me but
you can find out from a book in the patients' library! But what's all the
mystery about? All right, they don't know much about it but they can tell
you,you have it. You feel worse not knowing. You feel relieved once you
know. The young doctor wanted to tell me, but the neurologist and psychologist
didn't want to tell me, but I said I really want to know, I must know.
Since I've known everybody seems to know someone who has got it."

It would appear that the medical profession were very reluctant to
either acknowledge the diagnosis to the patient, or uncertain of the diagnosis,
or feared that the disclosure of the diagnosis would upset the patient too
much as was shown in the example above. Sometimes there appears to be a
conflict of definition between that of the patient and the doctor, because
of genuine diagnostic uncertainty.

"The problem of uncertainty is a basic component of many medical decisions,
and every physician must learn to live with it."[1]

However, Davis (1960) distinguished between 'real' uncertainty as a
clinical phenomena and 'functional' uncertainty as a management technique.
In his study of children with paralytic poliomyelitis, he suggested that
'functional' uncertainty was maintained by both the doctor and the patient:
on the one hand, the pretence of uncertainty serves to reduce materially
the expenditure of additional time, effort and involvement which a frank and
forward prognosis might entail; and on the other hand, parents tended to
maintain and even exaggerate the idea of uncertainty since it can represent
hope.

In this study, as in Blaxter's study, it was found that 'real' uncertainty
about the diagnosis was almost always disadvantageous as it was unable to
offer a legitimising label to the patient.

Who Discloses the Diagnosis?

Not only the timing of the disclosure of the diagnosis was problematic,
but the whole question of who told the patient was also difficult. In a
number of cases the consultant or the general practitioner had informed the

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[1] Mechanic, D. (1968) Medical Sociology. p. 179.

spouse of the patient of the diagnosis, thereby fulfilling the medical role
of finding out what was wrong with the patient,but leaving the husband or
wife with the decision of whether to tell the patient or not. Three of
the people interviewed claimed that their husbands had been told before them.
In two cases, the husbands were present when the wives were being interviewed.
They expressed the opinion that they had been placed in a terrible predicament
of not knowing whether to tell their wives or not. One husband discussed
how difficult and unpleasant it was to conceal the knowledge of the diagnosis
from his wife for two years. His wife then commented that, "It was terrible
that he knew and hadn't told me." She obviously still held some resentment
to both the doctor and her husband for the concealment of her diagnosis.
The most 'successful' disclosure of diagnosis occurred in the two cases
where the consultant had told the husband and wife together and had discussed
with them the impact of the disease on their lives.

All the respondents stated that they would have preferred to have been
told earlier and had a more frank and open discussion of the impact and the
effects of the illness with either the consultant or their general
practitioner. As one woman put it, "You can't come to terms with it until
you know what's wrong .... They just wanted to give me a stick, to be a
geriatric, you know, and I knew something was wrong but what?" It is
possible that there is a difference between the medical profession's
definition of the situation that multiple sclerosis is an incurable,
slowly degenerating disease, a tragedy; and the patient's definition of the
situation that it is an unpleasant but not a life-threatening disease.
In the literature, there are many examples of the need for the medical
profession to tell patients the diagnosis as soon as it has been confirmed
and to share with them the responsibility and the management of coming to
terms with the disease. Chevigny (1962) noted, "Adjustment to living begins
at birth and is, in the early years at least, an unconscious process.
Adjustment to a condition such as blindness, however, begins only when the
individual becomes aware that the condition will be permanent! The
importance of learning the truth has a profound effect on adjustment."
Chevigny found that the physicians appeared to adopt a policy of 'what
you don't know can't hurt you'.

The whole area of disclosure of diagnosis, particularly with respect
to disabling conditions and long-term illness requires more research. Fox
(1975) and other writers have noted that physicians are not trained to
manage uncertainty, nor have they had any training in being able to judge
patients' possible reactions to such information and knowledge, nevertheless,

they are clearly key informants in this context of the disclosure of the
diagnosis. Hence respondents suffered with problems of presentation
of self, as they were uncertain of what role obligations they were legitimately
allowed to relinguish.

The MS sufferers were very concerned to know the causes of their
disability, as they retained a great faith in medical science as a curer of
all ills. When the doctors were unable to perform this 'magical' function,
inevitably the doctor/patient relationship became strained.

Uncertainty about prognosis was not so problematic for the patients
to handle. Many of them expressed the view that they were lucky to be alive
and that it could have been cancer. Nevertheless, all the respondents had
gone through a period in which they felt very depressed at discovering
that their present state was a permanent state and, in fact, could get
worse. In Blaxter's study, she concluded "that functional uncertainty was
a management tool, if carried on beyond an initial period of adaption, was
observed to have disadvantageous effects for the patient," although she
acknowledged that the manipulation of information can be a valuable therapeutic
procedure in certain circumstances.

In both Blaxter's study and the present study, it is evident that
patients require a label which enables them satisfactorily to explain the
situation as they see it and to legitimate the roles which they were able to
play. If the uncertainty is prolonged, patients found the situation unacceptable
as they were no longer able to define themselves in relationship to their
capabilities. They needed an explanation to be able to give to others with
whom they interacted to legitimate their present status. Ten of the
respondents claimed to have experienced relief once they were given the
diagnosis. It may be that these verbal accounts of experiencing relief were
part of the strategies used by multiple sclerosis patients in an attempt to
deny the real significance of the disease. Some of them were clearly unaware,
at that time, of the prognosis and impact of the disease, although two who
stated that they experienced relief had previously nursed multiple sclerosis
patients and were well aware of the course that the disease could take.
Another woman said, when questioned about why she felt relief at finding
out that she was an MS sufferer, "Well, it's nasty, but it can't kill you."
And another woman commented, "Well, it could have been cancer, that's what I
thought it was, you know." Two had feared that they were suffering from
brain tumours and viewed multiple sclerosis as a "blessed relief". In
addition to feeling relief, the disclosure of the diagnosis gave back to many

of the respondents their credibility and legitimised their strange behaviour
which had previously been labelled as neurotic, hypochondria, malingering
or drunk. It also enabled them to view themselves as "better off" than
other people. For example, being blind or having cancer were seen as
'worse' diseases or illnesses than multiple sclerosis.

All the respondents would have preferred to have been told earlier of
their diagnosis and when questioned why, one replied:

Mrs. Hale: "Yes. Well, there again, the doctor surely should be able
to when they tell a person they've got MS, they should be able to explain
to them it's quite possible you won't get it ..... any feelings about it,
any further movement of it or anything for many many years. If they were
to explain, I think people wouldn't be so frightened. But if they just say,
'You've got MS,' then people see or hear of somebody that's in a wheelchair
who's got MS, they say, Oh well, I'm going to be like that soon. Whereas
it's quite possible that you get remissions and some people get better, some
people get worse. Some it happens quickly, some it takes years and years.
I don't think you can tell. I think it's ...... if you treat it as you
would a bad cold and think, oh well, it'll either get better or get worse
sort of thing, you know. And just enjoy the good moments."

Factors Affecting 'Good' Adjustment to Disability

'Good' adjustment to any disabling condition and ability to lead as
normal as possible a life may well be conditional on the early communication
of the diagnosis, and sympathetic and informed discussion between the patient
and the medical profession on the prognosis and the impact of such a disease
(Herxheimer, 1976).

When the patients were eventually told, many of them had no idea what
multiple sclerosis was. For example, one woman who was told while she was
in hospital, attempted to gain more information about the condition by asking
her children to look it up in the encyclopaedia or medical dictionary. It
appeared from the respondents' accounts that the majority of the patients and their
families were not given any information about the disease by either the consultant
or the general practitioner. Many were totally unaware of the implications
of the disease and it was only when they had been in contact with the Multiple
Sclerosis Society that they began to understand what it was and how it could
affect them. It would clearly have been helpful to these respondents if they
had been given some information on multiple sclerosis and preferably some

counselling to enable the patients and their families to come to terms with
it and avoid some of the unnecessary suffering and anxiety experienced
by them. Having reached the diagnosis, it is essential for the consultant
or the general practitioner to discuss it with the patient and his or her
family, instead of "washing their (the doctors') hands of us .... We are an
embarrassment, one of their failures". Many respondents expressed the feeling
of being 'turned out in the cold', ill-equipped to cope with the impact
and future effects of the disease.

In this study only the accounts of the multiple sclerosis patients were
examined and there was no way of validating them. It may be that in a
number of cases patients had been told by their general practitioner or
the consultant neurologist, but they did not wish to acknowledge that or
unconsciously rejected it, or they may have been unable at that point to
accept it. Associated with this are the problems of memory recall as a number
of studies have shown. Patients' ability to remember the directions and
contents of a consultation with a general practitioner or hospital consultant
are often very inaccurate and incomplete, even when questioned a short time
after the consultation and regardless of the severity of the diagnosis
(Houghton, 1968; Ley and Spelman, 1967; Spelman, Ley & Jones (1966). So
that it may be that for these reasons the patients claimed that they had
not known their diagnosis. Nevertheless, the consistency of the content
of these accounts provided some evidence that there are a number of problems
associated with the timing and disclosure of a diagnosis such as multiple
sclerosis.

The inability or inefficiency of doctors as information givers has
been noted in a number of studies (e.g. Fletcher, 1973; Cartwright, 1964;
Byrne and Long, 1976). The need for more effective communications between
doctors and patients is essential, particularly with patients suffering from
long term chronic illnesses where the management of the condition is mainly in
the hands of the patients and their families coping in their own homes.
Studies of patients' attitudes towards being given full and frank information
about serious illnesses showed that a large majority of them say they would
always want to know the truth about their outlook, and future (Cartwright,
1964; Ley and Spelman, 1967; and Skipper, 1965). The statement,
'Learn to live with it' can only be accepted and adopted when patients have
been given information about the illness and its management. Patients need
to be given information so that they can gain a greater understanding of
what has gone wrong with their body and that lack of information about their

illness and possible treatment results in high levels of patient dissatisfaction with doctors and the medical care service.

There are in addition to the problems already mentioned, the problems of the ambiguous symptoms of multiple sclerosis and the fact that there is no reliable diagnostic test at present - this hampers the doctors in coming to a clean, conclusive diagnosis. Some doctors also appear to hold the view that as patients with multiple sclerosis can remit for a number of years and live a relatively normal life, they are reluctant to tell them the diagnosis and spoil their potentially trouble-free, symptomless remission years (Office of Health Economics 1975). Nevertheless, respondents in this study have been very anxious about their symptoms and did not share the view that "ignorance is bliss".

Becoming Disabled

For all the patients the full impact of the meaning of multiple sclerosis on their lives only slowly evolved as they experienced a reduction in their normal activities and abilities. It was through the loss of some capability that the patients were made to reappraise their condition and themselves with respect to who and what they saw themselves to be and what the future held for them. The path towards disability in the majority of the cases was slow in contrast to a person involved in an accident where injury or paralysis are more or less immediate. So that in the initial phases, after having been informed of a diagnosis, the patient only very slowly adjusts to redefinition of him or herself. It is obvious that it takes a long time to make this adjustment, partly because of the slow progress of the disease and the fact that to learn to redefine one's self-conception may be a very painful and upsetting task. Litman (1962) found evidence that self-conception and response to rehabilitation were directly related. In his sample of patients, he found patients who maintained a positive conception of self consistently responded well to treatment, while those with negative self-conceptions tended to perform below expectations.

In the present study, one woman who had previously nursed multiple sclerosis patients in hospital said that it had taken her two years to "come to terms with it". A great deal of the first two years after diagnosis had been disclosed had been spent in a depressed state and she had undergone the reaction of "why me?" and feelings of extreme resentment at finding herself "struck down in the early prime of life". The bitterness and

resentment experienced by all the younger MS patients interviewed had
taken at least two years to 'work through'. For them the redefinition of
self included the recognition that they would probably be at best in a
changed job or at worst unemployed and unable to cope with their families.

Mrs. Owen: "I think it is something you have got to live through,
principally on your own. I think it takes about two years to come to terms
with it. I think it's a mental thing, I think you've got to think it through
and talk it through, but I'm not sure that outsiders can help - perhaps
someone with multiple sclerosis who's had the same problems. I think you
feel, Why me? You know, why should it happen to me, isn't it stupid!
Why isn't there anything known about it? Why is there such a great big
lie? And then you think, well it's not as bad as all that. I can cope,
we can get along, we can manage."

It can, therefore, be seen that respondents would like to have been
prepared firstly for the news of their diagnosis, and secondly to have been
given more information about the disease and its prognosis. Although they
all now acknowledged the fact that there was no cure for the disease, they
all felt that there were ways in which the doctors could have helped them to
come to terms with and face the prospect of being a multiple sclerosis
sufferer. A good example of a way in which the doctors' disclosure of a
diagnosis and information about the pattern of the disease would have helped
the patients was in terms of the employment that they sought. None of the
respondents in the study had been offered any re-training or been given any
guidance on suitable employment. This seems to be an area which needs more
investigation with respect to not just the communication of the disclosure
of the diagnosis but positive counselling and guidance of the patients
with respect to their future life-style.

Mrs. Earl: "Well, I think if the doctors had been straight forward
with me and told me, I could probably have really got down to terms with it.
I might have ..... You see it's been going on now..... what? 17, 18
years? At the beginning I might have learned to do something different,
knowing that I would be in a wheelchair. But it's been going on all
this time and I kept ..... as you know, I did help .... at the Forget-
me-not Centre. Well, that was, you know, sort of, it kept me occupied. But
had I known, perhaps all those years ago, I could have gone in to train
for something, to be an extra typist or something. I've taught myself to
type now with two fingers but that is no good. You know, I couldn't go to a

job, though I can do it for my own benefit. But if only .... I think they
told me then, you see, because when I first started it, we had a business
of our own. We had a shop but there were so many stairs because I lived
over the shop as well and we had four flights of stairs and with the
basement. We had to, sort of, sell that up and then we came down here. But,
as I say, had I known, I might have been able to be trained in that type of job
now it's rather late. You see, I'm 59 now. It's too late to sort of start
a training for anything like that. At least I think it is now. And I rather
feel as if I missed the boat. Because I've always been occupied, ever since
I left school at 14 and I've always worked and been busy and I can't resign
myself to the fact that, well, you just sit back and don't do anything.
Though I'd still rather do that. You know I still think I cope pretty well.
It's getting a bit more difficult."

Interviewer: "Supposing some young person, you know, somebody now
in their late twenties, early thirties, said, 'I've just found out I've
got MS.' What would you say to them, what sort of advice would you give them?"

Mrs. Earl: "Well, first of all you find out what degree it is, surely,
and then I would say, 'Right, think ahead. You probably won't get a lot
worse but you might do, so if there's a possibility that you'll not be as
good as you are now, then try and look ahead and train yourself or get
yourself trained for something that you can do even then, when you're not
as agile as you are now.' That, I think, is the important thing because,
when you're physically handicapped, you're not mentally handicapped, your
brain still works and you feel, 'Well, I could do that or I could do that
job'. You know, if I was able to, I think the thing is to readjust yourself.
When children leave school normally, they go in for training for something,
don't they? Well, if you find that your training, work ... the job that you're
doing won't be any use to you if you are handicapped, well, could you not
adjust that job, you know, turn it round so that you could still do it but
by being in a wheelchair or something. And I know it seems as if you're
thinking, 'Oh, I'm not going to get over it,' all that business but,
with MS, it doesn't go away completely and there's always a possibility that
it will get a lot worse. But you can raise the flag if it doesn't get a
lot worse but at least if you're prepared for it, it's not so bad when it
does get worse is it?
Because you'll find that most handicapped people want to do anything,
they want to do something. There are very few that sit back and say,
'Oh well, I'm a poor old soul now.'

You know, 'I'm not going to do anything because I'm poorly,' sort of thing.
Well, that isn't the attitude and I think that if doctors could prepare
patients and also in conjunction with the social services or whoever, the
training officers, colleges, Universities, if they could all get together
and say, 'Right, we will help these people to help themselves'."

This was the message conveyed by most of the respondents - "We need
information and advice to enable us to help ourselves".

Social Consequences of Being Disabled - Stigma

The Concept of Stigma

Throughout history, the crippled, the mentally retarded, the poor,
the mentally ill and others have been stigmatised as morally inferior
and viewed as helpless dependents incapable of mastering the elementary
skills essential for engaging in productive social and economic activities.
Goffman's conceptualisation of the term stigma was that "an individual who
might have been received easily in ordinary social intercourse, possesses
a trait that can obtrude itself upon attention and turn those of us whom he
meets away from him, breaking the claim that his other attributes have on
us. He possesses a stigma, an undesired differentness from what we had
anticipated. The attitudes that we normals have towards a person with a
stigma, and the actions we take in regard to him are well-known, since these
responses are what benevolent social action is designed to soften and
ameliorate. By definition, we believe the person with a stigma is not quite
human. On this assumption, we exercise varieties of discrimination through
which we effectively, if not unthinkingly, reduce his life chances. We
construct a stigma theory, an ideology to explain his inferiority and account
for the danger he represents, sometimes rationalising an animosity based on
other differences, such as those of social class. We use specific stigma
terms such as cripple, bastard, moron in daily discourse as a source of metaphor
and imagery, typically without giving thought to the original meaning.
We tend to impute a wide range of imperfections on the basis of the original
one and at the same time to impute some desirable but undesirable attributes,
often of a supernatural cast, such as sixth-sense or understanding."[1]

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[1] Goffman, E. (1968) Stigma: Notes on the Management of Spoiled
Identity. p. 15.

