UNIVERSITY OF SOUTHAMPTON

The Rehabilitation Process: A Study of a unit for the physically disabled

Terence Julian Scragg

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ABSTRACT

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THE REHABILITATION PROCESS: A STUDY OF A UNIT FOR THE PHYSICALLY DISABLED

By Terence Julian Scragg

This thesis is concerned with rehabilitation services for physically disabled people. The main location for the research was a regional medical rehabilitation unit. Additional fieldwork was also undertaken in a spinal injuries centre.

The aim of the research is to examine the rehabilitation process in order to more fully understand how the process is perceived by patients and staff of the unit. The research based on an interactionist perspective used methods of observation and interviews with a small sample of patients and staff. Interviews were also conducted with patients and staff of a spinal injuries centre.

The findings of the research, from both the unit and the centre, suggest that rehabilitation units provide programmes that are based on the medical model and that this influences the treatment of patients. These treatments are primarily the remedial therapies with their emphasis on physical restoration. A consequence of this focus is that psychosocial aspects of disability, which are considered to be equally vital in the lives of disabled people, is almost totally neglected. This neglect is a result of a lack of appreciation of the needs of disabled people, and a service model that does not prepare staff to work effectively in the psychosocial areas of disability.

A range of techniques are described which have been found to be effective in rehabilitation services and could be introduced into units in order to counterbalance the current programmes, and enable staff who are appropriately trained and supported to meet the wider needs of disabled people.

1 BACKGROUND TO THE STUDY OF A REHABILITATION UNIT

Historical Changes in the Focus of Rehabilitation

The origins of rehabilitation services can be traced back some sixty years. Even at the end of the nineteenth century concern was shown for the occupational needs of injured men who had fought in the Boer Wars, with the establishment of the Lord Roberts Workshops. Injury on a more massive scale during the First World War of 1914-18 stimulated many pioneering rehabilitation regimes, mainly in military orthopaedic hospitals, and the formation of provisions, such as the Artificial Limb Service (Taylor 1977).

Between the Wars the main initiatives were found in centres developed by the Miners Welfare Commission which set up early rehabilitation units in the 1920's. Many of these developments were concerned with orthopaedics, and orthopaedic surgeons were in the forefront of developing techniques to reduce the impact of disability in the individual (Lee 1975). With the onset of the 1939-45 War there was a strong shift of emphasis towards vocational rehabilitation, with physical medicine developing a role alongside other specialist services. Following the outbreak of war the movement of personnel into the armed forces meant many vacancies were left in industry and commerce. Some of these vacancies were filled with disabled people who were previously unemployed. But the transition from unemployment to working status was not always straightforward. The (then) Ministry of Labour and National Service inaugurated a scheme to provide training and resettlement of disabled people. As a result of the concern to establish a coordinated approach to the needs of all disabled people whether ex-servicemen or civilians the Tomlinson Committee (1943) made its recommendations.

The Tomlinson Committee examined medical rehabilitation, post-hospital and resettlement services. It emphasised that the effective physical and mental rehabilitation of the disabled person required the services to provide continuity of treatment. It also stated that a large proportion of people were capable of work or could be 'reconditioned' to overcome their unfitness for work. The Report also recommended that a country-wide network of special residential centres be established to meet the needs of those people who needed 'reconditioning' where they could be assisted to full recovery on a short course. The first Industrial Rehabilitation Unit (IRU) was opened in 1943 on an experimental basis. The subsequent Disabled Persons (Employment) Act 1944 empowered the Ministry of Labour and National Service to arrange industrial rehabilitation courses for disabled people (Cornes 1982).

It is clear from the foregoing that the current rehabilitation services were born in very different conditions from those they find themselves operating in today. The rehabilitation services were originally set up to deal with a national crisis, and their intervention was of a crisis nature. The typical wartime rehabilitee was a young to middle aged man suffering from injuries received in action, and was still under military discipline at the time of referral. The rehabilitation services grew up essentially within the context of techniques developed for servicemen following traumatic injury. The emphasis of these techniques was the rapid repair of the serviceman in order to return him to active service, or if discharged from military life to enter some form of occupation that enabled economic independence to be achieved.

However services developed in the context of the wartime emergencies of the first half of the twentieth century, and to a lesser extent, the requirements of particular civilian working groups, such as coal miners, are no longer appropriate (Hyde 1979). Patients referred for rehabilitation in the 1980's are mainly civilians of either sex, and of any age, with injuries accounting for only five per cent of all referrals (Carver and Rhodda 1978). Patients in need of rehabilitation are primarily physically impaired by 'progressive or fluctuating conditions including - lung disease, cardiac conditions, arthritis, mental illness and an unnecessary degree of deterioration in old age - rather than by the stable conditions more usually called disablement in the past' (Blaxter 1976 p.4).

Alongside the changes referred to above, shifts in social and economic conditions of a permanent nature have taken place, particularly in the area of work, with large scale unemployment that has significantly affected disabled people - whose unemployment rate is twice that of the non-disabled. There is evidence that many disabled people who are capable of working cannot secure employment, and that others take jobs that are unsuitable, and often less satisfying than the work they did before. For many people disability starts a downwards spiral into under-employment, absenteeism and finally long-term unemployment (Blaxter 1979). The move away from the stable handicaps of the past to looser definitions of disability, and the changing economic climate in employment makes it increasingly unlikely that rehabilitation objectives based on the repair of the human machine and return to economic independence are realistic for many of the disabled people now referred to rehabilitation services.

What Rehabilitation Sets Out To Achieve

The essential feature of a rehabilitation programme is the restoration of function, either naturally or artificially, through a training process in which the patient slowly learns new ways of performing basic functions. The process of rehabilitation is highly complex and involves factors beyond mere restoration of performance to some pre-morbid level. It involves rehabilitation of the spirit as well as the mind, and consideration needs to be given to the individual's morale and relationship to the society in which he or she lives and to which they are to return.

Nichols (1974), has divided rehabilitation into two types. Firstly, the management of patients with temporary disabilities who require intensive rehabilitation immediately following initial medical treatment which results in rapid return to work or home independence. Secondly, there is the rehabilitation of disabled people who have suffered major trauma, or with chronic and deteriorating conditions, where maintenance and support play an important part in the overall approach, and aims may be limited. The main aim is to return patients from hospital to the community and maintain them there, and wherever possible prevent them being re-admitted to hospital, except for specific treatments. Increasingly, these definitions of rehabilitation are seen as too limited. Rehabilitation is seen less as a primarily medical concern with its focus on rapid bodily repair or management of medical conditions, rather as an activity that takes cognisance of the individual and his environment. This approach demands an understanding of the interaction between diseases and disability, the individual and the community, and requires a broader ecological approach by professionals and others concerned (Mair 1972). Rehabilitation is seen as having a strong component that is concerned with supporting the disabled person to overcome problems in his social environment as well as problems within himself.

Where Does Rehabilitation Take Place?

Rehabilitation takes place in many settings, both within general hospitals, specialist units and the community. Medical rehabilitation is essentially a hospital service usually under the aegis of a consultant in rheumatology and rehabilitation. These hospital based services normally include physiotherapy, occupational therapy and speech therapy. In addition, social workers and psychologists make up the rehabilitation team. This approach to rehabilitation under the direct control of a clinician and based mainly on physiotherapy and remedial exercises is seen in a pure form in the specialist medical rehabilitation units. The main focus of these units after the acute phase of medical treatment is completed is concerned with reablement - the improvement of functional activities and resettlement in work or home.

Although rehabilitation units offer a specialist service to patients identified as needing the comprehensive facilities available, for the most part and for most patients however, rehabilitation takes place in the community. Much of this work mirrors the activities of the specialist units, with remedial therapists and other specialist staff based on domiciliary settings providing rehabilitation procedures in an out-patient clinic or the disabled person's own home. The rapid development of the personal social services in the 1960's and 1970's and services resulting from the Chronically

Sick and Disabled Persons Act (1970) requiring local authorities to provide services for disabled people, has created a range of rehabilitation services that far outweigh the specialist medical units in both size and numbers of people served.

Physical and Psychosocial Dimensions of Rehabilitation

Rehabilitation is recognised as a compendium of many components - medical treatment, physical therapy, retraining and resettlement. One or all of these components may be brought into action to meet the needs of the disabled person. What these complex and interlocking parts of the rehabilitation task have traditionally taken as their main objective is the restoration of physical function, ideally to a premorbid state of activity, in order that the person (whether temporarily or permanently disabled) is able to resume employment or live within tolerable limits of dependence. As major changes have taken place in the problems of people referred for rehabilitation and in the field of employment, the primary goal of returning the person to a job no longer holds good. The Tunbridge Report (1972) stated that where employment was not a major consideration patients fared less well in the rehabilitation services. The Report goes on to mention housewives and younger people as two groups who have suffered as a result of this narrow perception of rehabilitation intentions.

Alongside the questioning of the intrinsic nature of the link between rehabilitation and any resettlement in work, there has been an increased awareness that physical disability is often accompanied or even overlaid by psychological or psychosocial factors (Cornes 1982). This awareness has begun to influence the rehabilitation services whose procedures need to respond to the combined impact of disease or injury, and the changes this can cause in the individual - changes in self-image, in self-esteem, in social relationships and in feelings about the future (Brodsky and Platt 1978). These psychosocial factors will influence the person's responses to impairment and to treatments and procedures to ameliorate the effects of the impairment. Nicholls (1975) writing about the psychological aspects of rehabilitation identified many of the problems facing the rehabilitation professional as rooted in psychological problems, and that these needed a behavioural approach in order to fully understand and help the disabled person. He also goes on to argue that professionals should take account of the social and economic factors operating in the lives of patients undergoing rehabilitation.

Comments about the focus of rehabilitation procedures have not only been made by professionals. Increasingly, disabled people who have personally experienced rehabilitation have written eloquently of the way in which physical recovery can dominate the thinking of professionals, and consequently the direction and choices available to the patient within rehabilitation programmes. The mental and emotional adjustments that must accompany illness or trauma that cannot be 'cured' are reported to be disregarded or ignored by professionals, with the disabled person calling for rehabilitation to be seen as a 'mind and body problem' (Riley 1977).

Reasons for the Research Project

From the foregoing it is clear that there is reason to be concerned about the direction and content of rehabilitation services for physically disabled people. The deficiencies of the present system of rehabilitation have come under criticism in a succession of official reports including Tomlinson (1943), Piercy (1956), Tunbridge (1972), Mair (1973) through to Sharp (1974) and Snowden (1976) (Blaxter 1979). At an individual patient level research has shown that patients with very different conditions often do not receive the rehabilitation they require because staff are not fully aware of all aspects of their problems (Blaxter 1976; Hill 1978).

With these well documented shortcomings of rehabilitation services providing insight into some of the organisational failings of current services, and reports of patients either not receiving adequate help or leaving rehabilitation programmes unprepared for the personal and social demands they would face in the community, further research that would highlight aspects of current practice seemed valuable.