Goffman's model of stigma is of a general social process, not peculiar to specific forms of deviance or impairment, and physically disabled people are one of his categories of stigma bearers. Stigma is a derogatory label applied to an attribute that is socially devalued and is imputed to the social image of the individual or group. Stigmatisation shifts from a focus on the act or condition that discriminates a person to the actor per se.

Stigma is associated with the idea of lacking in moral worth and respectability; to be respectable an individual needs to be perceived by his reference group and societally significant others as morally worthy and therefore eligible for signs of personal appreciation (Ball, 1970). The concept of respectability involves the idea that society produces deviant labels for the unworthy or disrespectful people which can be assigned to some members by others or can be recognised and accepted (self-labelling) by the person himself.

The application of labelling theory to an examination of the social position of multiple sclerosis sufferers is complex. First, the diagnosis or clinical label, mulitple sclerosis, does not appear to convey to the general public the same kind of stigmatising and devaluing image as compared with other diagnoses such as schizophrenia, epilepsy or blindness. It would appear from the respondents' accounts that there was a lack of public image of multiple sclerosis, so that a disclosure of the diagnosis of MS would not necessarily have the same significance and meaning to the labeller, the medical practitioner, and the labelled, the patient. Many of the respondents had no conception of what multiple sclerosis was and had to seek further information about the disease. However, it is true that multiple sclerosis sufferers are physically deviant, in that they have an impairment which may exhibit itself in strange or anti-social behaviour and necessitate changes in the sufferer's whole life-style. The consequences of being a multiple sclerosis sufferer mean that they are secondary deviants as categorised by Lemert (1967) in that the deviance of their physical appearance and behaviour has resulted in a major alteration in their life-style and life chances, and hence, has become part of their lives.

The process of labelling is important in that, for most sociological writers, labelling is the application of a deviant label such as criminal, drug-taker, mentally ill etc., whereas, in the case of the multiple sclerosis sufferer, the clinical label is not in itself a derogatory stigmatising term, the stigma felt by the MS sufferers seemed to arise from their

gradual awareness that multiple sclerosis had or may in the future result in them being disabled and it was the awareness of the public image and treatment of the disabled that they found stigmatising.

Who are the Stigmatisers?

The stigmatiser is a person who is aware or knows of a deviant category and recognises it in people whose behaviour can legitimately be placed by him into a membership of a deviant group. For example, it may be the consultant who diagnoses multiple sclerosis and has to reveal to the patient his deviant identity as a disabled person, hence he is no longer like others. It may take time for the person to become fully aware of the significance of the disease. The medical profession labels patients and it is from these clinical labels that the stigma process begins to operate. If the label is pronounced by an official labeller, such as a consultant or general practitioner, it is much more difficult for the patient to refute it and it is more likely that the label will stick. However, in the case of MS, it is the behavioural consequences of being disabled and the application of the label 'disabled' that the respondents found most stigmatising rather than the clinical label, multiple sclerosis. This occurred when they were no longer able to 'pass' as normal and realised that they appeared in the eyes of others as disabled. It was the transmission of the derogatory label 'disabled person' that made them aware that they were stigma bearers.

A basic assumption in the study was that disabled people, in this case multiple sclerosis sufferers, feel themselves to be stigmatised and that this is crucial for the whole concept of stigma; in other words, people cannot be stigmatised unless they recognise that this process is being done to them.

Hence it is important to separate stigma as a concept from the consequence of being stigmatised. It seems accepted that stigma is a personally felt inferiority by an individual or a group in relation to a culturally defined reference group.

In the present study, the public image of multiple sclerosis was not assessed. However, the multiple sclerosis sufferers' accounts of the reactions and attitudes of the general public to them provide some information on this topic (see page 18). Naturally, these accounts provide information on felt rather than enacted stigma; they have been supplemented by a small number

of observations of multiple sclerosis patients going shopping in a supermarket.
These observations, made by the research worker, did provide some evidence
to show that people behave differently to visibly handicapped people than
they do to normals.

The Stigma of Physical Disability

The stigma of physical disability is largely a social phenomenon based
on reciprocity, in other words, the disabled person realises or is made
to feel stigmatised by inter-personal reactions and sanctions to them
(Dinitz, Dynes and Clark, 1969). In addition, the person may have knowledge
of public attitudes to disabling conditions. In the case of multiple
sclerosis, it seemed that the general public has a fairly limited knowledge
about multiple sclerosis, its causes and prognosis etc. and, therefore, if
a person is labelled multiple sclerotic, it seems unlikely that the possession
of such a label will automatically be stigmatising. However, the effects
of the impairment in terms of being wheelchair-bound and thereby adopting
a stigma symbol or exhibiting strange behaviour, such as unsteady gait which
is assumed to be drunkenness, provide the focus for stigma to be attributed
to the person.

Miss Dale: "If you stagger across the road because you are arthritic or
have multiple sclerosis and people don't want to know because you represent
invalidism and old age. You feel you are different and it's always in the
back of your mind, because you are incapacitated physically and don't walk
very well, because you have arthritis or have multiple sclerosis. It's
always in the back of your mind that perhaps you're not right in the attic,
you're not all right there. I honestly think this and this is another
reason why I write, I feel I've got to exert myself. I may be crippled but
I'm not mental."

Although in the study it was impossible to explore the attitudes of the
stigmatisers, there was a great deal of evidence from the respondents'
accounts that they did feel stigmatised in a number of ways. For example,
some of the respondents complained of being pigeon-holed or labelled disabled
and being treated as a deviant by normals who failed to realise or appreciate
their individuality. "We do not want to appear or to be known as a label.
We are all individuals, you know." The imputation of a derogatory label is
one example of the way in which normals focused on the devalued attribute of
the MS sufferer, thereby attributing a spread of the stigma to the whole

person and embodying a wide range of attitudes and views about physical disability, such as the general public's myth of equating physical disability with mental disability. For example, a number of the respondents in the study described how a large local store had given permission to stay open two nights before Christmas so that the physically disabled people in the area were able to come and shop with greater ease. The scheme worked very well and the following year the store decided to not only include physically disabled people but mentally disabled people. This clearly shocked the respondents who felt that the store was stigmatising them by linking them with mentally disabled people. However, they failed to see that their action of differentiating themselves from mentally disabled people was, in fact, stigmatising the mentally disabled.

Many of the respondents gave examples of stigmatising or discriminating behaviour towards them by normals. The story of going to a tea shop and being avoided by the waitress who asks the accompanying person or friend, "Does she take sugar in her tea?", or, "Would he like an ice-cream?", was stated to have been a common experience. The avoidance of contact with a disabled person and the assumption that one should address the accompanying non-disabled person rather than the disabled person seems to have been commonly experienced. The MS sufferers felt this behaviour was an affront to their intelligence, "Just because I'm in a wheelchair, I'm not a luny, you know." In these situations, it appeared that the waitress was assuming that the disabled person was either incapable or unable to communicate their desires and these had to be conveyed through the accompanying non-disabled person.

The respondents had stories of hotel managers, restaurant owners and cinema managers who had excluded them from their premises. The managers seem to have always given common sense reasons for the exclusion, such as fire risk. Nevertheless, the respondents felt that there was a policy of excluding them as unwanted and undesirable customers or clients.

Another tactic used by normals and mentioned by the MS respondents in the study is that of eye-aversion and avoidance of social or physical contact.

Mrs. Morgan: "Shop assistants won't look at you. Friends who you've known for a long time won't talk to you, they will say hello to my husband and ignore me just because I'm sitting in a wheelchair. Quite extraordinary."

The respondents' accounts of the way they experience non-disabled behaviour and reaction to them, may reveal more about their own pre-handicapping attitudes to wheelchair-bound people than the attitudes of normals or strangers. Their interpretation of eye-aversion strategy adopted by normals as embarrassment or a fear of catching whatever disease resulted in the person being wheelchair-bound is one of a number of interpretations that can be placed on such behaviour. For example, alternative interpretations could be the general embarrassment of normals, they had seen something attractive in a shop window, or they are in the habit of never looking at people regardless of whether they are disabled or not. However, the patient may interpret the behaviour as devaluing him as a person and thereby stigmatising him, whereas he may be stigmatising himself by his interpretation of the other's behaviour.

In the observational study, the research fellow observed that the attitudes and behaviour of shop assistants were noticeably different to disabled people than to non-disabled people. For example, on two occasions shop assistants failed to respond to requests for articles made by the disabled person and appeared to pretend they had not heard. The behaviour of the other shoppers in the supermarket was also noted by the researcher. This appeared to divide into two groups. First, the group of shoppers who were at pains not to notice the disabled person in the wheelchair, so that they looked the other way or became involved in looking for particular packets of peas, etc. This strategy of eye-aversion was used by both the shoppers and the shop assistants. The second group was that of being over-enthusiastically helpful. On one occasion, a shopper wheeled one of the respondents to the other end of the shop away from the shelves where the respondent was about to select some goods.

The behaviour of normals of avoiding physically disabled people has also been shown in experimental studies carried out by Comer and Piliavin (1973) and Kleck (1968) who showed that normals interacting with physically disabled people tend to terminate the interaction sooner, stand further away from the disabled person during the interaction, thereby attempting some form of social distancing strategy and showing evidence of feeling less comfortable emotionally in interaction with physically disabled people.

Hence the person is physically and socially disabled, for beneath the physical disability is a social definition or value judgement of the moral or social worth of that person. He is discredited or discreditable, not just

by the disability but because he is socially judged to be a different type
of person from normals. Various authors (Richardson, 1971; Dow, 1966;
Matthews and Westie, 1972) have all found uniformity of reaction to physical
disability. Both children and parents exhibited uniform preferences in the
ranking of various types of physical disability in Richardson's study
and he proposes that this was evidence of cultural uniformity with respect
to their attitudes to various physical disabilities. He also found evidence
to suggest that physical disability was more stigmatising than skin colour
in determining children's preferences, and suggested that different physical
disabilities have varying degrees of severity of social stigma. Physical
appearance is the only visible clue from which to infer personal characteristics
of a stranger, so that the person's physical disability imputes a devalued
status based on the stranger's cultural belief of stereo-types about
physically disabled people.

Explanations for the normals exhibiting such behaviour are provided by
Goffman (1968) who agreed with Richardson's findings that people react to stereo-
types and have expectations of physically disabled people as stigma bearers.
In contrast, Fred Davis (1961) argues that people do not have stereo-typical
responses with respect to physically disabled people, as the physically disabled
do not comprise a distinct minority group or subculture; but that it is the
ambiguity of the situation of disabled and non-disabled actors meeting
that results in embarrassment and faux pas. For example, Davis claimed
that in mixed encounters, which last for longer than just a fleeting moment,
the disabled person has to deal with problems of the "profound stickiness of the
interactional flow and in the embarrassment of the normal by which he
conveys the all too obvious message that he is having difficulty in relating
to the handicapped person as he would to 'just an ordinary man or woman'.
Frequently he will make faux pas, slips of the tongue, revealing gestures
and inadvertent remarks which overtly betray his attitude and place the
handicapped person in an even more delicate situation."[1]

Another explanation of normals' reactions to disabled people is that
given by Titley (1969) in his study where he claims the general public
appeared to attribute to disabled people the personality characteristics of
alienation and introversion.

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[1] Davis, F. (1961) Deviance Disavowal: The Management of Strained
    Interaction by the Visibly Handicapped. Social Problems, p. 121.

Problems Associated with a Spoiled Body Image

One of the major problems for the disabled person is that of coping with a spoiled body image, in that this becomes the visible sign of their disability and a focus of the stigma. The importance of body image is obvious in that interaction starts off by an assessment of appearance and the body is part of the equipment for conveying messages to others (Benthal and Polthemus, 1975). Appearances, as noted by Stone (1970), are that stage of social transaction which establishes the identity of the participants. Imputations of identity are influenced by spoiled body images. The problems for the multiple sclerosis patient varied according to the severity and stage of the disease. For those in the early or less severe stages, they were usually able to carry off a normal appearance so that they were discreditable in Goffman's terms in that they were able to conceal their disability, but the respondents who were wheelchair-bound could be categorised as discredited and unable to hide their disability.

In western society there is a notion of desirable physical appearance. Outward appearance is particularly important to women and many of the MS sufferers regretted the difficulty and the problems experienced in their self-care and personal appearance. For example, they quoted the difficulties of getting to the hairdressers or buying clothes. A number of them relied on mail order catalogues for buying clothes, but this often had disastrous results as many of the clothes advertised for disabled people lacked aesthetic appeal or often tended to look institutional and unfashionable. Naturally, this does not enhance the MS sufferers' confidence in public places or their self-esteem. The problem about the type of clothes that disabled people can wear has been discussed by Nichols (1976) where he points out the fact that frequently disabled people cannot cope with buttons and zips etc. and that this inhibits the range of garments they can buy. One female respondent suggested that disabled people needed to acquire better or special dress sense[1] and she advised the wearing of caftans and long skirts as these more elegant clothes would enhance the appearance of disabled women. Nevertheless, it must be remembered that such clothes are often expensive and one of the major problems faced by disabled people is their lack of money.

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[1] In American rehabilitation journals, attention is now being turned to the problems of clothes for the handicapped.
Hanselmann and Friend (1976) Rehabilitation, October.

Those patients who were wheelchair-bound and therefore visibly physically disabled, clearly conveyed a message of a spoiled body image and were unable to conceal this from strangers. This inadequacy or spoiled body image spills over from the physical defects and spoils the whole person. MacGregor's study (1951) shows that patients with facial deformities also experienced impaired social lives and felt imputations of negative moral character imposed on them by normals, which had resulted in some of the patients producing psychiatric disorders. This was despite the fact that facial deformities are in one sense irrelevant to social interactions in that they do not of themselves directly hinder or interfere with a person's capacity to interact. Yet they provided the basis for imputation of identity and stigma. Hence, MacGregor's study provides support for the thesis that incapacity overrides other personal attributes and becomes central in the restructuring of the victim's identity, in that the new identity is structured by the reactions of others and results in a stable set of definitions of a person's conduct and character, and little connection with their actual physical limitations. In other words, a generalisation of the deformity to the whole person is made so that the person has to cope with both the physical consequences of the impairment and the social and psychological consequences resulting from a spoiled body image and an imputation of stigma.

The acquisition of a spoiled identity in the case of the multiple sclerosis sufferers was slow in that all the respondents stated that it had taken up to two years to realise the full impact of their impairment, including its social meaning. In the case of the MS patients, it was not just the appearance of their body which was stigmatising, but it was the way in which the body moved or did not move as the case may be which presented problems in terms of other people's reactions to them.

Body Behaviour

Body behaviour is important in any interactional situation. A number of the respondents mentioned that they had learned new ways of performing activities and regaining independence. One woman explained how she had had to learn to carry things in her mouth, which for her was the most practical and efficient way of conveying things from one room to another. Nevertheless, she feared public disclosure as she thought that normals would not understand her behaviour and interpret it as a sign of mental deficiency.

Another problem associated with MS is the loss of sensation in various parts of the body, such as fingers. For example, one young woman had gone

to a party and was offered a glass of wine. She put out her hand to take
the glass of wine and smiled at the host. She stood there for sometime
until she realised that her host was looking rather embarrassed, she looked
down at her hand and found that she was still not only holding the glass
but her host's hand as well. She had had no sensation of this and clearly
this was rather a difficult situation to explain.

It was these kinds of small problems in everyday interaction that
accumulatively became a burden for the MS patients. Individually each of
the incidents were small and would perhaps appear insignificant, but
accumulatively over time the MS patients began to feel embarrassed and often
would attempt to withdraw from social settings and the possibility of another
embarrassing encounter. It is unfortunate that the respondents were not able
to discuss the problems associated with body image and behaviour with any
of the caring professions.

Aids and Appliances

By the third interview, a few of the respondents had begun to freely
discuss some of their problems which they felt resulted in their devalued
self-esteem. One important factor was the imagery associated with the aids
and gadgets given to disabled people. One woman had mentioned how it had
been particularly upsetting to toilet train her two year old daughter, while
she herself was experiencing incontinence. One daughter of another respondent
commented to her mother that the incontinence pads looked like nappies.
This innocent, though rather tactless comment, deeply hurt and degraded
the mother who, from then onwards, refused to wear the incontinence pads
and has consequently reduced her life-style by remaining in the house rather
than venturing outside and thereby possibly experiencing a public display of
a 'little accident'. The relationship between childhood and dependency, and
the social position of disabled people was evident by the respondents'
references to the various equipment and aids given to disabled people.
For example, the wheelchair was equated with a pram; the commode with a potty;
the incontinence pads with nappies etc. These aids publicly displayed the
stigmatised, devalued and dependent status of the user. Many of the
respondents attempted to either conceal the fact that they were using
incontinence pads from other members of their family (however this
concealment was usually for only a limited period), while another strategy
they adopted was to make fun of the situation and take the tension or
embarrassment out of it.

Some respondents were not so successful in their attempts to distract attention from the aids which visibly reinforced their disabled status. Wheelchairs produced a great deal of hostility and resentment by the disabled people. Frequently the local authority had supplied them to the patients but these had remained unused. The wheelchair was such a visible sign of their devalued status.

Miss Dale: "I loathe sitting in a wheelchair, it's such a badge of invalidism."

Another problem with wheelchairs was that the people's spacial location was often lower than the other actors or participants in the social setting so that at a party a person in a wheelchair experienced other people looking down and talking down to them as they were positioned in their wheelchair.

Mr. Irwin: "Being in a wheelchair inhibits you an awful lot. As I say, front door steps or transporting me from here into the car is most awkward in bad weather, you know, so you've got to be really determined to go out. It's bad enough if you're able-bodied but, being in a wheelchair, you've got a horrible slur on you before you even start because, you know, if you're in a wheelchair, you're about nine points mentally retarded. I think that's a sort of automatic reaction. There's another point on that score, if you went to school with a person, you'd see them in the street, you'd recognise them. Sitting in a wheelchair, you're looking up their nostrils and thinking, 'Is it Joe Bloggs, or isn't it? Surely he's not that old.' It's hard to identify them looking up at them from a wheelchair. You yourself are not exactly at ease but they've got a phobia and most people in wheelchairs have got phobias. I think as far as I can see, I've accepted I'm in a wheelchair and act accordingly. But I don't think sitting down there helps. You see, when you're in a wheelchair, you're, well, you're not a free agent."

Mrs. Morgan: "The wheelchair makes you feel inferior and enhances the visible signs of the power of others over you."

It would appear that many of these aids, although given and made for the best purposes and with the best intentions, act quite often in the opposite direction in that they draw attention to and devalue the disabled person and by so doing they act as a cue to normals who respond in a stereotypical manner to 'people in wheelchairs' regardless of the condition or

the disease which resulted in them being wheelchair-bound. This is not to say that it is useless to provide aids to disabled people as many rely on them for mobility. However, the respondents' statements do make sense in the light of the known non use of such equipment. It would appear that there needs to be more research into possible ways of overcoming some of the visual and spatial problems of wheelchairs and to attempt a programme to educate the public.

Expressed Sympathy

Another problem that the MS patients had to face was the expression of sympathy given by normals and their attempts to focus on the impairment as a pitying object. This reaction was the one most dreaded and found to be most upsetting by the MS patients. "Oh, why can't they just treat us as human beings and stop pitying us." The reaction of friends and neighbours to the knowledge that a patient had multiple sclerosis was frequently gloomy and pessimistic about what the future held for them. As Dembo and his colleagues (1956) suggest, the healthy person expects the injured person to mourn the loss of limb or handicap and to act accordingly. If the patient does not act in such a way as the healthy person expects, the healthy observer will devalue the disabled person in some way. The normals' perceptions and expectations of the ways in which disabled people should behave are exhibited in their verbal expressions of sympathy and claims to understand the emotional needs of the disabled. However, disabled people frequently are quick to see through these superficial verbal expressions as was shown in the present study and that carried out by Stevens (1976).

The respondents' need for sympathy and understanding was experienced in the early stages after the doctor had disclosed the diagnosis to them. Once the respondents began to adjust and cope with their changed life-style, they no longer needed or wanted people to pity them. The respondents wanted normals to encourage them to live normal lives as opposed to normals forcing them into a helpless dependent role.

Studies of bereavement such as Glick, Weiss and Parkes (1974), found that widows disliked being assigned to the role of marginality - the implication that widows had entered a form of early retirement - but, although they might be protected, deferred to and understood as entitled to special consideration, they had lost standing as full members of society. The assigning of a marginal role or position was also experienced by the respondents who found they were no longer regarded as full members with the family.

Children's natural curiosity posed additional problems for the respondents, particularly those who were wheelchair-bound, as frequently young children will stare and question their mothers on, "Why is the lady in that funny chair, what's wrong with her?". All the wheelchair-bound multiple sclerosis people interviewed had at some time or another experienced this situation and they complained that they would have much preferred the mother to have just said, "Hello," to them and allowed them to give their own explanation of their condition to the child. Instead, what usually occurred, was the mother attempted to quieten the child or drag it away. This action may have encouraged the child to consider disabled people as strange or evil people.

Respondents' Explanations of Normals' Stigmatising Behaviour Towards them

The respondents were questioned about their opinion of the reasons for the normals' reactions to physically disabled people and they gave two main reasons:

(1) The embarrassment felt by normals is not knowing how to cope with the ambiguous relationship of a stranger who is disabled, in other words, that normals are ill-equipped with a role prescript for such situations and,

(2) Fear that whatever disease put the person in a wheelchair might be contageous.

One woman complained, "We are continually having our ego ground into the earth by the reactions and the words of other people. It seems to be embarrassment, thoughtlessness, or fear of catching the disease that explains why people treat us this way." Although the respondents gave common sense explanations for normals' reactions to them, they were still deeply hurt by them and felt stigmatised.

Many of the respondents felt that these problems of being discriminated against or devalued by normals could be reduced or overcome by more public discussion on the subject of multiple sclerosis. The cloak of secrecy attached to disabling diseases, although often seen as a mechanism used by normals to protect the disabled person, can clearly have the opposite result. Many of the MS patients interviewed were very resentful and bitter about the way in which society treated them. "We are not wanted and we are

made to feel not wanted." And they gave many examples to illustrate such
points. It was noticeable that younger respondents were the ones, who tended
to feel more stigmatised than the older ones who clearly were more resigned
to their condition and accepted the full impact of multiple sclerosis by
adopting a disabled role. Singer (1974), in her study of patients with
Parkinson's disease, also found that younger patients were more lonely, bored,
experienced greater role curtailment and had negative evaluations of their
health and themselves. She attributed this largely to their comparative
reference group, in other words, that these patients compared themselves
and their present situation with their peers. This seemed to also be the
case with the multiple sclerosis patients, and it is clearly an important
finding that perhaps needs to have greater research carried out into it
because, if it is true that the younger disabled patients feel themselves
to be less socially accepted and more stigmatised than older patients,
there is a need for more rehabilitation and counselling of these young
people.

Coping Strategies

Coping Behaviour

The disclosure of the diagnosis did not trigger off immediately any
changed identity or acceptance of the disabling condition. It took time for
the individuals to admit to themselves that they were disabled and no longer
able to lead their previous life style, and must create a new life for themselves.
This long term adaption required the assistance and was influenced by the
attitudes of significant others in the patient's everyday social world
(Zahn, 1973). None of the respondents in the study had been offered any
form of rehabilitation or retraining, so that new techniques and coping
strategies, discovered by the respondents for carrying out everyday
activities and their new approaches to their everyday lives, were largely
a result of trial and error.

Coping behaviour is a way of resisting and rejecting many of the generalised
imputations of deviance and stigma attributed to deviants by normals.
The question was, how did multiple sclerosis sufferers handle the imputations
that they were deviants and not 'normals'; the respondents were aware of the
normals' view of their devalued status and consequently had either to
accept or reject it. Hence a social encounter between a physically disabled

person and normals necessitates the disabled person experimenting with various
role postures and assessing the potential problems of such encounters, e.g.
length of journey, availability of toilet facilities and the kind of actors
likely to be present in the social setting. Jobling (1977) discusses
how he, as a patient suffering from psoriasis, experimented in the same
way in an attempt at 'impression management'. Frequently uncomfortable
interaction is the result of such encounters and this indicated to the
physically disabled person that he or she has not been accepted as 'normal'
and failed in their impression management.

The threat of a devalued status exhibited in social interaction can be
influenced by the visibility of the disability. Physically disabled people
are unable to control this except in a very limited way, such as ensuring
that they are seated in a chair before any person enters the room or providing a
common sense explanation for their appearance such as "legs are a bit stiff
today as went for a long walk yesterday". Nevertheless, normals know the
rules of sociability and realise that they should not be focusing their
attention on the person's physical impairment and so many attempt to
'talk their way out of it' or disguise their awareness of the impairment.
On occasions, this tactic is successful, but in the majority of cases,
it would appear that their overt friendly attitude or over enthusiastic
concern to avoid drawing attention to the physical disability, in effect,
results in the physically disabled person becoming acutely aware of the rather
crude strategy that the normal is unsuccessfully attempting to operate.

How do physically disabled people cope with these sort of problems in
social interaction? It was not part of this study to consider personality
adjustment of the person experiencing a physical impairment. Nevertheless,
it was part of the study's objectives to explore the methods and strategies
that patients used in order to 'manage' their presentation of self and cope
with any perceived threats to their conception of self. They appeared to be
'passing', 'normalisation' or 'withdrawal'.

Passing

The strategy of passing is used when the disabled person wishes to
conceal from the others in the interaction that aspect of his or her identity
which he knew to be discrediting. This aspect or attribute that the person
is attempting to conceal is, therefore, known by the individual and regarded
of a lesser value than that which he or she is attempting to 'pass' as.

Passing is different from the other two strategies of normalisation or withdrawal in that, in the former, the individual who is passing is aware of the attribute to be concealed, while the others in the social setting remain unaware. The respondents in the study provided some examples of instances in which they had attempted to pass; for example, one woman, when asked by a stranger what was wrong with her foot (she was limping badly and had an unsteady gait) claimed that she had sprained her ankle. A man who works as an architect claimed he needed new glasses rather than acknowledge to his colleagues that he had multiple sclerosis and was suffering from impaired vision.

Mrs. Owen: "It depends on the stranger, I suppose. Let's think, one of my problems is shaking hands with a stranger because my hands are bent up as you can see and it's very difficult to shake hands with someone. At one time I didn't used to tell people I had multiple sclerosis. I used to hold things in my hand or keep gloves on or something like that so it was not possible to shake hands with people, but now I say, 'I've got multiple sclerosis.' That's interesting, isn't it?"

Mrs. Apple: "Yes, so I used to go to the adult education, and then they moved to the nisson hut which is just round the corner about a couple of hundred yards away I suppose, but it's too far for me to walk to the loo and it's a three-hour class, so everytime I've been there I've had to come out after two hours and tell them that I had to collect Rachael, which was true but I would never have been able to stay the full length of the class because I just daren't because there are no toilets there you see in St. Peters Lane, which again is up two flights and along a corridor."

To pass successfully may require the assistance of a benefactor or collaborator who will share the patient's secret and collaborate to provide a public image or impression of normality. Edgerton (1967) discusses the importance of benefactors in his study of mentally retarded patients, and it was clear in the present study that the assistance of a friend, spouse or neighbour was sometimes needed in order to maintain a public image of normality. One respondent had managed to conceal her recent hospitalisation from neighbours by the spouse reporting that she had gone on holiday so that, through the management of the patient's biography and concealment of past events, she was able to remain normal. One woman was able to pass by eliciting the assistance of a friend's arm and the friend was able to place the woman in a chair so that strangers entering the social setting would not know that

she was wheelchair-bound. Naturally, this attempt at passing could be maintained only for a limited period as any deterioration in the patient's condition increased the likelihood of the visibility. However, it seemed important to the respondents that they were able to appear normal even for short periods.

Mrs. Apple: "Just to be thought to be 'normal' sometimes is wonderful and worth all the effort involved!"

However, multiple sclerosis patients are usually only able to use this strategy in the early stages of the disease or when the disease is in a period of remission. So that, when a patient's valued conception of himself is threatened and alternative conceptions are unacceptable, some MS sufferers use the strategy of passing to forestall any reduction in their conception of self. Normals' reactions provide feed-back which either confirms or rejects the patient's attempt at passing. Being seen to be 'normal' or 'like other people' enables the respondents to deny the necessity for a changed self identity and slows down their awareness of the impact of multiple sclerosis on their self-conception.

Normalisation

Normalisation is an attempt by an individual in a position of disadvantage to 'adjust' the perspective of the other, so that it is more compatible with his own; that is to say that the disabled person indicates in a number of ways that those aspects which distinguish him and his situation from and cause them to be viewed as different by 'normals' are to be seen from a more advantageous perspective. In other words, the disabled person is saying that things are not as they appear to be. He challenges the commonly held expectations about the disabled. The strategy of normalisation is not a denial of the disability but a rejection that the disability is the main attribute or total identity - in other words, his rejection of the social significance of the disability rather than a rejection of the disability per se.

Davis (1961) discussed the process of deviance disavowal and stages in transactional terms through which a physically disabled person and a normal undergo in their negotiation of a definition of a situation. The process of deviance disavowal in which the physically disabled person refuses to render himself as a 'non normal' and encourages the normal to

respond to him as another normal and so invoke a redefinition process in
which the disabled person projects images and attitudes and conceptions of
self which encourage the normal to identify with him. The normal is led
into a larger or wider repertoire of appropriate responses. The problem of
sustaining the normal position achieved through deviance disavowal is that
it continually needs renegotiation with every new stranger encountered by
the disabled person.

Chevigny (1962) described this more than thirty years ago in commenting
on his experience of becoming blind. A number of the respondents made the
same point. For example, Mrs Earl: "I usually bring it out into the open,
first I say, 'I'm sorry, I can't get up and run about but, if you overlook
that, I'm the same as you,' you know."

Mrs. Owen: "I think that people are afraid of the wheelchair,
they don't know how to take it, so I think it is up to me to explain to
them. Julie pushes me along the street and I say, 'Hello,' to people and
they (strangers) look at me as though, 'I don't know you,' but I feel so
silly. I'm going along so slowly and they're looking at me and they are
embarrassed. If you're walking you pass people quickly but the wheelchair
is so slow. They don't say, 'Hello,' they are a bit hesitant. But I feel
I must make the first approach. I'm a friendly person and I like to talk to
people."

Mrs. Field: "You see, you have to make people realise that under this
appearance there is a real person, a normal person trying to get out. I
try to appear happy and pleasant when I meet people and sometimes I try to
draw their attention to a topic or a piece of work (piece of knitting)
that I'm doing. In that way, I hope, I'm making them realise that I am
normal really and no different from them."

However, it is sometimes necessary for the disabled person to back
down from or retreat from the position of being a normal. For example,
when faced with a request to dance or take part in a sponsored walk, or when
they are unable to pick up a heavy object. It is in these sort of instances
that the disabled person has to retreat back into a disabled status in order
to be able to legitimately request or elicit help from the non-disabled
in the social setting or contract out of the activity. So that physically
disabled people pass in and out of the various strategies or normalisation
repertoire within the context of their daily lives. The examples of Mrs.

Owen and Mrs. Field show the ways in which they attempt to 'break through' the commonly held, taken-for-granted attitude and values of normals towards disabled people, so that special consideration could be made without threatening their normality. Normalisation or attempts to cover up their disibility were sometimes problematic for the respondents and occasionally they had to pay the price of discovery. On these occasions, it became essential to re-normalise the physically disabled person's status and role, by lowering their expectations and developing a new set of actions and roles. This new coping mechanism replaced the old system. The two major problems that they had to face in their attempts to normalise were firstly the handling of the uncertainty of the impact of the disease and secondly the potential breakdown of the strategies of passing and normalisation that they were using.

Hence, the respondents adopt the policy of pacing as described by Wiener (1975) in his paper on patients with rheumatoid arthritis, this is the way in which disabled people weave in and out of their normalisation repertoire. It required the patients to recognise and identify the activities which take time and make allowances for the extra time to do these tasks. For example, it took on average three-quarters of an hour for the respondents to get dressed.

Mrs. Kay: "I found out I'd got MS in May, and then in August we went on holiday with my mother and father, my husband said - I wasn't very well at the time. The first week we had on our own, I came back from the beach once too exhausted to cook a meal. My husband said he'd get down and do it himself. He wouldn't necessarily cook what I wanted to cook - but go to the fish and chip shop but he'd cope very well. My mother and father came down after a few days. And I felt all the time that I had to keep up the norm. I've got to cook the meals, got to walk where they walk. All the time my mother was saying, 'Are you sure you're all right? Do you want to sit down? I'll do it dear.' There was a constant battle between myself who didn't want to do these things, feeling I had to do them for the sake of appearances and coping with her over-protectiveness."

Mrs. Morgan: "It's just that here (reference to the University), apart from when I'm walking around, I don't have to be an invalid because I just go and do my own thing and if I want to come back here and read, I do, whereas at home I just sit in a chair and things are done for me, you could call that protective I suppose, but it's a totally different life, I'm not really an invalid here."

Withdrawal

The patients who withdrew from social interaction, shared a similar perspective as 'normals' of the world as an uncaring place and of themselves as stigma-bearers or devalued, second-class citizens.