Setting for the Research Project

The focus of this research is a specialist medical rehabilitation service which consists of a rehabilitation unit comprising remedial therapy and workshop facilities and a ward for patients undergoing rehabilitation. For convenience the remedial therapy areas and wards are known collectively as 'the unit'. The unit provides rehabilitation facilities for up to twenty patients with a wide range of disabling conditions caused by traumatic injury or diseases, and draws its patients from a large catchment area.

The main purpose of the research was to more fully understand the rehabilitation process in a medical rehabilitation unit. In undertaking the fieldwork it was hoped to reveal something of the rehabilitation process as it was perceived by patients and staff, by uncovering some of the thoughts and actions of the participants themselves. This would increase the understanding of what were seen as the crucial areas around which this piece of research evolved.

The particular areas that emerged as main issues from the period of observation and from an extensive review of the literature on rehabilitation services were; 1) the patients' understanding and involvement in the rehabilitation programme; 2) the relationship between patients and staff, particularly the opportunity provided to discuss doubts and uncertainties experienced; 3) the preparation for the patient's integration into the community prior to discharge; and 4) staff cooperation and the practice of teamwork. This exposition is mainly concerned with the patients' and staff's perspectives on what were identified as these central issues.

In undertaking what was a project with limited aims it should be emphasised that the arguments and analysis that grew out of the research are essentially exploratory and speculative. The main intention was to reveal something of the texture of life as it was perceived by the participants themselves of a particular rehabilitation unit. This could help reveal the kinds of consequences it seemed to have for the actions and relationships of both patients and staff; and suggest how far the rehabilitation process was sensitively tuned to the needs of disabled people.

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*In addition to the fieldwork undertaken in the unit a further brief period of interviewing was arranged at a national spinal injuries centre. See chapter 7.

Summary

Rehabilitation services originally developed in response to injuries sustained in war. Early facilities were concerned with treating the war disabled and where possible returning them rapidly to active service or economic production. Alongside these developments the treatment of industrial injuries with facilities to treat coal miners further extended the range of techniques and services available.

Disabled people treated as a result of war or industrial accidents tended to be younger people with traumatic injuries. Services today are now more concerned with disabled people whose conditions are progressive or chronic where the earlier techniques would be inappropriate. Traumatic injuries are still the concern of the rehabilitation services although these now constitute a minority of the disabled people treated.

The medical rehabilitation services which have developed to treat the more serious disabilities are primarily in hospital based units. Here a multidisciplinary team offers a service concerned with improving the disabled person's functional abilities and achieving early resettlement in the community. Rehabilitation techniques used in these units are beginning to take account of both the physical and psychological aspects of disability. The earlier 'bodily repair' approach is now seen to be inadequate although evidence exists of its persistence.

Concern has been expressed about the quality of rehabilitation services through official reports, academic research and more recently the statements by disabled people. These concerns have prompted this research which examines some aspects of the rehabilitation process in a medical rehabilitation unit.

The Scope of Rehabilitation

The term 'rehabilitation' is derived from the Latin and means restoration, and has been used variously to describe the renovation of land or property, and the reform of criminals. Its application in the field of health and sickness has developed universally and is used to describe an increasing range of services and specialists who have as their raison d'etre the restoration of the individual to his normal capacity following injury or illness (Mattingly 1977).

The traditional view of rehabilitation was largely restricted to the activities of the medical and remedial professions which tended to be concerned with early discharge from hospital, coupled with attempts to get the patient back to work. This view of rehabilitation has gradually been expanded and loosened now that individuals who suffer various long-term disabilities that cannot be cured, and may not be able to sustain a job, are the major recipients of rehabilitation services. The aim in such cases is to enable the disabled person to operate as fully as possible within the limits imposed by his disability. This approach is concisely stated by the World Health Organisation definition - 'rehabilitation is the combined and coordinated use of medical, social, educational and vocational measures for training and retraining the individual to the highest possible level of functional ability' (WHO 1969).

This definition indicates that rehabilitation is not just a problem for the medical and para-medical professions. Rehabilitation has many dimensions and involves a wide range of professionals and others concerned with the disabled person. Consequently the scope of rehabilitation is wide and encompasses the prevention of deterioration through to resettlement.

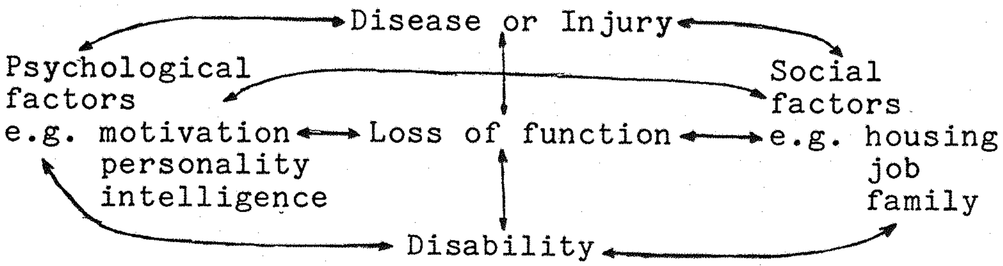
Describing the scope of rehabilitation Mattingly (1977) sees the main aim being to minimise the patient's disability by the following action:

1. Preventing complications of bed rest, such as bedsores, muscle wasting, joint stiffness and contracture by good nursing, physiotherapy and early mobilisation.
2. Restoring the patient's physical and mental health by drugs, remedial exercises, speech therapy, activities of daily living and vocational tasks. In addition psychotherapeutic help may be given by way of personal counselling to assist patients in areas where medical and physical improvements are limited.
3. Provision of aids and appliances, to compensate for loss of function, especially mobility, which includes crutches, calipers, surgical shoes, artificial limbs, wheelchairs and motor vehicles.
4. Resettlement at home including home nursing or care attendance, the loan of aids and appliances and the use of residential and day services. Resettlement also includes work in open or sheltered employment following occupational assessment and vocational training.

It is clear from the above description that rehabilitation is a multi-disciplinary activity. Rehabilitation in a hospital setting is mainly about prevention, restoration and compensation for the loss of function. The amount of restoration achieved and the maintenance of an optimum level of functioning will depend on medical, personal, social and environmental factors, many of these factors being outside the direct control of medical and other staff. The doctor may be able to reduce the severity of a disease process or ameliorate its sequelae by various therapeutic measures; likewise physiotherapy, occupational therapy and other remedial activities may increase function, but these interventions have only an indirect influence on the motivation of the patient (and his family). Social factors such as jobs and housing, and psychological factors related to constructing a new way of life following disablement cannot easily be dealt with effectively within a medical rehabilitation setting.

This psychological-social axis, as it has been described by Warren (1977) has been given very little emphasis. The main emphasis has been on the disease-loss of function-disability axis to the neglect of the other equally important dimension. This is illustrated in figure 1.

Figure 1. Factors interrelating levels of disability



(Warren 1977)

Warren argues that rehabilitation must be concerned with the interractions occurring along each of the pathways.

Medical Rehabilitation Centres

Medical rehabilitation centres, of which there are twenty-five in the United Kingdom, provide specialist facilities for the intensive rehabilitation of patients who are seriously disabled by injury or disease. The average length of stay in most centres is approximately six weeks, although individual patients often need treatment for several months. In the unit that is the subject of this research the emphasis was more towards long-stay patients, for example, those with brain damage and other long-term disabling conditions.

Each centre differs to some extent in its approach and the facilities it has to offer, but nevertheless they share a common approach to disability which distinguishes them from rehabilitation departments in general hospitals. They offer the patient an intensive full-day programme of assessment and treatment from Monday to Friday each week. This is organised under the direction of a medical consultant and uses a multidisciplinary team coordinated through case conferences. The focus of activity is on the solution of the problem of how to perform the activities needed for daily living, the provision of aids and appliances, and on liaison with community organisations.

The range of facilities would include the following:

1. assessment of disability and its effects on the individual's independence at home and at work.
2. tests of functional activities such as walking, climbing, driving and use of public transport.
3. intensive treatment to strengthen weak muscles and mobilise stiff joints.
4. retraining in activities of daily living, such as dressing, washing, eating and preparing meals.
5. provision of aids, including crutches, calipers, hoists and wheelchairs.
6. assessment and training in communication problems.
7. work assessment and vocational training.

Although this list is by no means comprehensive it constitutes the core of activities in medical rehabilitation centres (Mattingly 1977).

This is a descriptive account of the services centres offer, but Mattingly gives little indication as to whether the centres and the provision they make meet the needs of disabled people. He describes the growth of the centres as being closely linked with services developed during the two world wars primarily to treat injured servicemen. The serious loss of manpower caused by the unsatisfactory treatment of injuries in the first world war led to the establishment of orthopaedic rehabilitation centres. A further growth in provision took place during World War II, when again manpower shortages, not only in the armed services, but also in the factories affected the war effort. The particular problems of shortages of highly and expensively trained Royal Air Force aircrew due to injury, resulted in orthopaedic units transferring patients to the rehabilitation centres for intensive full-time treatment. Such was the success of these units and their intensive regimes during wartime, that following the cessation of hostilities they were retained and form part of the service now available within the National Health Service. Naturally after the war it was found impractical to apply the strict regimes worked out in the military hospitals, and some of the success attributed to these hospitals was probably due to the strict regime where servicemen were under military discipline during their rehabilitation.

Warren (1977) indicates that the intensive rehabilitation that was a feature of these units has been questioned, and their effectiveness needs monitoring by research studies. Nevertheless he was encouraged to see the Tunbridge Committee recommending the establishment of new rehabilitation centres in district general hospitals run on similar lines to the wartime medical rehabilitation centres (Tunbridge 1972).

The Tunbridge and Mair Reports

Probably the most important publication, at least in terms of information about the hospital rehabilitation services, is the Tunbridge Report entitled simply Rehabilitation (Tunbridge 1972). This report whose recommendations have largely been unimplemented and, in the view of one writer, ignored by the DHSS (Guthrie 1977), nevertheless provides a useful source of information and has served to stimulate debate about the future direction of medical rehabilitation services.

The Tunbridge Committee, made up exclusively of members of the medical profession, identified a number of factors that were seen as reasons for failure in present provision.

These include firstly, a general lack of appreciation among both medical and para-medical professions of the importance of effective rehabilitation, and a lack of interest in rehabilitation as a specialism by the medical profession. Secondly, rehabilitation objectives were still often concerned with return to employment, even though for many patients return to work was not a relevant consideration. Thirdly, poor organisation and coordination of rehabilitation services was aggravated by the absence of medical direction. Fourthly, there were problems associated with the remedial professions and their use of obsolete methods and inadequate training. The medical direction of remedial therapists created further problems, with many doctors having little detailed knowledge of remedial techniques. Lastly, Tunbridge identified a paucity of research on the need for rehabilitation and an evaluation of rehabilitation techniques.

At the same time as the Tunbridge Committee were meeting a similar committee of the Scottish Home and Health Department under the Chairmanship of Professor Alex Mair was producing a report entitled Medical Rehabilitation (Mair 1972). Like the Tunbridge Committee it found a number of striking inadequacies in services in Scotland, but went much further in identifying areas of concern in the rehabilitation process.