Miss Dale: "We are an embarrassment, people want to forget us and shut us up in geriatric wards. We are not a pretty sight, you see. They don't want to be reminded of us."

Withdrawal into social isolation can be viewed as a process whereby the individual increasingly becomes socially and psychologically separated from his former relations and social activities, with decreased opportunities for adequate replacement of old friendships and social activities.

Some patients believed that no one could possibly understand or know how it felt to be a multiple sclerosis sufferer or to be disabled, and so they dithdrew from social interaction in an attempt to avoid threats to their own self-conception. These patients felt themselves to be completely set apart from 'normals'. "We are second-class citizens, freaks." Neither did they associate or identify themselves with others who were disabled or chronically sick.

Mrs. Read: "I didn't want to know. I suppose I put my head in the sand. I didn't want to see all those others with it."

Withdrawal was also used by the MS sufferers when they found that the pain had become intolerable or that they were unable to cope with the depression which sometimes is associated with multiple sclerosis. "When I feel bad, I just have to go away and be by myself."

Mrs. Earl: "It does hit you and it is an awful job to sort of snap out of it. You can't sort of switch on and off easily. But, as you've just said, most people get depressed, don't they? I mean, fit people get depressed. It's just, I think, if .... normally, if you're able-bodied and you get depressed, you can work it off. You can polish the house or you can go out for a long walk or something like that, but when you're handicapped you can't do those things. Therefore, you've got to try and do something to break the awful feeling .... And you see you can't write letters when you're in a mood like that because you sound so sorry for yourself and that's no good. And you lose interest in books and you don't want to do anything.

You know, and it's rather like if you've had a really bad dose of flu and you feel so apathetic and everything's too much trouble and I think times like that it is rough. But if people were taught to try and sort of overcome that you realise that you go through a bad patch. You think, oh well, this time next week, I'll be all right. Let it go, let it pass. You'll be all right."

Mrs. Morgan: "All my muscles went into spasms. I can remember reaching down - agony, I just couldn't move - every time I wanted to get up I had to be hauled to my feet from under my armpits and brought up like Frankenstein's monster, painfully moving - because I can't walk, I have to consciously move my hips to make my legs walk - which was very painful. Well, it always is, I mean it is never - it always hurts to walk. This seems to be one catalogue of my catastrophes ...."

Several respondents commented on the excessive pain they experienced with multiple sclerosis and, although pain is recognised to be a subjective feeling (Beecher, 1969; 1965), it was a surprising finding as the majority of medical text books do not appear to comment on the pain of multiple sclerosis. This may require further research. A number of the respondents, particularly the women, mentioned that they experienced depression, although it was impossible to disentangle whether the depressive episodes were in some way associated with their sex or whether, in fact, this was related to multiple sclerosis or a more common sense explanation that people who experience disablement also experience depression. Nevertheless, the standard text books do not mention depression, although they do mention the euphoria associated with multiple sclerosis.

It was only possible for these patients to temporarily withdraw from social settings in which they might experience the ambiguities of their social status and a threat to their self-conception. It was impossible for them to withdraw totally from the social world and it would appear that, as with the other two strategies, the MS sufferers passed in and out of the adoption of a process of withdrawal.

Sometimes withdrawal was by the friends or acquaintances rather than the MS sufferers themselves. (See also page 76). Gradually many of the multiple sclerosis sufferers lost touch with their old friends who no longer came to see them. For those patients who experienced the withdrawal of their previous friends, this was a very hurtful period and they were often

unable to understand why their friends no longer wished to see them. This
is similar to the experiences of bereaved wives (see page 47).

Mrs. Morgan: "I have less contact with many of the people that I
used to know. I found that people I had written to I never heard from again.
The time I lost most of my contacts was the exact time when I needed them
most, when I felt I was dying, that sounds terribly dramatic, but I did,
I really thought I was dying and I really wanted to see my friends and it
was a great source of misery to me that they couldn't be bothered to come,
it may not have been that way to them but it appeared to me as I was lying in
my bed."

For some, it would appear that there was mutual withdrawal in that
patients made no attempt to broach the split in their relationships with their
previous friends. They were usually bitterly disappointed that their
friends reacted as they had and often it was these patients who then withdrew
themselves from any social contact and would not go out or even talk to their
neighbours, but lived socially isolated lives. Clearly, a number of patients
had found it very difficult to maintain and sustain the reciprocities in
social relationships, as they felt they were continually on the receiving
end in the relationship and that they were unable to give back anything -
in other words, they saw it as an exchange situation in which they were
greatly disadvantaged by having nothing to exchange. Those normals who
continued to define the situation as centring on the patients' disabilities
to the exclusion of their other attributes were often rejected by the
respondents as they found themselves unable to negotiate for a redefinition
of their disadvantaged status and did not want to appear in a subordinate
second-class role.

Part of the problem of the patients' inability to maintain the reciprocity
in a social relationship is that he or she is no longer able to share
similar experiences with normals. For example, one young woman could no longer
go out with her friends to a disco and one man could no longer visit his
friends as they lived in a large block of flats without a lift.

Sometimes withdrawal was used as a self-protective response by patients
who found that they were suffering from socially unacceptable symptoms
associated with multiple sclerosis, i.e. bowel and bladder incontinence.
Frequently the patients said that they would not go to a show or to a theatre
as they might have an 'accident'. The women found that the incontinence

pads would only last for two hours and often journeys or entertainments were for longer periods, so that this presented a major problem. A number of the patients interviewed had experienced at least on one occasion a 'public accident' and the memory of this occasion haunted them. Incontinence made the patient aware that his or her condition could offend people and produced profound embarrassment. Withdrawal acted as a strategy to protect these patients from again experiencing embarrassment from an obvious lack of control over their body functions, but it was at the cost of retreating further from the social world.

In addition to social strategies discussed, the respondents exhibited evidence of Wiener's (1975) psychological strategy in which they juxtaposed their hopes of relief, cure or remission against the dread of progression. All the respondents found difficulty in handling this and sometimes they appeared to be particularly elated because they thought the medical profession had found the 'key to open the secret to multiple sclerosis' with the current publicity about the virus theory. However, these moods were rapidly replaced by feelings of depression and despair (see page 55).

The three strategies of passing, normalisation and withdrawal, discussed in this section, are not unique to persons with multiple sclerosis or even disabled people. They are used by everyone in their everyday lives and are part of the mechanisms by which people cope with social interaction in order to sustain their self-conception. However, the difference is that normals use strategies only for short periods when their identity is under threat or stress, whereas for multiple sclerosis patients these stretegies are part of a continuing way of coping with their social environment. Passing, when successfully used by an MS sufferer, permitted them to appear 'non-disabled' to others, although usually only for a short period of time. Normalisation projected attitudes and postures which conveyed an image of normal and capable attributes of themselves, which they wanted to be viewed as by others and seen as essential to their identities. Withdrawal from social interaction was a means by which the patient protected themselves from social settings in which they thought they would be viewed disadvantageously or negatively. These strategies were used by the MS patients to help manage the impact on themselves of living with a slowly disabling disease.

MS Sufferer and the Family

"There must hardly be a chronic ward or residential home that hasn't a crippled patient who is there simply because his or her marriage partner has given up the physical and emotional struggle and walked out." Louis Battye (1966).

Spouses

Disability, as has been noted by many writers, affects not just the victim but the whole family. The impact and significance of one member of the family being disabled necessitated alterations and adaptations within the whole family structure and relationships. A number of writers on the problems associated with people suffering from disabling conditions have noted evidence of marital strain and tension in the husband and wife relationship, once one partner has become disabled.

In the present study, there was a range of relationships, the majority were married, some were separated, either living alone or with a young family, and two were unmarried women (see pages 6 and 7). It was evident from the replies of the respondents that they felt that the relationships and roles within the family had altered as a direct result of their disability. One of the major areas in which the respondents felt that the disease had affected them was in the husband and wife relationship. Before the onset of the disability, the respondents were all fulfilling traditional segregated marital roles. However, the onset of the illness necessitated changes in these roles. These changes or role reversals have been associated with the disabled person's adoption, either voluntarily or through the process of persuasion by the spouse, of a more dependent role.

The Problem of Dependability

The problem of dependability appeared to develop gradually. There was a slow erosion of the patient's previous status and power within the family. The dependability took a number of forms, physical, emotional and financial. There were some differences between men and women with respect to the question of dependability in that men felt more threatened by financial dependability through the loss of their role as breadwinner in the family, whereas women were more anxious about the usurption of their emotional and supportive roles within the family. The question of dependability is a crucial one

as every disabled person has to face it. The spouse and the disabled person
have to negotiate changed or modified roles and status within the family.
In the sample, a number of successful negotiations appeared to have occurred,
but it was also evident that a small number had not. For example, in one
case, the wife had adopted a totally dependent role, whereas in another case
the wife had been unable to come to terms with a subordinate role and
consequently the marriage appeared to be near to breakdown.

Social relationships are very fluid and the roles can be renegotiated,
so that the disabled person does not have to accept a permanent dependent
role. Nevertheless, once the disabled person had submitted or agreed to
an invalid status in which they accepted a dependent role, this usually
became immovable or permanent.

All the respondents acknowledged that their impairment had produced
a major strain on their family, in particular with the spouse.

Mrs. Morgan: "Sometimes I think you go through a period where you feel,
why should your husband have to put up with this as well, you know. I
did go through a period when I thought, poor David, why should he have to
put up with me. You know, he can't do this or that anymore because of me."

The MS sufferers did feel a certain strain on their marital relations
due to the burden they placed on their spouses or relatives through the
necessity of having to be dependent to a certain extent on them and being
unable to maintain their pre-disability roles.

The price of family harmony seemed to be an acceptance of a dependent
or subordinate role by the disabled person.

Mrs. Field: "I worked in the jewelry business and I fell down the
stairs, when I got to the bottom I'd got all diamonds and rubies on me,
I looked lovely and I killed myself with laughing."

Mr. Field: "No, you see, what she done was, she hurt her spine. She
knocked the back of her spine."

Mrs. Field: "But I can do marvellous things now ..... swimming .....

Mr. Field interupts: "She also hit the back of her head. It made
her a little bit ..... you know ...... (laughs).

Mrs. Field: "He says I'm a little bit, you know, but I can't help it, poor dear."

In this illustration, the husband seemed to be overtly devaluing the MS sufferer's self-conception by implying that the multiple sclerosis was somehow associated with her being "a little bit (funny in the head)". In another example, the same husband seemed to wish to convey to the interviewer the message that his wife was very helpless and dependent on him. "She can't do anything, not even dress herself. I have to do every-thing - I cook, wash and clean her. It's a life!"

One interpretation of this situation is that the woman was not allowed to dress or look after herself and that these restrictions on her activities were imposed by her husband who failed to take account of her remaining capabilities. The maintenance of this marital harmony appeared to depend on the wife accepting the subordinate role, although in fact she was capable of performing many activities. In other words, she had accepted her husband's definition of her situation as an invalid.

Mrs. Morgan: "You see, oh it changed my identity, one's own identity is quite great, as time passed then you accept that this is the way you are now. I mean, it takes a long time to remember the way you were and the way you are now. It was a question of you can't do it so you accept that you can't do it. I used to say, I can I know I can, and then he, my husband, used to get cross with me, and literally physically move me and sit me down, so in the end, if you can't beat them, join them. And I was never very keen on housework anyway, so it wasn't so much of a hardship. But we live in a four bedroomed, largish house and there is a lot of work to do and I just know that it is not getting done and this is a constant source of frustration. I can't do anything about it because literally I can't do it myself. I said to George (my husband) if I could just have one wheelchair set up in the house, I could move from room to room, but he doesn't agree with that. I can't, no that's no good. So I have got to sit in my chair like an old granny in my corner and just stew inwardly, and I can see all those things happening, that want doing and I just have no one to ask because, you know, 'Aren't I doing enough already,' attitude, which is only understand-able. At home my husband tries to protect me and in some ways he makes me an invalid."

The Adoption of a Subordinate Role within the Family

The subordinate role that the MS sufferers found themselves coerced into is similar to that found by in-mates in various residential institutions for physically or mentally handicapped people. For example, Miller and Gwynne (1972) found in their pilot study of residential institutions for the physically handicapped that the 'warehousing' residential institutions[*] did depersonalise and devalue the in-mates. This process had also been noted in the early work of Goffman where he commented on patients entering and living in mental institutions in the United States (Goffman, 1961).

In some cases, the wives expressed the view that their husbands felt very anxious about their disability and had become too protective of them. This was similar to the findings of Wright and Owen's (1976) study of housewives with rheumatoid arthritis. In the present study, all the respondents, except the Fields, had developed multiple sclerosis after they had been married, so that it was not possible to comment on Wright and Owen's findings that those who had been disabled before marriage fared better than those where the onset had been after marriage.

All the MS sufferers had experienced feelings of conflict, in that they felt that their close relatives were redefining their self-conception for them by limiting the range of activities that they were allowed to undertake and thereby reducing their roles and degrading their self conception. Nevertheless, the problem appeared to stem from the fact that all of these people were disabled to a degree that necessitated another person assisting them. In other words, it was impossible for them to be totally independent of their relatives.

Mr. Irwin: "It's my diagnosis on this sort of point. It always was my diagnosis that for every disabled person, whatever the disability, whether multiple sclerosis, blindness, deafness or whatever, when limbs are affected there has got to be another person involved. To push that person in a wheelchair, perhaps dress them. My wife has to dress me now, sort of be my lackey, if that is not a wrong term, but there has always got to be a second person involved with that initial person. There has got to be a secondary person there always."

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[*] The warehousing model of residential institutions, as defined by Miller and Gwynne, was associated with humanitarian values and saw its primary task as the prolongation of physical life. In contrast to the 'horticultural' model which was associated with liberal values and saw its primary task as the development of the fulfilled capacities of the individuals entering into the institution.

Mrs. Irwin: "Well, you see, it's frustrating to watch someone trying to do a thing. You sort of want to rush to help him, but you can't. I mean you mustn't, I mean you (the disabled husband) get cross with me sometimes when I try to help you."

Many of the respondents' spouses or relatives were too eager to help them and protect them.

Mrs. Kay: "There are times when I feel that my husband doesn't protect me enough, and there are times when I feel like saying, 'For God's sake, leave me alone, I'll lead my own life. If I want to do that and exhaust myself by doing it, it's my choice'."

It is obviously a very difficult problem for the spouse and the disabled person to become aware of the changes and modifications in the activities that the disabled person is capable of performing. This is frequently complicated for the MS sufferers by the very nature of the disease which can vacillate from day to day, so that an 'unwise' person may view the MS sufferer's performance as malingering or not trying. One husband commented about his wife, "She makes mountains out of mole hills. One day she can do it, the next she says she can't ...... well, I ask you, she makes everything a problem. It's her, not the disease you know."

Naturally, these kinds of misunderstandings about the vacillating nature of multiple sclerosis lead to strain and tensions within the family unit and many of the respondents reported quarrels and rows with members of their family which resulted from misunderstandings about the impact of multiple sclerosis on the patient.

Mrs. Owen: "No, no one talked to my family about it. Tom is haunted by it, he doesn't understand. His school master said, 'I told you your mother would not be able to do what she used to do,' but he doesn't understand .... They don't understand me. I've tried to explain it to them, it's not just me! But they don't. We need someone to stay and explain it to them. We have more rows because, being housebound, I get ratty and cross and I don't want to be. It's quite exciting being taken over to the shops, that's ridiculous isn't it! Someone to talk to. The problem is MS changes. One day I can walk and the next I can't. Tom calls me a hypocrite. The times he's called me a hypocrite. How do I get through to him? Some days I can walk without a stick but I have to take it with me to get from the path onto the grass. I try to walk a bit but they don't understand."

Extended Family

However, it is not only the immediate family who have problems in negotiating and coming to terms with one of their members being disabled. The extended family also has some influence in this process.

A number of the respondents commented that they had managed successfully to redefine or re-normalise their roles and status within their immediate family (family of procreation) but that they had found much more problematic their relationships with the family of origin or the extended family, who seemed to wish to curtail the boundaries of their independence and activities.

Mrs. Pack: "My father-in-law is just one of these people. He will make me sit down and will do everything for me if he can, but I don't think that's a good thing."

These problems may stem from the only occasional contact that the sufferers had with their relatives and the lack of communication between these two groups about the impact and consequences of multiple sclerosis. All the respondents made significant efforts to show their independence, as this was important for the maintenance of their own self-conception which was dependent on being able to display publicly, through impression management, the activities that they were still able to do. Visible signs of their achievement were an effective way of spelling out and reducing the relatives' devalued view of them.

It is not only the redefinitions and negotiation of the disabled person's self-conception that is problematic for them, but they were very worried about their marriage relations and in particular the anxiety of the husband getting a girl-friend or going off and leaving them.