Mair found, as Tunbridge, a lack of interest on the part of many doctors in rehabilitation and laid the blame primarily at the door of medical education. Medical education was specifically criticised for failure to teach students to see patients as the "whole man". Secondly, rehabilitation was often seen as the clinical resolution of physical disability without consideration of the patient's attitude, his educational status or his social environment. Although doctors were skilled at applying highly complicated techniques, they had difficulty visualising their patients outside a hospital setting. Thirdly, like Tunbridge, Mair found poor coordination and communication among the rehabilitation team and others in contact with the patient, but the report went further in identifying fundamental problems of communication between doctors and patients, and the absence of a coordinated plan that took into account the patient's needs and linked them to a resettlement programme. Mair stressed that medical involvement is but one element of rehabilitation and that many of the disabled person's needs can only be identified by other professions and agencies. Mair saw medical, social, educational, psychological and vocational factors as all being relevant in this context. The problem doctors face is that their contribution may be limited and that supporting disciplines, or other skills are needed. Without these additional dimensions the implementation of a planned programme of rehabilitation may be impossible. Fourthly, Mair identified a lack of research into the effectiveness of rehabilitation and saw this hindering the development of rehabilitation services. Lastly, anomalies in remedial departments were found with inappropriate use of remedial therapists and little support and advice on suitable techniques.

The Tunbridge Report's recommendations proposed the development of rehabilitation as a specialised medical practice with a separate hospital based service. Access to this service would be controlled by a medical consultant and the rehabilitation service should be headed by a consultant in rehabilitation who would direct it. The Mair Report, although concerned with Scotland, came to similar conclusions and recommended that medical rehabilitation should be a specialty in its own right, with consultants appointed in specific hospitals.

Critics of the Tunbridge Report have attacked what they see as its blinkered and outdated view of rehabilitation. Agerholm (1972), herself an eminent medical practitioner, criticised the report on a number of grounds. Firstly, for the narrowness of the committee membership which, as stated earlier, was made up entirely of doctors, even though rehabilitation is recognised as one of the most multi-disciplinary activities in the health service. Secondly, Agerholm saw the report as regressive, which tried to put the clock back and handicapped people into hospital. Thirdly, the committee paid little heed to the wider meaning of the term rehabilitation, and concentrated on building a model of rehabilitation based around a separate hospital service under medical direction.

Agerholm's broad criticism of the report was its lack of awareness of the impact of hospital life on the patient and of the need to work as speedily as possible to restore the patient to the community and to reduce dependence on treatment and doctors to the minimum. She argued that rehabilitation services should be concerned with "restoration of patient to person". She feared the emphasis on a hospital based service would risk turning persons back into patients.

Wing (1977) writing from the standpoint of psychiatry, criticised the report on issues that have equal force in other rehabilitation settings. Wing saw the main omission as the lack of recognition of the 'essential continuity between medical and social factors in rehabilitation and resettlement'. This area was insufficiently analysed and taken into account by the committee. The significance of these factors operates at two levels. Firstly, at a personal level, the patient in the rehabilitation process moves between a primarily medical phase to a primarily social phase of treatment. The interaction and understanding of the relationship between the medical and social factors is crucial for a full understanding of the patient's situation. At an organisational level the separate medical and social services, which have different perspectives and skills to offer, also need to be recognised if the patient is to receive from both the appropriate range of services to meet his needs. Professionals involved in the early stages of treatment need to be aware of the services and appropriate skills available to the patient in later stages of treatment.

Critiques of Rehabilitation Practice

Further criticism of rehabilitation practice is to be found in the comments of a number of writers. Mayer (1982), writing from the perspective of a medical consultant, raises a number of questions about rehabilitation, and sees it as a diffuse and nebulous practice with the way ahead obscure. He feels that much of the work in rehabilitation is undertaken without clear objectives and much of the activity plays a social support rather than remedial role. He also sees room for improvement in the relationship between staff and patients. The attitudes of staff have a direct influence on the expectations of patients, and on the adjustment the patient has to make to the world outside the rehabilitation centre. But, unlike his medical colleagues, Mayer also sees the helpers as needing advice and support. Adjustment is a two way process with helper and patient both striving for understanding.

A further area of concern to Mayer is the lack of recognition that disability is as much about the personal feelings of the patient as it is about the primary impairment. But in spite of this knowledge there is little evidence of training in counselling skills for helpers. The concerns of patients who find the lack of counselling a serious deficit should also be taken into account. Mayer sees difficulties in this area when staff are sometimes unable to respond sensitively if faced with patients who are difficult or have unexpected setbacks. In order to fill the gaps in existing practice Mayer sees value in calling on those disabled people who have experienced the rehabilitation process, in order to offer counselling help to patients, but also to assist staff so that the outcome of rehabilitation is more effective.

Nichols (1977), another medical consultant, also has doubts about much of the current practice of rehabilitation and sees it (rehabilitation) using an essentially empirical approach with little of its therapies critically evaluated. More precise knowledge is required of the therapeutic value of both medical care and the specific remedial techniques. These comments follow his earlier criticisms (quoted in Taylor 1977) when he argued that physiotherapy was often little more than a form of expensive social support. Nichols sees two particular areas of concern: first, the development of indicators of the outcome value of rehabilitation interventions so that more rational planning could take place. Second, the need to clarify the factors that affect the disabled person's recovery and assist him overcome residual disability. Nichols divides rehabilitation into three main problem areas. Firstly, there are problems which require clinical medical treatment and respond to acute medical care. Secondly, there are problems concerned with physical function, which can be improved with the application of remedial techniques. Lastly, and in Nichol's view most important, are the psychological aspects. The adjustment problems, work capacity and functional ability are more strongly related to psychological state than organic disease. Furthermore, psychological factors influence the person's response to the treatment required.

The concern over patients who have difficulties during their rehabilitation or reject the programmes devised for them is a growing area of discussion, particularly from the standpoint of disabled writers. The traditional view is summed up by Somerville (1974) who, writing on stroke rehabilitation, sees success dependent on the cooperation of the patient. He also sees it as essential that the relatives and friends should agree to cooperate to a certain level. He believes all staff involved with the patient should aim at handling him in a firm but sympathetic manner if success is to be achieved. Nichols (1974) is also concerned that the patient in the rehabilitation process cooperates, and maintains that successful treatment is dependent on the patient understanding, adjusting to his situation and accepting treatment. Roberts (1977), writing from the standpoint of the disabled person, is concerned that the argument used by Somerville and Nichols is one of faithfully continuing the tradition of doing to people what is good for them, whether they like it or not. Some patients do not succeed in rehabilitation programmes and drop out early. They are often seen as failures because they refuse to accept the treatment devised for them. Focus needs to shift to why the services may not have been able to meet the individual needs of the patient. Roberts sums up this approach as the 'manipulation and retraining of the patient as if he were in a reformatory'. Certainly the writers on rehabilitation, particularly those from a clinical standpoint, rarely mention the patient who does not succeed because, for some reason, he is unable to adjust or cooperate with the treatment regime. Regretably, as Roberts points out, the Tunbridge Report ignored this problem, and thus a significant gap was created in its findings.

Blaxter (1970), a sociologist, in a wide ranging survey of disability and rehabilitation, sees the need for a number of changes in services. Medical and administrative definitions of disability have broadened and become more flexible since the early days when provision tended to focus on a narrow definition of disability. There was a single model of rehabilitation which usually meant treating acute illness or trauma, followed by physical restoration and readaptation in the community, with the disabled person maintaining a stable level of functioning within residual limitations. This model fitted the type of condition, particularly those resulting from accidents, to which rehabilitation techniques were first applied. Rehabilitation now has to concern itself with a much wider range of impairments where the onset is not often clear, the prognosis uncertain and the residual limitations progressive or fluctuating. In the case of the former conditions the pathway from operating theatre to physiotherapy to vocational training and mobility assisted by the provision of aids is relatively straightforward. Where a slow and gradual deterioration is concerned the pathway can be a continuing round of G.P.'s surgeries, out-patient clinics and hospital consultants with the involvement of numerous social agencies.

This analysis suggests that the earlier simple static model of disability requires considerable refinement. The Parsonian concept of the sick role is difficult to apply to disability or long-term chronic illness. The role played by disabled people is much more complex and the variables affecting successful role adaptation following disability have been little studied. Blaxter sees the whole career of the disabled person as a relevant area of concern, including his previous experience of health and sickness, his family, his job and particularly his situation at each point in time during the rehabilitation process. Disability is rarely static and the disabled person has to redefine and re-negotiate his role continually. The earlier simple model of rehabilitation tended to assume a linear process from impairment through to outcome that was clear cut and defined. The emphasis tended to be placed on the last stage of the process - has the rehabilitation been a success or failure? This crude linear model is limiting and takes no account of the interaction of the disability with the individual's history, family structure or environment. Emphasis has been laid on the personality with particular personalities linked to specific disabilities. Blaxter feels this link has tended to be given undue attention in the past. A wider perspective, looking at the individual within the context of his total situation and the rehabilitation process itself, could be more profitable.

The Disabled Person's Perspective on Rehabilitation

Another perspective on rehabilitation practice is that of the disabled person who has experienced at first hand what it is like to become disabled and to be subjected to the rehabilitation process. Such expressions are a fairly recent development, but are growing apace as more and more disabled people voice their feelings about what they experienced. They can be seen as part of the revolt against the professional domination of services and information that is typified by the consumer-led movement that has revolutionised expectations among disabled people in America, and is now beginning to make an impact here (DeJong 1979).

Writing about treatment in hospital different authors describe a situation where they see themselves as the subject of a rehabilitation process that takes little account of their feelings, and prescribes treatments and activities that often mean little to the person in the context of their life and disability. Davis (noted in Tirbutt 1984), a former nurse who was paralysed in her mid 20's as a result of spinal injuries sustained in a motor accident, writing about her time at Stoke Mandeville Hospital, felt the treatment she received in hospital to be as shattering as the effects of her injury. For her, rehabilitation was a de-humanising process with little opportunity to make decisions; feeling cut off by lack of communication between staff and patients, and the lack of privacy with everything being done within the gaze of others. Even worse, and something she still feels bitter about ten years later, was the lack of information from hospital staff that she might be able one day to live an independent life in the community, marry and lead an ordinary unremarkable life in her own home. The time lost while living in institutions after leaving Stoke Mandeville, adds to the feeling of bitterness towards the rehabilitation services that she feels increased the handicap, and saw only an instituionalised future for a person with spinal injuries.

Scott (1983), who also suffered a spinal injury as a result of a road accident, also spent time at Stoke Mandeville Hospital. He too describes the total lack of responsibility due to the severity of injury, encouraging the patient to become mentally inactive and preoccupy himself with his present predicament. Patients were experiencing probably the worst crisis of their lives and were naturally worried about the future and what lay ahead. Nevertheless, they were given little idea of the world they were about to re-enter. Patients tended to be filled with preconceived ideas of what they would not be able to do - rather than emphasis placed on what was possible. For Scott, meeting other disabled people who were returning for treatment offered the opportunity to learn about what was possible in spite of being disabled.