Mrs. Morgan: "But, I mean, if he got himself a girl-friend, I shouldn't be shocked. I quite expect it. In a way, he is entitled to something. You see, one day soon, maybe, he will suddenly think, 'Oh, well, this is too much,' and get a girl-friend. It poses enormous strains on the loyalty of any marriage. Although we are both active and independent, I've been like this since I was 30 and that's no age. And the divorce rate for people with MS is very high. So is the suicide rate. You do begin to feel, 'Hell, I don't want to live like this.' I feel that way sometimes. I get scared sometimes, because if I fall and I can't move, I have to scream and scream for help. I can't do anything."

The strains and tensions in the marital relationship may directly result from bad communications and exchange of knowledge and information about the nature and the problems associated with multiple sclerosis. Zahn's study (1973) showed that the more visible the impairment, the easier it was for the non-disabled spouse to legitimise the partner into a disabled role and to accept any role reversals necessitated by this, and led to better inter-personal relations. The problems already mentioned with a disease such as multiple slcerosis meant that it was not until the disease had been diagnosed and thereby legitimised by the medical profession, that the spouses were fully able to accept the fact of their partners being disabled.

The problems faced by many of these MS sufferers and their families seem to stem largely from their lack of information and understanding about the impact of multiple sclerosis on the patient. It would appear that one way in which these families could have been helped, would have been by providing them with some counselling service in which an explanation of the disease would have been given and also the opportunity to talk through its effect on family relationships. In addition, it would seem that these families should have been provided with some back-up and supportive services to help the spouse cope with the situation of one member of the family being disabled. In the present study, it did not appear that there were the supportive networks found by Blaxter in her Aberdeen study.

Mrs. Earl: "Yes, what we need is a bit more backing, I think, because no one thinks about them (husbands). My husband, he can't go very far, he can't go out and leave me. He doesn't want to do it but that's not the point. He works nights because of me so he goes to work at a quarter to six at night and comes home at just after two in the morning. Then, of course, during the day he's got to do the shopping and all the jobs that I can't do, but I try as much as I can. Obviously, he's tied down. He can't go anywhere. He can't sort of join anything, because he won't go without me, and I can't go to these places. Well, a wife would be in the same position. You know, if her husband had a disability. I think, if people were to think of something to give him a break."

A few of the respondents commented on the burden of their disability in terms of its impact on the other family members and felt that some of this could be alleviated by better back-up of supportive services provided

by the health and social services. These findings are similar to those
discussed by Johnson and Johnson (1977) which illustrated the wide
gaps between provision and need for support services.

The MS Sufferers' Effect on Familial Role Performance

The roles that people play within the family are determined by a
number of factors; age, sex, occupation, social class etc. The significance
of these roles to the patient's self-conception was evident in the reaction
to the threat posed by multiple sclerosis to their performance of any of
them. For example, women with young families strove particularly hard to
stop the disease affecting their obligations and commitments to themselves
and their families. For these patients, the pressure to perform in compliance
with the behavioural expectations of one's familial role seemed to be
greatest.

Role of the Mother

The role of the mother is defined here as the major child rearer and
the supportive agent in the family. In other words, the mother is the
person who tends to bear the major social emotional responsibilities for
all the members of the family. In the study, usually the husband or
sometimes a friend had taken over the physical care of the children, although
in two cases the mothers had struggled to learn ways of coping with such
problems as putting on a nappy or filling up a kettle with water with weak
wrist control. However, the problems of behaviour and discipline presented
by the children to their mothers were viewed by the latter as more problematic
than coping with the physical care of the child. The child's disruptive
behaviour presented the mothers with their most serious doubts about the
effects on the child of having a disabled mother. In one case, a mother
thought that her child's very disruptive and aggressive behaviour was
because the child resented the fact that his mother was not like 'normal'
mothers. From the mothers' accounts it seemed that the consequences of
a mother having a disabling illness did affect the children.

The impact was thought to be greatest for those children who had previously
known their mothers non-disabled; in one case, the two teenage children
found it so embarrassing to have a mother who was wheelchair-bound that
they refused to go out with her in the wheelchair and would not bring their

school friends home as they previously had (from the mother's account).
Both the older children in this family no longer discussed their school
friends or problems with their mother and this was given by the mother as
an example of the way in which she was no longer able to perform as a
'good' mother. Whether the children felt cheated in some way, as suggested
by Davis (1973), it was impossible to tell from the accounts of the mothers
that were gathered. Naturally, there are a number of possible explanations
for the disruptive behaviour and secrecy of adolescent children. However,
the interpretation placed on the incident by the mother influenced her
relationship with her children.

It is certainly true that many of these children had to take up a
number of additional roles and responsibilities that would not normally
have been required of their peers. For example, shopping, cooking, dressing
one's mother, collection of medicines etc. and some embarrassing and
unpleasant tasks, such as a fifteen year old boy who had to carry his mother
to the toilet and attend to her there. The mothers thought that these
responsibilities and chores strained the mother/child relationship and gave
examples of the children's accounts of their frustrations on being requested
to carry out some of these tasks.

It is possible that some of the children feared that a <u>courtesy stigma</u>
would be attributed to them by others. In other words, the children
were afraid that the stigma or devalued status of their mother would spill
over onto their own self-conception. The children observed the reactions
of others to their disabled mother on such occasions as going shopping
with her. For example, one daughter had taken her mother shopping in the
wheelchair and commented on the shop assistant's strange behaviour to her
mother, including eye aversion and abrupt conversation. In this study,
it was impossible to assess whether the hostility or embarrassment felt
by the children, as expressed by the mothers, resulted from a fear that they
would be devalued by normals because of their association and relationship
with their mothers. The mothers hoped that, because they were aware of
these problems faced by their children, they were able to make up for them
by trying to maintain their role as the emotional and supportive agent
in the family.

The Role of Housewife

The role of the housewife, a traditional female role, appeared to be a more acceptable area of activity for role reversal and adaption than that of the role of mother (as defined above), although some women had maintained many of their domestic activities by the use of special facilities or by altering the physical environment, for example, lowering of shelves etc. Each family had tried different methods of accommodating some of the problems resulting from the incapacity caused by the impairment. For example, four patients had bought deep freezers which meant that they only needed to shop only once a week and this was usually with their spouse or relative at the weekend. However, these sort of solutions were expensive and prohibitive to the poorer families who were unable to afford such facilities.

Mrs. Kay: "I think my husband has helped because he has not told me to sit back and he will do things, which I think a lot of people do, so that I have never felt disabled particularly. I have never felt that I am no good any more, because I have just sort of carried on. I mean, when it got to the stage when I couldn't make cakes any more by hand, he bought me a mixer and so now I do everything by mixer and I've got the various attachments. When I couldn't wind my watch any more and found this very annoying, as I had to ask him every day to wind my watch up and that irritated me enormously, he bought me an automatic watch - these things have helped enormously, helped my independence I suppose."

Social services had provided the patients with some gadgets and made some structural alterations to their homes, but this was a far cry from the range of aids on the market to help disabled people. All the respondents claimed that they had been given no guidance on how to cope with house maintenance and home-making, and expressed the opinion that some occupational therapy would have greatly aided them in their attempts to maintain their independence and carry out their roles within the family, thereby reducing their dependence on agencies such as homehelp and meals-on-wheels etc. From the accounts of the women in the sample, it would appear that they did not object or feel that their role as home-maker had been usurped by an agent such as home help; instead they recognised that their impairment did present a number of physical problems, which meant that they were unable to carry out heavy domestic tasks.

The delegation of some tasks to the home help had relieved these women of certain activities which previously many had found unrewarding. In the cases where the majority of domestic tasks had been taken over by the husband, it would appear from the wive's accounts that the husband's reactions to this role reversal had been fairly non-committal. However, the wives did mention that they felt the standard of domestic housework was not as high as they had previously maintained themselves. This was a source of some frustration to many of them and yet they felt unable to criticise their husbands as this would possibly endanger the whole family harmony and perhaps lead to the husband leaving the family.

All the women in the study felt a certain strain and tension in their marital relationships, because their husbands had to undertake a number of extra tasks and chores directly as a result of their inability to carry them out. In some cases, the patients felt that they had been coerced into a dependent or subordinate role and that they had to accept this as they felt unable to renegotiate or redefine their situation due to their total dependence on the spouse.

Mrs. Morgan: "My husband has been ever so good but now I have to lose my identity, because I daren't criticise him, you see. You daren't because if you criticise you have a row and if you have a row he says, 'Right, I'm not going to do it again.' And you depend totally on the other person which is hardly fair on the other person. Fortunately my husband doesn't seem to mind but I don't know whether he really does, but I do know that I've got to sit there and shut up. I mean, I daren't say, 'Oh, my God, the curtains need washing,' or, 'Look at the dust on the window sill.' I can't do it because he would say, 'Don't I do enough for you?'"

A good account of some of the problems of household management is described in Earnshaw's study of a number of disabled housewives.

The Role of the Husband

All five men in the sample had been married, although, at the time of the study one was widowed and another separated (see pages 6 & 7). Currently all five were unemployed and clearly regretted this state and felt that, to a varying degree, their status and position in the family had been threatened by it. They seemed to feel that a 'normal' husband was of

necessity the bread-winner and the wage earner. All the men felt that their loss of job or early retirement and confinement to home had meant financial hardship for their families and a devalued conception of themselves as an unproductive person. Disengagement from work was usually a slow process of reduction of hours and downward mobility. All the men appeared to have been members of families in which the marital roles were segregated before their disablement, and now, as disabled people, they were unable to fulfill their previous roles, nor were they welcomed in any attempt at role reversal. None of the wives of these men had decided to seek employment to supplement the family's income after the husband's disability and unemployed status, and, in fact, one woman had given up the work she had previously done in order that she might look after her husband. One major problem experienced by these men was the solitude and boredom of being confined to home, and this is discussed in greater detail (see page 73).

The Role of the Father

None of these respondents were actively participating in the role of father at the time of the study, as they either had no children or the children had grown up and left home by the time that they were interviewed (see pages 6 & 7). However, they were able to discuss their feelings about being disabled fathers with young children at home. There were a number of problems, apart from the financial hardship the whole family experienced as a result of the father's disablement; the fatigue and physical inability of the father to actively participate in family affairs, such as outings, playing football with sons etc. One respondent commented that he felt that his son was very embittered and hostile towards him as, from the father's account, he felt that his son thought he did not want to play with him and he compared his father with the fathers of his friends who were all participating in such events. In the latter stages, when the patients found themselves confined to home, both they and their children found it difficult. From the fathers' accounts it would appear that the children, particularly sons, were often rebellious and hostile towards them. The children recognised that the father's authority in the family had been reduced and would be openly disobedient. The fathers knew that they were unable to operate their previous form of punishment such as spanking and felt that their authoritarian role had been eroded. This is similar to the findings in Davis's study (1973) when she found that the fathers felt upset and challenged by their children's reactions to their disability.

In the present study, the respondents were no longer actively involved in the role of father. However, they retrospectively worried about whether they had been 'good' fathers to their children and worried whether they had somehow jeopardised their children's life chances and life-style.

An Account of a 'Typical' Day

All the respondents in the study were asked to describe a 'typical' day. These data provided insightful information into both practical and social problems faced by disabled people. It is important to note that, for the MS sufferers as with many other disabled groups, one of the major problems in their lives was fatigue. They found that they had to learn to ration out their activities during the day in order to conserve their energy for activities that they considered important. Hence the patients developed their own timetable to get through the day. The process of redesigning their lives and adopting strategies of time conserving and time scheduling are crucial for the management of life with chronic illness (Reif, 1973).

At the time of interviewing, none of the respondents were employed and all the men were severely disabled so a major part of the day was spent at home. There was some similarity between the patterns of activities for both men and women. In the sample, a whole spectrum of activities and levels of independence and capability were evident in that two women 'managed' to live a fairly 'normal' life as mothers of young children, whereas, at the other extreme, there was one woman who was bed-bound and incapable of total self-care.

Most respondents rose between 7 and 8 a.m. and spent up to three-quarters of an hour getting dressed. They all viewed self-care activities of dressing and washing themselves as important to the maintenance of their self-conception, even though in a number of cases dressing themselves was a painful and often difficult task. Sometimes the patients needed to ask their children or spouse to assist them in this activity and this assistance was rationalised as important to keep some energy, for example, exercises at the Day Centre, for writing their poetry, etc. All but one man could either manage to get downstairs by themselves or lived in a bungalow, hence the stairs were not a problem.

Although many of the activities engaged in were similar for both men
and women, there were some differences relating to their specially defined
roles of wife and mother, or husband and father. A few women prepared
breakfast for the family but, in the majority of cases, breakfast was
prepared by the spouse or relative and was brought in for the patient to
eat.

After breakfast, most of the patients' husbands left to go to work
and the children went to school, so that for the remainder of the day, at
least until four o'clock, they were left on their own. Some of them
washed up the breakfast things and tidied up, attempting to do some light
housework, but for the majority of them, household chores were carried
out either by their spouses or by the home help. The home help visited
over half the patients in the study and, apart from her domestic role,
she provided an important social contact for these people. In two cases,
she was regarded as 'part of the family' and in no cases was there any
evidence that the women felt resentment towards the home help as the usurper
of their domestic role within the family. Instead, she was usually regarded
and accepted as a 'treasure'.

It seemed that once the MS sufferers had acknowledged that the disease
had produced a number of physical limitations on them, they readily accepted
the need to off-load some activities onto other agents such as home helps;
thereby enabling them to conserve their energy for the more 'important'
tasks of listening to their children learning to read or their husbands'
worries and generally retaining the maternal role in the family. The men
stated that they needed to schedule their day to enable them to do the
household accounts, as the role of "treasure" was important to them in
maintaining their position in the family.

For the rest of the morning, those respondents who were ambulant
(both men and women), either went shopping by themselves or with a neighbour
and the remainder who were not mobile spent the morning listening to the
radio or watching television or reading the newspaper. The respondents had
their lunch between 12 and 1; only four out of sixteen prepared the meal
themselves and the rest ate meals prepared by a relative, a neighbour,
or a home help or, in two cases, by a voluntary organisation's meals-
on-wheels service. The afternoons were usually spent at various activities.
For example, a number attended clubs for the disabled and some attended
the local day centre. One woman attended adult education classes and two

other young women were leading relatively 'normal' social lives in that
they spent their afternoons going to meetings such as mothers' meetings,
or having tea with friends, and picking up their children from school.
Nevertheless, it was clear for all the patients that their life style had
been affected by multiple sclerosis, in particular by the fatigue experienced
by all of them which curtailed the range of activities they were able to
enjoy and participate in.

Many sufferers were bored and experienced feelings of social isolation
similar to those expressed by other groups, such as housebound mothers of
young children (Oakley, 1975). The main difference was the lack of choice
of activities for the MS sufferers, partly due to problems of mobility and
partly to the fatigue associated with the disease itself which curtailed
to a very large extent their social life; whereas the mothers in the Oakley
study were physically able to leave their homes. For most of the respondents
whose sight had not been impaired by the MS, the television was the answer
to their pursuit of leisure and they spent a great deal of time watching
it. A few regularly took rests in the afternoon and they all mentioned
that they had to have cat naps sometimes during the day to recoup their
energy.

Most of the respondents went to bed fairly early, between 9.30 and
10 in the evening. Usually their evenings were spent watching the television
(like the majority of 'normals'), or sometimes they attended meetings such
as those of the MS Society. All the respondents had curtailed their social
engagements in the evening, on the grounds of fatigue or difficulty
of going out in wheelchairs. Some acknowledged that they felt bitter or
jealous at seeing people dance, play badminton, act, etc., activities that
they could no longer do.

Mrs. Morgan: "Then on Friday night I used to play badminton and my
husband was playing in a mixed match, and I did an unforgivable thing,
something I thought would never bother me, but it all came back. I was
upset and jealous of the thing because they had been playing and I can't
even walk - dreadful!"

Mrs. Kay: "But I can't dance, and people do try to heave me around
and I usually end up on the floor - but people - some of the young staff
(at husband's firm) do come and make me get on my feet and hold me under
the arm-pits and I do get around, so I don't miss out, but I do get upset

because I want to dance the same as everyone else, you know, having been very fit I miss it, I still do. The only thing I miss out on is badminton and squash and that sort of thing, of course, no one can hold me up to do that."

Weekends

For some respondents, the monotony and boredom of their everyday lives was relieved at the weekend when their spouses or relatives took them shopping, to the sea or visiting friends etc. Unfortunatley, not all the respondents were able to look forward to the weekends as times of company and entertainment. For those respondents who lived alone and were housebound the weekends were frequently periods of acute loneliness. They missed their contacts with such people as home helps, milkmen, postmen or attendants at the Day Centre. Instead they were marooned in their homes. The lack of social contact and attendant problems experienced by these respondents were particularly noticeable at times of public holidays.