A further area of concern to Scott was the approach used by remedial therapists which consisted or proving to the disabled person how disabled he had become and how useless he was. This approach had one of two effects, either patients rebelled against it which gave them the incentive to continue, or it reinforced in their minds that they were useless burdens on their wives, families or society in general. Scott saw this as a very hit or miss approach when patients were already feeling their life was ruined. For some people it meant suicide. Scott felt that to begin by convincing the patient how disabled he was, was a fundamental mistake, and denied the importance of building on achievements from endeavours. He sees disabled people needing something that will give them hope and encouragement to continue life.

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*A further more detailed discussion of the disabled person's needs is contained in Chapter 8.

Riley (1977) describes herself as enormously energetic and physically active prior to a cerebral haemorrhage, followed by brain surgery and subsequently a left hemiplegia. Following time spent in an intensive care unit and hospital ward she was discharged to a rehabilitation unit. By this time the realisation that her physical life as she had known it was over coincided with a severe depression. During her time at the rehabilitation unit she became more depressed and attempted suicide while home for a weekend. Following this attempt she was referred to a psychiatrist who subsequently provided the help and support she felt she needed. Riley makes two main criticisms of the rehabilitation process. Firstly, that the feelings patients had about their situation were totally ignored, with priority being given to getting them into physical shape to return home. Secondly, that the rehabilitation programme did not adequately prepare her for life in her own home. The physiotherapy and occupational therapy was seen as successful, but it did not prepare her for her feelings on returning home to her family, and the adjustment to a different way of life.

A further theme of the writings of disabled people who have experienced rehabilitation is the absence of any personal counselling in the rehabilitation programme. A young person (quoted in Hyde 1979), summing up his feelings about the treatment he received in a rehabilitation unit was critical about the inadequacy of counselling available. He felt strongly that there was insufficient advice about coping outside the hospital, and in areas such as sexual needs and future work options. Roberts (1977) commenting on the Tunbridge Report, sees the lack of reference to counselling as a serious omission. He sees rehabilitation as a personal re-building exercise during which the trainee (patient) needs frequent opportunity to discuss his problems with someone to whom he does not feel inferior. Roberts identifies several basic rehabilitation problems that cannot be solved by medical, physical, or even financial improvement. For him counselling should be an essential part of rehabilitation, particularly as evidence from practice indicates that many patients do not make progress, or that skills acquired seem to have no outlet as far as the patient can see.

Counselling is also commented on by Shearer (1983) in an article on Stoke Mandeville. She describes a rehabilitation worker from California visiting the hospital and asking to see its counselling programme. When told there was no such programme, she found it very hard indeed to believe that such a programme did not exist. In the same article Joan Dawe a tetraplegic describes what that lack of counselling can mean to a disabled person. Joan Dawe and her husband, who is also tetraplegic, have their own home which they run with a minimum of help: they have their own car and are active in the local community, travel and have a multitude of interests. People who are newly disabled and visit them are often amazed at the way they live. The point made in this article is that patients undergoing rehabilitation, and particularly those preparing to leave hospital, are often given no help in preparing for re-learning to live. In the words of Scott (1983) rehabilitation tends to be about superficial knowledge about how to do things done before the disability (p. 16).

What all these writers state unequivocably, is that the person who can teach the newly-disabled most are those who themselves experienced disability, and have been finding out for themselves how to cope with disability. Roberts (1977) sees the assistance of the completely rehabilitated person as offering great assistance not only to the patient but also the overworked body of professional workers.

Davis, in Tirbutt (1984), sees the value of counselling from others with similar injuries as valuable, but recognises that it may be unpopular with doctors and other professionals. She states that doctors have said that counselling is not necessary, and if it is needed then they can do it. Davis's point is that more is learnt from people who have similar disabilities than from anybody else. She sees the attitude of the professionals as one of hanging on to their specialisms.

A disabled person describing her experiences with professionals (quoted in Shearer 1981) states 'none of us is at our best in our relationships with helping professionals. We meet them in the first place because we are not at our best. We are vulnerable to their power and superior expertise. We often make ourselves more vulnerable by taking off our clothes for them. We tell them all sorts of intimate details we would never normally confide to strangers' (p.110). **For disabled people** these relationships are complicated as they often last for long periods because they need the services that the professional workers promise, or because without them they cannot gain their passport to 'ordinary' opportunities. These complications in relationships between professionals and patients in rehabilitation, because of the professionals' view of 'cure', because doctors and nurses are trained to cure the 'incurable' may present them with particular problems. Being trained to put right the bits of people which go wrong rather than see the whole person, they may be particularly likely to assume that an unrepairable inability in one area must mean that the whole person is 'helpless'. Shearer sees that even the invaluable contribution of the rehabilitation professional to helping rebuild the disabled person's life, may have its dangers. The concentration on one aspect of rehabilitation may distort the process, for even the best units sometimes have little to offer people who seek sexual and emotional counselling.

A further perspective on rehabilitation is given by a group of disabled people (Finkelstein 1983). The disabled people interviewed considered that there was very little consultation between rehabilitation professionals and the disabled person. The routine was devised largely by the staff and the patient treated as a body rather than a person. The lack of privacy and the loss of any opportunity to direct your own activities was marked. For this group of disabled people the rehabilitation ward was described as 'a grown up school', with all the control and direction that implies.

When it came to constructing a view of what the future might look like and what was possible with a large level of disability other disabled people offered the clues. Watching other people perform activities and cope with physical demands was the real learning experience. The rehabilitation professionals were seen as not offering positive images about the future and seemed unable to whole-heartedly prepare the disabled person for life in the future.