Miss Gay: "I would put it in order of priority sustained care, by which I mean there are all the weekends and an awful lot of them. I would like to stress that I do not think that people shouldn't have holidays, of course they should, but I do think that nine days' holiday (reference to Christmas period) is too much. You cannot run a body like this, I mean you may be able to stop a factory or a shop, but we are bodies. A farmer cannot leave his cow, they must be milked morning and evening, because the milk gets re-cycled back into the blood stream. The body goes on and it's just as well if it does otherwise we would all be dead. You can't quite treat a human being in the same way. If you are a handicapped person, you do need some help. I mean, sometimes I can't move. When I was fit I could pick up a pail or a dust-pan or brush or do something. But not now. I mean, it's very frightening to be lying in bed and know that no one will come to see if you are all right until Monday. Like last summer, water dripping down from the first floor rooms. And there was nothing I could do about it, it's just got to come through until Monday morning. I think people should just check if one's all right."

The variety in the accounts of a typical day reflects to some extent the severity in the stage of the disease but also the personality of the patient. Two patients (one man and one woman) stated that they spent every day 'working'. One wrote children's stories and the other wrote poetry;

this activity was viewed by them as work, although obviously it did not
provide any form of adequate income. It may have been an 'escape route'
in which they were able to work through their frustrations and fantasies
(Cohen and Taylor,1977). Two other women were very active on a number of
local charities and committees and again they viewed this as their work.
The concept of work to these people is defined as a 'reason for living' -
activities that gave significance and meaning to their everyday lives.
It enabled them to no longer feel second-class citizens or under dogs,
non-productive in a capitalist and materialistic society. For they
felt that they could now contribute to the community and were performing or
working towards the social good. The respondents who did have 'a reason
for living' whether it was writing poetry, listening to their friends'
problems, helping out at a geriatric day centre by feeding the elderly
patients, or performing as a mother within the family unit, these were the
patients who had 'successfully' come to terms with the disease. The other
respondents whose everyday lives were to some extent stripped of meaning,
were more embittered about the impact of the disease and would often
make fairly depressed statements about, "I don't know why I bother to live.
I'm just a burden to everyone." Naturally, the ability of the MS sufferers
to fill their days in some meaningful way, not only reflected the stage of
disease and of personality, but also the resources available to them in
terms of transport, money and friends.

Friends and Neighbours

The multiple sclerosis sufferers, in common with other groups of disabled
people, experienced social isolation, although they needed social contacts
to help both 'filling up their day' and 'knowing what was going on around
them. Social isolation can be viewed as the process whereby the individual
increasingly becomes socially and psychologically separated from his or her
former relationships and social activities, with decreasing opportunities
for adequate replacement of old relationships and social activities (Davis, 1973).
The process by which these multiple sclerosis patients had become socially
isolated was gradual and not sudden. For example, one young woman had
written five letters to a former friend who failed to reply to any of them.
At first she had rationalised this and made excuses for the fact that the
friend had not replied, 'the post is bad, the letter got lost in the post,
she must be away on holiday'. Only gradually did she realise that her friend
no longer wished to be in correspondence with her and this deeply hurt her.

As has been previously stated (page 56), similar processes have been found in studies of bereavement. For example, Glick, Weiss and Murray Parkes (1974) found evidence of both permanent and temporary disruption of relationships of widows with their former friends. Many of the widows complained that a particularly painful aspect of their period of reorganisation of their individual lives was the withdrawal of some of their friends and social contact with them after having sworn steadfast solitude. Hence, they found that their previous social network had been reduced, particularly friends who had formerly been friends of the couple. By the end of the first year, they had established a very different sort of friendship network from that which they had maintained during their marriage. In the present study, the respondents and their families experienced a very similar process, that of a changed friendship network.

Underlying the general process of social isolation, is the change in the patients' relationships with others. Frequently the patients were unable to sustain the reciprocities in a relationship sufficiently to maintain it, in some cases the others defined the situation to focus on the patients' disabilities to the exclusion of their other attributes, and these relationships were rejected by the patients if they were unable to normalise or redefine the situation to their own advantage. Part of the problem is the patients' ability to maintain reciprocities and share similar experiences with the others. For example, one young woman could no longer go with her friends to a disco or play badminton or act in the local amateur dramatic society; another young woman was unable to look after her friend's children so that it would always appear that she was on the taking or receiving end of the relationship; and another man could no longer visit his friends who lived on the second floor of a block of flats.

Mrs. Earl: "... you do lose your social activities - well, I think they don't come because - for instance, friends we have got, we have got two friends down at Herne Bay - they are always asking us to go and see them but for me to go there, they live right on top of a hill, there are about five stone steps up to their front door, then a flight of stairs up to the toilet, which is very difficult. It is much easier for them to come to me. If I go and see my sister, this is quite a problem, so of course it sounds awful but, if people ask you to go and see them, you immediately say, well, where is your toilet? Is it upstairs or down? If it is upstairs, I am sorry I can't come. They think you are just being funny ...... it is just silly really. We find that, we came here to live on this estate. We thought it

would be nice and we like Faversham, but it is very lonely here because you never see any neighbours, the neighbours never come to you, they never knock on the door and say, 'How are you?' because they know that I have got my little car and they see me go out and about and I suppose they think, 'Oh, she's all right.' But they never, even at Christmas, didn't knock at the door and say, 'Happy Christmas', because it is an estate with young people with young children. They are busy - they lead very full lives."

Disabled people have a great need of friends for acting as sounding-boards or people with whom they can talk through their problems, both medical and social. The need for a listener was mentioned by a number of respondents who found that their spouses or relatives were either reluctant or unable to listen to their problems because of being too closely involved.

Mrs. Ball: "Lots of questions I think, to be able to talk to your friends about it or someone who is not emotionally involved is a good thing. They make you pull yourself together, they say 'Don't be so stupid'."

The MS sufferers' need for such friends were often unmet as people were reluctant or embarrassed to become too involved with them and yet clearly there was a need for special sorts of friendship or counselling of these patients.

The study's findings were similar to those of Davis (1973) in that those patients who developed multiple sclerosis in middle life maintained better relationships with others as they did not feel that having problems in health was incompatible with their expectations of this phase of their lives. When multiple sclerosis did occur in this age group, it generally did not progress as rapidly as it did in younger adults and it seemed to allow for fewer discontinuities in relationships with others, work and their self-conception.

A number of respondents in the study had changed their circle of friends since the onset of MS to include a significant number of multiple sclerosis sufferers. The changed circle of friends was partially explained by the disabled person expressing the opinion that they felt happier and more relaxed with their 'own', as they were understood and did not have to maintain all the social norms and reciprocities of social interaction. They felt that their 'own', other MS sufferers, accepted their definition of the situation and their conception of themselves, instead of coercing them

to reduce their self-conception or redefine it as was the case with normals. Sometimes the need for these special friendships did develop with members of the MS Society and other MS sufferers themselves.

Occasionally, these needs were filled by neighbours, although the majority of respondents tended to be fairly non-committal in terms of their views and relationships with their neighbours. Only one family who had lived in Faversham all their lives felt themselves part of a social network of neighbours who they had known for 'donkeys' years and would do anything for them. In contrast, one problem appeared to be that three of the families had been rehoused by the local authorities into more suitable accommodation, i.e. single storey buildings, but they had failed to establish new relationships and friendships with their neighbours and now felt intensely socially isolated. It was evident that the majority of the respondents were not living in close-knit communities (in contrast to Blaxter's study in Aberdeen) and that, although the neighbours were prepared occasionally to perform such tasks as shopping for them, they were reluctant to become emotionally involved in any way. There was very limited evidence of community or neighbourhood supportive networks.

Leisure

Barker et al (1953) showed that disabled people were not involved in as many physical and social settings as non-disabled people and consequently experience reductions in their opportunities for initiating social relationships. The variety of leisure activities available to any disabled person related directly to their resources, financial, and transport and the facilities offered by the local community. In the study area, the local community offered a range of clubs, including those specifically catering for the disabled or specific disease groups, for example, the MS Society. In addition to these, there were weekly swimming sessions at a local indoor swimming pool, Adult Education classes and, for the more severely disabled, attendance at a local day centre.

Swimming was found to be particularly beneficial to the MS patients.

Mrs. Field: "I get on smashing, I'm a good swimmer and I love it. You use all your muscles. In the water, you look like everyone else!"

Respondents attending the swimming sessions commented that it brought back to them a sense of independence and freedom as they found swimming mentally and physically relaxing. Studying for the Open University degree was an activity undertaken by two respondents who found it gave structure and meaning to their day such as watching Open University programmes and writing essays. They felt that they were involved in the whole educational process and that they were in some sense 'rehabilitating' themselves; in other words, they were in the process of redefining and restoring their self-conception.

Clubs catering specifically for a disease group, such as the local branch of the MS Society, were for the majority of the respondents one of their main sources of leisure entertainment, partly because the club provided transport and partly because the club functioned for an identifiable group with whom the respondents had or faced similar problems.

Mrs. Owen: "I find being with MS people a help. I go to the local MS Society. Last time we went for an outing to Aylesford Priory. Now that I have got multiple sclerosis I go out and I meet people. Before (prior to disclosure of the diagnosis) my world was 41 Westmoreland Avenue. I like talking and listening to those people. At the other meeting I did get a helpful hint. I spoke to Mrs. Lee about incontinence and she asked me how I was getting on. You know, what they were like (reference to the incontinence pads). 'Well,' she said, 'Put the pad inside your pants.' That was a helpful hint. You can talk about these things, it's nice if someone can help you with it. That's what I want."

The clubs which specifically cater for the disabled, for example, the Kent Association for the Disabled, the Physically Handicappped and Able-bodied Club (PHAB), attracted a number of the respondents in the study. All the clubs appeared to provide a social centre and entertainment for disabled people. Many of the respondents, particularly the older ones, stated that social contact was the main reason for attendance at such clubs. In contrast, the younger MS sufferers attended the clubs in order to be able to gain information and support from others who were their 'own kind'. These clubs did provide some information and welfare support for their members. However, a number of the respondents had rejected the clubs as places catering for the old and/or providing activities that they were not interested in. One woman commented that "playing bingo, having a cream tea and a nice sing-song" was not her idea of a jolly afternoon.

Multiple Sclerosis Society

The MS. Society was divided in its role and goals, for, at headquarters level, it was mainly involved in fund-raising and promoting public and professional education, whereas local branches functioned to a limited extent as a self-help group and social centre for patients. The MS Society in fact performed both supportive and educational functions identified in Gussow's (1976) paper on the growth of self-help groups in America. The problem with the disease specific groups such as the Multiple Sclerosis Society is that the commonality of the group is based on the fact that they are all multiple sclerosis sufferers, rather than any other factor such as a common interest in gardening or drama etc. Sometimes there did appear to be conflicts between the expectations of the members and those of the MS Society. However, the Society clearly did perform an important function of providing information to recenty diagnosed MS sufferers. All the respondents in the study had contacted the headquarters of the Society in order to ascertain more information about the disease. It was noticeable that the respondents claimed that they had had no information or advice provided to them by the medical profession. The act of contacting the headquarters of the Society did not however automatically result in them attending meetings at the local branch of the Society. Often there was an interval of at least two years between being told the diagnosis and contacting the MS headquarters for information and joining the local branch.

Miss Guy: "I wouldn't join the Society*. I didn't want to know, I was an ostrich I suppose, putting my head in the sand, I didn't want to know and I certainly didn't want to join any handicapped club or anything like that because I wasn't as bad as that. I was better than them."

Mrs. Apple: "You see I know a lot of people round here who have multiple sclerosis but they don't belong to the Society*. Now I can understand it but I think it's because they haven't really come to terms with it themselves."

The respondents' ability to face up to the fact that they had multiple sclerosis clearly took time and it was not until they acknowledged the social meaning of multiple sclerosis that they considered joining the local MS Society. Some had been reluctant to go to the club as they did not wish to see other MS sufferers who were more severely disabled and would provide evidence of what their future prospects were liable to be. Nevertheless,

* The respondents are referring to the local branch of the Multiple Sclerosis Society

all the respondents in the study had at least on one occasion attended a meeting at the local MS Society.

A few respondents did feel that membership of and attendance at the MS Society was stigmatising in that this was a club specifically organised for disabled people who were labelled and differentiated from 'normals' or the able-bodied. One person would not acknowledge to her neighbours that she was going to the MS Society meeting. Outings were organised and seats reserved for the MS group and, although in practical terms it is necessary to make special arrangements with theatres etc. to cater for disabled people, this organisational factor was thought to be stigmatising, particularly by the less severe MS sufferers. Respondents who attended regularly the club meetings, did seem to gain information, for example, handy hints on managing problems such as how a wheelchair-bound young woman could wash her baby or advice on the most comfortable kind of incontinence pads to buy. It also enabled some of the respondents to try out various strategies and to gain cnnfidence by experimenting with activities within their 'own' group.

Mrs. Earl: "Everyone does something, or most of them do. They start with, 'Oh, I don't think I can do anything because I'm disabled,' and I say, 'Well, so what? We're all disabled but we all do something. You don't have to do it but if you'd like to you're welcome,' and they usually ask me, 'Can I do this?'. I met a new lady yesterday and she said, 'I don't think I can do anything, I'm not very good.' So I said, 'Well, have a look round and see what you fancy.' And you know she ended up in the painting class. I fitted her up with a painting outfit and she was well away. She loved it. People don't know what they can do. They're afraid to attempt it themselves but if they see someone else they think well, if he or she can do it, perhaps I could, you know. And they end up doing it and they're quite good at it. Anyway it doesn't matter if they're not good at it, they've tried."

Another activity that clearly did go on at these clubs was the exchange of information on the success and failure of new ideas and treatment for multiple sclerosis. For example, there was some discussion of gluten-free diet. Experimentation with various diets and exercises were commonly tried out by the respondents who stated that, "If the doctors have given us up, we must try and do something. And Sunflower oil can't hurt you, you know, in fact, it might help. It helped my friend at the club." These various

self medication strategies adopted in the ideology of self help, are part
of the MS sufferers' ways of coping and managing with their illness.   All
the respondents expressed the attitude that, "You can't just ignore it, you
know.   You must fight it, otherwise you're done for!"   Clearly multiple
sclerosis was seen as a disease that had to be fought and if the medical
profession, as perceived by the patients, had given them up, they had to
find alternatives in the form of diet or exercises.   These activities were
important to them as they were outward signs to their family and friends
that they were 'fighting it' and trying to manage the disease.

Holidays

The high spot of many of the respondents' annual calendars were their
holidays.   Holidays were the opportunities of getting away from it all,
and for some of the respondents they were the opportunity to give their
family a break.   The respondents' discussion of holiday plans revealed a
great deal of information on the strains and tensions which they felt they
imposed upon their families by being disabled members of the family.
Some saw their holidays partly for their own enjoyment but also partly
to enable the other members of the family to have two weeks without the
burden of caring for them.   Most of the older respondents and the more
severely affected younger respondents, had taken the opportunity of going to
a caravan of the local MS branch at a caravan park close to the seaside, or
to a holiday centre catering for disabled people.   All appeared to have
enjoyed this experience immensely and mentioned that it had been a change
to meet new people.   The social contact of the various holiday centres was
particularly appreciated by the more severely disabled people who were often
socially isolated in their everyday lives.   The respondents did not appear to
find attendance at a holiday centre specifically catering for disabled people
as a stigmatising experience, instead they praised the facilities that were
laid on for them and the consideration that had been taken to cope with the sort
of problems that they had.   Also, they claimed that it was sometimes a relief
to interact with their 'own' as they found this form of interaction more
comfortable and less strained.

A few of the younger respondents had taken 'normal' holidays with
their families but they had often experienced a number of difficulties.
For example, long car journeys, the food offered at the hotel if they were
on gluten-free diet, spatial arrangement of the hotel, e.g. width between

tables in the dining room, and the stairs etc. One family had taken a
cottage on a self-catering holiday but the patient had found the strain
of cooking and going out on excursions had totally exhausted her. Multiple
sclerosis tended to force people into the adoption of certain routines
which enabled them to cope with their everyday lives. For example, taking
fairly frequent rests or only going out for two hours as that was the length
of an incontinence pad, and hence these were interrupted when they went
on holiday, and sometimes proved disastrous and too stressful for the patients
to cope with.

Caring Agencies

The two agencies with whom the respondents had most contact were the
general practitioner and social worker (apart from the home help service
which has already been discussed in another section). However, this contact
was not always viewed very favourably by the clients; the main criticism
levied by MS sufferers at both agencies was that they did not understand
what it was like to have multiple sclerosis and attempted to push the patient
into accepting their (social worker's or general practitioner's) definition
of the situation based on their stereo-types of the disabled.

Mrs. Earl: "I think doctors need to get to know the difficulties of
patients. You see, they only know the actual physical reasons for your
disability but they don't know always the problems behind it. You know,
the silly little things like, 'Oh, I can't get my shoes on or my stockings,'
that sort of thing, you know. They don't actually know .... the silliness
behind it because you do, ... when you're in a wheelchair, you can't reach
certain things. And you tend to get a bit frustrated because you can't
reach, but a doctor doesn't ..... he's not behind you and he doesn't know
all these little details and you can't waste his time by saying, 'Well,
you know, this is wrong or that's wrong.' You've got to try and cope yourself.
But if you had, as I say, a discussion group, they would get to know these
things more. Don't you feel?"

In the literature, there are a number of examples of conflicts between
the expectations of the clients and the caring agents. For example,
Mayer & Timms (1970), Byrne & Long (1976) and Blaxter (1976). In the
present study, one woman who was currently at the University, was asked
by her social worker, "Can't you find something else to amuse yourself

with at home instead of going to Kent?"

Mrs. Morgan: "No one will take me seriously - if I were all in one piece I don't suppose they would bother to question my motives, but because I can't walk properly, I suppose I could find something to amuse myself at home instead, but I don't want to. I want to be independent."

Other writers such as Scheff (1966) and Scott (1965) have both pointed out the ways that agencies use stereo-types of their clients which depend not only on the agency's goals and historical development but the market from which it seeks its resources. Scott found in his study of agencies for the blind in the United States, that there was an excess of services for children, employable adults and the totally blind, and an absence of services for the partially blind, the elderly and the multiply disabled. Fund-raising campaigns were necessarily projected in terms of stereo-types concerning youth, work and hope. Scott's description of the overall attitudes of society towards minority groups such as the blind or disabled etc. appeared to fairly accurately match the picture in this country (as discussed by Blaxter (1976)).

"Social welfare problems are, therefore, set within and responsive to, a variety of organisational and community pressures which are highly determinative of programmes, policy and implementation .... The causes of the specific problems, and therefore the needs of a handicapped person are not the same factors which determine what kinds of welfare services are offered to them. Clients' needs and the kinds of available welfare services run in two separate orders, which may coincide at certain points." (Scott, 1965).

Mr. Irwin: "We are all individuals, you can't pigeon hole us."

Although the disabled are now recognised as not being a homogenous group, it would appear that the various agencies operating in the field of caring for disabled people are continuing to use a global approach. The process of referral to social work agencies was usually via the general practitioner and hence meant that these professionals were operating in the context of a medical definition of the client's situation. Associated with this is the fact that few conditions or problems are static and unchanging, especially multiple sclerosis whose very nature and distinguishing feature is its vacillating over time. This meant that the patients, their families

and the caring agents were continually involved in the need to redefine
and renegotiate the patient's situation. Clearly this is problematic for
the social workers and general practitioners who may prefer to use static,
permanent concepts and definitions of their clients' situations. The
problem is that the multiple sclerosis sufferers, in common with other disabled
people, have nominally accepted categories offered by medical and social
work professionals in order to claim their various benefits and legitimise
their status. However, this definition is not the definition which is
meaningful to them or used by them in their everyday lives, i.e. they do
not think of themselves as disabled, but as people, men, women, mothers
etc., who happen to have a disability. Nevertheless, social workers, the
medical profession and local authority administrators, in their attempt
to meet the 'need' of various disabled groups, require and produce static
definitions which enable the administrative process to carry out the required
activity, i.e. to meet the needs of the disabled.

The major problems appear to be that the professionals' assessment
of the needs of disabled people are not necessarily shared by the
clients. There appears to be a danger of the professionals taking over the
initiative from the disabled person. Ideally the disabled person should
determine the timing and initiate the help-seeking process. It is important
for disabled people to be able to articulate the problems as they perceive
them and not have to accept a professional definition of their problems and
solutions to these. Professionals need to be available to advise and discuss
matters with their clients, but they should not decide what these problems
are for the clients. The danger is that the professionals become involved
in both stigmatising and devaluing disabled people by coercing them
into an acceptance of a stereo-type - the disabled person.

Mrs. Morgan: "It is no use trying to explain what my problems are
because, you know, there was this barrier and she wasn't prepared to sort
of lean over backwards to hear my side, and the sort of problems I had, the
fast that I perhaps did have higher expectations for myself and for my
children for the future - take no part in it, it's arbitrary, it has got
to be black or white - there aren't any shades of grey .... That's not
so good .... Social workers are not so good I don't think."

In addition, there is a shared assumption amongst the professionals
that the family will be the major coping and caring agent. However, this
is not always upheld in practice and in two cases in the study, the family

were very resentful at the pressure they felt was brought to bear on them
by the medical profession and the social workers to do their duty by the
MS patient.

Doctors

Attitudes to the hospital doctors were generally unfavourable, all
the MS sufferers were cross and embittered by the delay of the disclosure
of their diagnosis (as they perceived it) and the process of buck-passing
from one specialist to another (see page 25). After the specialist had
eventually announced that the patients had multiple sclerosis, the patients
felt ignored, abandoned and forgotten by the medical profession. "We are
an embarrassment to them, they want to forget about us. We are the forgotten
chronic sick, filed away under incurable."

A number of the respondents stated that they would like to have had
regular visits to the hospital to see the consultant. However, it is
questionable what the outcome or value of regular consultations at the
hospital would have been. Clearly the respondents felt that it would have
kept them in touch with the medical profession and when the 'break through'
occurs they would have been one of the first to benefit from it. Nevertheless,
the ways in which hospitals operate would have meant that the majority of
them would have only been seen by the junior medical staff, a group of people
who are usually changing every six months, and he would have probably only been
able to tell them their condition was the same or worse. It is questionable
the value of this information to the multiple sclerosis sufferer. Jobling (1977)
discusses his own experience of psoriasis and attending numerous out-patient
clinics "Over the years, I saw a bewildering succession of younger, junior doctors
who relied heavily on the 'notes' and a few standard questions for their assessment
and conduct of my case. Not only was responsibility for the failure of the
therapy diluted and dissipated thereby, it meant that no single, recognised,
known individual with whom one could build up suffieiently close relationship
to broach difficult questions."[1] However, the request for regular hospital
consultations can be seen in the context of the respondents' feelings of rejection
by the hospital consultants.

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[1] Jobling, R. (1977) Learning to Live with It. In Medical Encounters
eds. Davis, A. & Horobin, G. p. 76.

Mrs. Morgan: "Generally speaking, doctors aren't interested in diseases they can't cure, not really. My consultant is very very nice but I don't think they're really very interested in diseases they can't cure - whether it's any psychological reason I'm not sure but that's the impression I have."

Mr. Irwin: "The medical profession - they don't know what multiple sclerosis is. They don't know what the common cold is even, you know. It's as simple as that. I'm a cynic of the first degree, and if they don't know what's wrong with you - multiple sclerosis. You know. It's a good way of chickening out for the medical profession. You know, whether you've got multiple sclerosis or not is another thing. Perhaps I'm doing them an injustice but I would like to have known that I'd got multiple sclerosis earlier but they fobbed it off - arthritis, neuritis, and some nervous disease and it must be cramp and all sorts of things they fobbed me off with, you know. If they delay in saying it, straight out, they are just fishing you see, and buck-passing."

The majority of the resentment and hostility was addressed to the consultants rather than the general practitioners. The general practitioner remained the family's friend for most of the respondents, although two had changed their family practitioner after feeling that he had not taken their early symptoms seriously and had been unhelpful in advising them the best ways of coping with the disease.

A study by Firth (1975) illustrated the lack of knowledge general practitioners had of the services for disabled people provided by both statutory and voluntary bodies. The majority of general practitioners will have had little experience of coping with multiple sclerosis patients as they are unlikely to have more than two or three patients on their practice list and this would involve them in between 10 to 12 consultations per year (Office of Population Censuses and Surveys, 1974). There appeared to be an agreed view that something more ought to be done by the medical profession, but apart from the suggestion of an annual check up and a suggestion by three respondents that general practitioners spend more time communicating with them and counselling on their problems, these ideas were largely unformulated and unspecific in the minds of the respondents.

Nurses

Nurses act as important 'caring agents' in the community, however the respondents in this study seem to have had only limited and spasmodic contact with the community nursing services. The services of a district nurse were usually provided by a referral of a general practitioner rather than patient initiated. Hence the contact was made on the basis of a 'medical need'. For example a respondent commented "She only comes in, gives me an injection - she's in and out in a few minutes". The respondents claimed that they were rarely visited by a district nurse; and that on the occasions when the nurse came, she only stayed for a short time and carried out some minor medical procedure. This finding is in contrast to those of Blaxter (1976) and Sainsbury (1970) who both found that patients were benefitting from nurses extending their role into the provision of services which might be defined as social rather than medical, such as running errands, contacting agencies on the patients behalf, or giving the patient personal advice. These tasks were time consuming and had little to do with medical treatment.

The patients in the present study did not seem to have established the same relationship with the district nurse as noted in Blaxter's (1976) and Sainsbury's (1976) studies. This meant that with a scarce resource such as district nurses the MS sufferers, unless at the severe stages of the disease, had very little contact with this agency.

The respondents were generally favourable to the nurse and felt that they were receiving appropriate community nursing care, although their appraisal of her was from the viewpoint of her skillfully undertaking minor medical procedures such as giving injections. The only criticism to be voiced about the district nurses was by two women who felt that the nurses lacked sensitivity and understanding in discussing patient's problems such as incontinence. One woman described how the district nurse had openly and loudly discussed this 'waterworks problem' and displayed the incontinence pads to her, while two council men were putting up a rail in the same room. The respondent expressed her embarrassment and discomfort, firstly at having such a problem, and secondly at the public disclosure of it by the nurse.

Although the district nurse was defined by the respondents as acting as a medical rather than a social agent; they had a limited conception of her role. For all the patients the doctor remained the key figure in relation to medical problems associated with M.S. They did not want to discuss in detail either their medical or social problems with a nurse.[*]

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[*] The general public's limited boundaries of the role of the nurse in the general practice setting are discussed in a paper: Cunningham (1977)

Social Workers

There was a great deal of criticism about social workers who appeared to 'carry the can' for everybody. This can partly be attributed to the respondents' confusion and inability to distinguish between social security, social work departments and voluntary social services etc. Many respondents misunderstood the functions of social workers and this is similar to the findings in Blaxter's study (1976) and may have accounted for the high level of dissatisfaction mentioned in the study by Johnson and Johnson (1977). The social workers' infrequent visits and lack of knowledge and understanding of the problems faced by disabled people were mentioned by all the respondents. Many respondents felt that the social workers did not provide enough assistance or a correct evaluation of both the practical and emotional adjustments to disability. For example, one couple were rehoused in a bungalow heated by coal fires, neither the wife suffering from multiple sclerosis, nor the husband with a heart condition could carry the large quantities of coal into the house or easily maintain the fires.

Some respondents felt that the social workers devalued and stigmatised them by 'bringing everybody down to a common denominator."

Mrs. Morgan: "By the time she (the social worker) had gone, I wished I could have hidden the colour television and that sort of thing. She made me feel as if I was too materialistic and I had no business to have things as I was ill and must cut my coat according to my cloth. She piled the onus of my house onto the shoulders of my children. I think she must be all in favour that by hook or by crook I should be dragged down, that my children shouldn't go to piano lessons and ballet lessons because I can't afford it now and I thought, 'well, that's my business' and I thought they ought to go. I don't see why they should suffer. I thought, 'Well, really, it's no good trying to explain my problems to her'."

Mrs. Kay: "This must be so because you don't - you are not told about the things you see, and if you happen to find out, by chance usually ..... you are usually fobbed off by something or other. People rarely say, 'Ah yes, I know about that.' They say, 'Speak to Mr. so and so, of such and such department,' so you get put through to this department. 'Ah, it is nothing to do with me, you must speak to so and so of so and so.' 'Oh, it is nothing to do with me, try so and so,' and by the time you have been put through to about six people, none of whom have any idea what you are

talking about, you think, why do I bother? I 'phoned up about my home
help when I first couldn't walk - the voice at the other end said, 'What
size of house was it?' 'Four bedroomed.' 'Oh, quite a big house.' And she
said, 'it was a pity I didn't live in a one-roomed flat wasn't it,' which I
thought was gross impertinence but I didn't say so at the time."

Mr. Irwin: "They don't want to know you, that's the social workers,
really I'm sure some of them are helpful but they say we've over-spent our
annual expenditure and that's it."

Mrs. Irwin: "I think the thing that really gets my back up
about the social worker is that she was talking about going in and she said,
'Of course, you're very fortunate, you know.' And I said, 'Yes, thanks
to us looking into the future and moving when we did.'"

Mr. Irwin: "Yes, you see, we anticipated this."

Mrs. Irwin: "Because we tried to help ourselves financially
and not go begging, people just don't want to know. People but social
workers as well, take sympathy on those that live in council houses and
try and get everything."

These respondents stated that the social workers were unsympathetic
to their plight and unable to understand the sacrifices that they had made
in their attempts to prepare for the future. For example, moving from a
house to a bungalow. The attitude that, "You're all right. What are you
worried about?" was claimed by the respondents to be expressed by a number
of social workers who clearly had not been very well informed about the
problems of multiple sclerosis. Hence there was a great deal of criticism
of social workers who appeared to be trained to be problem orientated, to
solve the problems identified by them (in some cases rather than by the
client) through case work. Whereas, for a number of disabled people,
the problems can be solved by the allocation of aids and finance to enable
them to improve the quality of their lives. Clearly social workers are
not trained in the counselling of disabled people and there is a great need
for them or other qualified professional counsellors to meet this need
experienced by disabled people.

Voluntary Agencies

The agency found to be most helpful was the voluntary associations;
for example, the local branch of the MS Society, whose activities and
services differed from those of the doctors and social workers in that the
former discussed everyday problems in detail with the MS sufferers and negotiated
or provided a lay version of the medical explanation. They did not encourage
an acceptance of the disabled role, nor did they provide an alternative
to the official morality. Instead they taught the members to recognise
the existence of external problems but not necessarily to accept them.
To fight multiple sclerosis seemed to be the slogan of the members of the
MS society and that is exactly what they did! Other voluntary organisations
such as Red Cross, Women's Voluntary Service, 'Meals on Wheels' were
praised by the small number of respondents who received their services.

Possible Solutions to some of the MS Sufferers' Unmet Needs

Therefore, it would appear that there is clear evidence of a need
for self-help groups who would be involved in self education and would be
disease specific groups. The majority of the Multiple Sclerosis Society's
local branches seem to provide social contact for their members rather
than a forum for discussion for the illness with which they all suffer,
although some respondents mentioned exchanging ideas and advice about ways
of coping with the problems of disability. There is a need to explore ways
by which multiple sclerosis sufferers and other people suffering from
chronic diseases could meet regularly to discuss the problems that they
experience. As has been stated, the regular attendance at out-patient
clinics would not appear to be the answer. However, for a self-help club
to invite a consultant to come and discuss with the members the neurological
problems associated with multiple sclerosis would appear to have some value,
in that most of the respondents mentioned the fact that they would have
liked more discussion about the disease. The MS Society did provide
a great deal of medical information about this disease. Nevertheless,
the respondents would have liked to discuss the significance and meaning
of this information with a qualified person. It is possible that a register
of diseases should be kept by general practitioners so that they would be
aware of the patients on their lists who suffered from these various chronic
disabling illnesses. In addition, there is a need for an information document
such as the one produced by the Spinal Injuries Association in which a whole
range of medical and social problems are discussed (Fallon, 1975).

An alternative solution currently being tried out in America is the establishment of a centre designed to cope with the rehabilitation in the broader sense of multiple sclerosis sufferers (Harting et al, 1976). The centre is staffed by neurologists and clinical psychologists with access to a consulting physician. It aims to relate the medical management of the patient's condition to the understanding of the disease and its implications and expectations. It also attempts to clarify the patient's family's understanding of multiple sclerosis in terms of the impact on family life, vocational planning and inter-familial relations. The staff discusses practical problems stemming from the multiple sclerosis condition such as physical control, mobility, fatigue, bowel and bladder control, to sexual functions and functional adjustment. It provides MS patients with an opportunity to share their experiences with other MS patients. The centre adopted the belief that by communicating and giving accurate information to multiple sclerosis sufferers and allowing them to share their emotional experiences and discuss common problems has resulted in the MS sufferers making more informed, adjustive responses to their disability. Harting produced evidence to show that MS sufferers quickly cohese as a group and discuss the common characteristics of their condition and its impact on their lives. Frequently, these individuals were able to gain a more realistic perspective on the condition and sense of belonging to a group who were also experiencing similar problems. The establishment of such a group is in line with what Goffman called 'own' group in which alternative definitions of their situation are offered to the members. Although the scheme has only been operating for a short while, already physicians and psychologists are claiming its success.

In Britain at present, there is to my knowledge no such scheme as that reported by Harting. However, the MS Action Group has set up a telephone counselling service for MS sufferers. It has been in operation for a year and it claims to have helped a large number of victims to solve or even talk through problems ranging from how to get an attendance allowance to coping with feelings of being blue and suicidal.*

In addition, the MS Society has recognised the need for establishing local self help groups and has launched the CRACK programme which is

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* Personal Communication - Sally O'Connell, secretary of the MS Action Group.

specicifically to set up local groups for the younger MS sufferers. These
groups aim to provide social contact such as meetings in pubs or visiting
each other's homes and opportunities for young MS sufferers to discuss
their problems. The idea is to exchange ideas and share experiences.
In addition a number of articles have appeared in the newsletter produced
by the Society in which problems faced by young sufferers are discussed;
for example, the pros and cons of having a baby if you are an MS sufferer
and what to tell the children about their father having multiple sclerosis.
(Davoud, 1975) This scheme is at present in its initial stage and it is
impossible to comment on whether it is fulfilling some of the needs expressed
by the MS sufferers in the study.

CONCLUSION

This study of a small group of MS sufferers has thrown some light on problems experienced and perceived by the physically disabled themselves. These include changes in family membership status, the seeking and social significance of a diagnosis, felt stigma and attempts to cope with it, social isolation and alteration of friendship networks.

One of the most significant problems to be voiced by all the respondents in the study was that there had been unnecessary delay between the time the medical profession reached a diagnosis and the time the consultant or G.P. told the patient. Although, in this study, it was impossible to validate such statements, the finding that the majority of the respondents spontaneously complained of the delay in the disclosure of the diagnosis, and that some had even resorted to opening the consultant's letter to their general practitioner or self-diagnosing after having read an article on the disease, provided some support for the identification of this as a problem area. Also a number of studies (Fletcher, 1973; Byrne and Long, 1976) have shown the inefficiency of doctors as information givers. The respondents explained that it was only after having been told the diagnosis that they were able to begin to adjust or accommodate to their disability. The diagnostic label was important as it legitimised their strange behaviour; such as falling down, inability to pick up small objects, and unsteady gait, and gave back to the patients their credibility. There was a general consensus amongst the respondents of experiencing relief on hearing the diagnosis, and one woman said, "Well, it's nasty, but it can't kill you. It's not cancer!" Although the uncertainty of the diagnosis in the early stages of the disease and the public image of the disease as always crippling raises problems for the doctor, there is a case for further consideration of how best and when to inform the patient about the diagnosis.

All the respondents challenged the idea that they had altered their self-conception as a result of their realisation of their disability. They all claimed that, although their bodies were disabled, it had not affected their minds or their personalities, "I am just the same under all this." Although they all categorically claimed that they had not changed as a result of being a multiple sclerosis sufferer, they did feel to a greater or lesser degree that relatives, friends and professionals had all attempted to get them to accept a dependent, subordinate role which implied the internalisation of a disability identity and an exhibition of dispair at their plight. Bolding (1960) suggested that the self image of a multiple sclerosis patient is a compromise between the present state and the feeling that ultimately he will become a helpless, devalued person, unacceptable in

the eyes of the person(s) to whom he looks for much needed support. Bolding found his patients acutely concerned about the possibility of future loss of somatic or intellectual functions because of the progression of the disease. In the present study, the respondents rarely expressed such a view, most of them lived for the present and refused to face or consider the future. It is possible that, in a non-structured interview, it would be very difficult to explore the psychological feelings and motivations of MS patients and that, in fact, it requires a psychologist to explore this area. However, patients did discuss their concern about the impact on their children of having a mother or father who was disabled. They discussed the major problems resulting from the two unusual features of multiple sclerosis, the remission or exacerbations which cause enormous adjustment problems for the patient and the patient's family and close friends. This placed a major strain on marriages and married respondents in the study discussed this at great length, and stated that they had not been assisted in their marital difficulties by any professionals.

The provision of information and professional counselling of multiple sclerosis patients and their families would have been welcomed by the patients and might have alleviated a number of their problems. At the present time, any counselling or advice giving to MS sufferers seems to be done on an ad hoc basis with no one professional group taking responsibility for it. The Multiple Sclerosis Society is performing a valuable service by providing for its members information and guidance about the disease. Nevertheless, the respondents would have liked the opportunity to discuss this information and perhaps local MS branches should begin to question whether their function is to provide an entertainment and social centre or establish discussion and self-help groups. The MS Society has established a movement for its younger members, CRACK, which may fulfill this purpose. However, it is too early at the present time to examine this. Even if it does, there remains the responsibility for a professional, either consultant, general practitioner, district nurse or social worker to take up the task of informing the family about mulitple sclerosis and its impact on the patient. Perhaps the MS Society should consider its role in influencing the understanding and knowledge of the professionals and in identifying locally professional workers who would be prepared to meet groups of MS patients.

In the study, it was found that a medical diagnosis such as multiple sclerosis was significant to the patients only at the early stage of the disease as a way of legitimising their strange behaviour. It significance

became markedly reduced and in some cases almost marginal as they began to
learn to live with it. The majority of respondents found that on the whole
the general public's lack of knowledge of and the pessimism of the public
image of multiple sclerosis have meant that to acknowledge the fact that
you were a multiple sclerosis sufferer was in most cases unhelpful, and in
some cases only produced expressions of gloom from the 'normals'. The
general public seemed to have very limited information and understanding
of this disease and its impact on the MS sufferers. This was regretted
by the respondents who thought that there was a need to educate the general
public to view multiple sclerosis from a positive and optimistic view-point
rather than from the negative image of a 'wheelchair-bound, incontinent
cripple'. The patients felt that, if the public had a more favourable public
image of multiple sclerosis, they would not view the patient as such a
tragedy and would be less inclined to pity or feel embarrassed in social
encounters with them.

All the respondents had found that there had been changes in their
social network of friends in that some friends had withdrawn from them and,
on occasions they had withdrawn from their friends. The respondents had
found the experience of their friends no longer maintaining contact with
them to be very upsetting; particularly as their need for friendship and
understanding was greatest in the period immediately after they had been
told the diagnosis. The MS sufferers felt that the breakdown of these
relationships had often been caused by their friends' embarrassment and the
resultant strained interaction between them. MS sufferers also found
difficulty in maintaining the reciprocities of social relationships. Here
again, the respondents thought that some of the embarrassment and difficulties
in social encounters that they experienced could be overcome by more
education of the general public about multiple sclerosis and that this
publicity should stress the positive rather than the negative picture of
the disease, for example, by drawing attention to the remission years.

The concept of disability and its relevance to the MS sufferers was
to a large extent self-defined and self-fulfilling. Lees and Shaw (1974)
noted in their book that, in a number of surveys of handicapped people,
respondents had declared themselves non-impaired when they had had obvious
impairments. Respondents in the present study acknowledged that they were
MS sufferers in the first instance and that they were disabled mainly in
the context of medical and social service definitions. In other words,

the concept of disability seemed to be an administrative term without any real significance or meaning for them. The label was used by them on occasions when the respondents were faced with administrative bureaucracy, of, for example, the Health and Social Services, when applying for alterations to home, provision of wheelchairs, or attendance allowance. The MS patients accepted that they had a disability but would not accept that they were disabled people, rather they saw themselves as men or women who happened to have a disability. They rejected the attempts by relatives and professionals to impose onto them and their way of life a stereo-typical concept of a disabled person. This study has shown that there are differences between the social meaning of disability as perceived by official bodies and by the patients themselves. The professionals' use of clinical or administrative definitions of disability may result in differentiating the disabled from the non-disabled and thereby stigmatising them.

Some of the problems experienced by the MS patients stemmed from the social construction of disability rather than from the physical disability itself. The physically disabled person is made aware of his devalued status by the reactions of others and he has to learn to face and to cope with the social and psychological consequences of his disability, which may necessitate him changing his life-style and friendship networks. The task of learning to cope is not always successfully achieved and in many instances the respondents withdrew from social contact rather than face a situation in which they felt themselves to be stigmatised. The disabled need to be able to show the normals their ordinariness and this requires self-awareness and resources in that they have to be able to 'break-through' the embarrassment and hostility exhibited towards them by normals; some manage to do this and yet others fail and become socially isolated. This study was not able to explore in great depth why some fail and some manage to cope. However, it would seem that this cannot just be related to personality traits and there is a need for more research to explore the possibility of training disabled people to cope in social and psychological terms with their disability as part of their rehabilitation.

There was some ambiguity about attendance at clubs; many of the respondents attended clubs for the disabled, although they did not see themselves as disabled and did not associate the club members as 'their own'. In other words, the club was seen as a place that offered a social centre and certain facilities, but this did not mean that there was a sense of identity between the MS sufferers and the other members. Whereas, their attendance

at the Multiple Sclerosis Society was viewed as interacting with 'their own'.
"We understand it and help each other, you know. We've all got it."

The danger as perceived by the MS sufferers with an acceptance of the
label 'disabled' was that it stigmatised them, by allowing people to treat
them as second-class citizens and non-productive members of the community.
Nevertheless, their rejection of the label did produce its own problems in
that some of their actions were misunderstood by normals and sometimes
normals failed to respond to their non-verbal requests for help. MS
sufferers had the difficult task of deciding whether to conceal or reveal
their disability. They weaved their way in and out of the coping strategies
of passing and normalisation, depending on the social context in which
they were interacting. The use of coping strategies largely depended on
whether the social event was perceived by the members as marginal or central
to their own personal social world. The severity of the disease is another
factor as MS sufferers in the more severe stages would be unable to attempt
to pass. Evidence from other studies (Jordan, 1973; Zahn, 1973) showed
that relatives and caring agents were able to cope much better with disabled
people once they had acknowledged their devalued status and accepted their
reduced life-style. In the present study, there was some evidence that
spouses had attempted to coerce the respondents into a dependent, subordinate
status within the family unit.

The MS sufferers were found to experience felt stigma and saw their
disability as a potential threat to social interaction. The vacillating
and unpredictable nature of the disease sometimes resulted in the exhibition
of unusual and unpredictable behaviour which disrupted the customary
pattern of everyday life and drew attention to their disability. It was
this that the MS sufferers found problematic and which made necessary a
decision whether to reveal or conceal the true identity of their disability.
It is interesting that the MS sufferers did feel themselves to be socially
stigmatised and provided a number of examples of behaviour that they interpreted
as prejudicial against them. Blaxter (1976) found that "the perception
of stigma appeared to depend very much upon the nature of the impairment,
it was strongest in all those conditions which threatened the taken for
granted world of everyday interaction."* The people in her sample who
felt most strongly their disability was a stigma were those suffering from

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* Blaxter, M. (1976) Meaning of Disability. page 198.

ataxias, spasticity, severe multiple sclerosis, deafness, blindness and
epilepsy. The respondents in the study stated that they had become aware
of the stigma attached to their disability and that it was problematic in
an interactional context, in other words it was when they were confronted
with other people, particularly strangers, that they were made aware of their
inferiority and devalued status. Hence it was on such occasions that the
respondents had to consider the potential problems of encounters with
strangers; for example, an invitation to supper or to a theatre required
the respondents to pay attention both to the practical problems of length
of journey, availability of toilet facilities etc. and also to consider the
sort of people who would be there with respect to the respondents' potential
for the adoption of various coping strategies to either conceal or display
their disability which was based on the actors' assessment of the situation
and of the other actors in the social setting. In extreme cases, the MS
sufferers' decision to conceal their devalued attribute had resulted in
them withdrawing from all social settings, so that in some cases the social
isolation of the MS sufferer resulted directly from the stigma they felt
was imposed on them by 'normals'.

The circumstances under which impairment is recognised as disability
varies according to the capabilities of the individual and the situational
requirements, such as flexibility of role requirements, availability of
alternative role occupants and willingness of reciprocal role members to
accept modifications in their role requirements. Age is one of the important
variables as it is related to respondents' evaluation of their capabilities and self-
conception; Haber (1970) found that older disabled men have a lower evaluation
of their working ability and self-esteem compared with younger disabled
men. In the present study, the attitude of the MS sufferers did vary by
age, in that the older respondents were more resigned to accept a dependent
status and more concerned with being cared for, while the younger respondents
were concerned to find a cure and were more likely to feel stigmatised.
Similarly, Hyman (1970) and Singer (1974) found in their studies that younger
people were more likely to feel stigmatised than older people.

Haber (1970) found that women, older people, the less educated and
unskilled workers had the least adaptive capacity and ability to face the
demanding requirements caused by disablement. He found that functional
limitations were a primary consideration in the evaluation of disability
and in a later paper he and Smith (1971) argued that the focus of rehabilitation
services should be on an elaboration within the existing role relationship
rather than a proliferation of special role repertoire. This requires a

successful renegotiation of definition of the situation between the husband
and wife and Fink's study of a group of disabled women (1968) shows that
role ambiguity and ambiguous unshared expectations were often related to
reduced need satisfaction and marriage satisfaction. The severity of the
physical impairment was not the crucial factor, but what appeared to be more
important was the state of the relationship within the marriage.
In the present study, all the married respondents felt that their marital
relations were strained due to the fact that they were now MS sufferers
and they gave no indication of marital tensions prior to the onset of their
disability; naturally, it was impossible to pursue this point further.
However, the evidence of tension and strain in the marriages of all the
married respondents does illustrate the need for counselling of MS sufferers
and their families.

It was noted that financial considerations did play a significant part
in that problems associated with disability were not nearly as onerous in
the cases where the respondents were financially well off and able to buy
such additions as convenience foods and goods, for example, a deep freeze or
Kenwood mixer.

It is acknowledged in the literature that disability affects not only
the individual but also the whole family. All the respondents spontaneously
mentioned that they would have liked more information themselves about the
disease and in addition they felt their families needed a better understanding
of it. In recent years, writers such as Feldman (1974) have argued for a
new holistic model or rehabilitation in which the individual receives both
necessary diagnostic and therapeutic treatment, and rehabilitation care which
is orientated towards the psychosocial functions and maximum quality of
life. The wholeness of the model confirms the value of the patient as a
human being and places the meaning of illness as a personal event to the
patient. In America, a new centre has been set up to cope with the rehabilitation,
in the broader sense, of multiple sclerosis sufferers (Harting et al, 1976).

It would, therefore, appear that successful adaption to disability
depends not only on the individual's techniques and abilities to develop
coping mechanisms, but also on the resources and the organisation of the
immediate family and the wider social structure. Despite the expansion of
the social services since the late 1960s, the aim to meet all needs of the
disabled remains largely unmet. In this study, the multiple sclerosis
patients have had the opportunity to voice some of the problems and the needs

of disabled people as they see them. They discussed the social reality of dealing and living with disability. There are a number of areas which this study has highlighted and which clearly requires further research.

(1) There is the need to analyse the timing and process of disclosure of the diagnosis such as multiple sclerosis. In conjunction with this, there is a need to understand the difficulties and reluctance of the medical profession to pronounce the diagnosis to the respondent, particularly in the light of the fact that the respondents in this study stated that, before they can adapt or adjust to their disability, they need to have their condition legitimised by a clinical label or diagnosis.

(2) There is a need to study the availability and the nature of information and supportive services currently available to the MS sufferers and their families and to consider ways in which these can be improved, with particular reference to exploring the possibility of the development of self-help groups and discussion groups involved in imparting information and advice to fellow sufferers.

(3) To explore the possibility of establishing counselling services in which groups of MS sufferers and their families could get together to discuss either individually or as a group their problems resulting directly from multiple sclerosis. It is possible that, if these groups incorporated a trained counsellor, they may be able to develop teaching programmes on the various coping strategies and skills which disabled people can use in interaction with others. It would appear that an important part of rehabilitating any disabled person, whether they are suffering from a progressive disease or not, is to enable them to develop social and psychological strategies of coping with social encounters. As John Donne stated, "No man is an island," and disabled people need to be able to learn to manage their presentation of self. They must learn to be able to control their ability to conceal or reveal their devalued status.

Although at this present time it is unknown whether such
skills can be learned, it would appear to be a very valuable
area to explore, as so many disabled people are socially
isolated because they have withdrawn from the social
world in which they feel stigmatised and, if they could
learn interactional skills for coping with such embarrassing
or strained interaction, this would enable them to lead
a much fuller life, and perhaps no longer feel alienated.

(4) There have been a number of articles (Warren, 1970;
Johnson and Johnson, 1977) recommending the establish-
ment of centralised medical and social services for
the disabled.   The type and functions of the clinic or
centre are debatable.   Johnson and Johnson (1977) argue
for an assessment clinic offering regular check-ups to
disabled people and, in contrast, Warren (1970) discusses
a broader concept of a centre offering a broad range
of information and advice to disabled people and their
families.   It would seem an appropriate time to test out
some of these ideas in experimental clinics or centres,
and to evaluate their success or failure from the disabled
person's view-point.   Some of the methods used to collect
data in the present study, with small modification, could
be used to evaluate such an experimental scheme by
providing data on the self-perceived problems and needs
of the disabled and comparing these with the data from
the experimental centres.

Although these problems and needs have been identified in an exploratory
study of a small group of MS sufferers, their relevance is not specific to multiple
sclerosis.   Diseases such as diabetes, rheumatoid arthritis or muscular dystrophy
could be explored within the context of these problems.   The aim of this explorator
study was to identify some of the self-perceived problems of a small group of
disabled people, multiple sclerosis sufferers.   The findings of this study are
broadly consonant with the results from a number of other studies of disabled
people, for example, Blaxter, 1976; Topliss, 1975; and Sainsbury, 1970.   Together
they can provide policy-makers and caring agents with insightful data about
the ways in which the services could be improved or changed to make
the disabled people and their families adjust and cope with their disabilities
and to make their lives as normal and as worthwhile as possible.

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