On the surface the rehabilitation programme appeared highly organised with its confident staff and well thought-out routines. But from the disabled person's standpoint the whole process was haphazard and unstructured with the major help and coping models the personal experiences of other disabled people. The perception of the staff and their view of what the disabled person needed, often involved pessimistic views about future coping strategies. The professionals tended not to touch on the disabled persons' need to come to terms with the biggest change in their lives. Yet there was an imperative need to plan for a future that gave some hope of living in non-institutional places and coping with changed family circumstances in spite of inevitable increased level of dependency.

Finkelstein (1979) writing about the role of the disabled person in the rehabilitation process sees a growing awareness of the social nature of disability, and that rehabilitation should be concerned with overcoming the problems disabled people face by the use of social solutions.

The social problems Finkelstein is talking about include disabled people working together with professionals, rather than passively accepting the help of others. The greater involvement of disabled people is central to Finkelstein's approach which he sees as part of the transition from the era of medical rehabilitation and the doctor's domination over the lives of disabled people to that of the concern of disabled people to participate actively in their own affairs and push towards greater social integration.

Finkelstein believes that if things are really to change in rehabilitation it is not enough for doctors to abandon old roles, but that disabled people should be given a say in the rehabilitation team as full and equal members. He goes on to describe the work of the Spinal Injuries Association which has argued for the professional involvement of disabled people in rehabilitation. This Association feels that some of its members, who are all paraplegic or tetraplegic, could give great help to new patients by counselling. They see this as a first move in some of their members becoming part of rehabilitation teams, and providing a more comprehensive planned rehabilitation programme to all patients.

Summary

This chapter has described the scope of hospital-based rehabilitation and examined the elements that make up the process. Medical rehabilitation units which provide the main specialist facilities in hospitals are described, with the comment that the role of these units has not been effectively researched.

The last decade has seen the publication of a number of official reports on rehabilitation. Although these reports have been largely ignored they have nevertheless provided a source of useful information on the rehabilitation services. The reports have tended to look for solutions to problems in rehabilitation by more medical control even though evidence indicates a relative lack of interest by the medical profession in rehabilitation. Furthermore criticism has been made that the reports showed lack of appreciation of the needs of disabled people whose problems could not be met solely by improved medical treatment.

A further perspective on the practice of rehabilitation is now provided by disabled people who have criticised the effectiveness of much current provision. These accounts have offered a perspective on rehabilitation that has been absent from the professional accounts.

The official reports and the comments by people who have experienced the services indicate that the rehabilitation in hospital units has a number of features that raise doubts about its effectiveness in responding sensitively to the needs of disabled people.

3 RESEARCH METHODOLOGY

Theoretical Perspective

The sociological perspective which forms the basis of this research is known as symbolic interactionism. This perspective sees people interpreting each other's actions, and on the basis of these interpretations decide which course of action to employ in response. Emphasis is placed on the individual's subjective construction of events rather than on 'official' interpretations and definitions (Blumer 1969). Firstly, this perspective is able to explore and reveal social situations as they are perceived through the eyes of the actor. Secondly, it focusses on the importance of 'meanings' in the exploration of social interaction. These 'meanings' are part of the complexity of common knowledge and are often unintelligible until they are interpreted using the interactionist perspective. Thirdly, by providing a mirror in which the actor sees himself as others see him, this perspective can offer the opportunity for the actor to reflect on the ways his actions are perceived by others. Fourthly, interactionism provides a healthy balance against those macro theories that ignore the nature of social processes as they occur, a criticism that could reasonably be levelled at many studies of the rehabilitation process that take no account of the experiences of the actors involved.

The major criticism of the interactionist perspective is that this method of sociological analysis is episodic and social psychological in its orientation. Furthermore research reports as a result tend to be lengthy and descriptive. It is argued that by focussing on the minutiae of social interaction this perspective fails to illuminate the nature of the influences of the structural factors operating in a particular situation. In spite of these reservations, some features of the interactionist perspective have real value in seeing a rehabilitation unit as a setting which consists of people acting, and as a result the life of the unit is seen to consist of their actions. The understanding of the rehabilitation process that can emerge from observations and questions is designed to ascertain ways in which people view and interpret their situation in which they find themselves, the actions they choose, and how these actions collectively form a pattern of interaction over time. How the disabled person views his world, or a segment of that world, i.e. the rehabilitation unit, is important in determining the help that person needs (Glassner and Friedman 1979).

Consistent with the interactionist approach the initial aims of the research were:

1) to explore the reality of the rehabilitation process from the perspective of patients and staff;
2) to identify and illustrate the differences where they emerged between the patients' and staff's perceptions and definitions of the rehabilitation process;
3) to explore the effectiveness of rehabilitation team practice.

Methodology

Many areas of interest grew out of the research process and were not clearly identified beforehand. This is not uncommon in projects of this kind. King (1978) in his study of an infants' school referring to his interview with teaching staff stated - 'I was unable to give any clear idea of what I was trying to do, because I did not know exactly myself' (p. 4). Similarly Cohen and Taylor (1972) in their study of long-term prisoners describing their methodology state 'we started without a problem and evolved a set of methods while we worked, and ended up with a collection of observations, anecdotes and descriptions rather than a table of results' (p. 33).

I was also conscious from my review of the literature on research methods that it is not always desirable in social scientific terms to have exact definitions prior to an enquiry of this sort commencing. It is wise to avoid too tightly formulated a view of the nature of the problem, but look at the data that emerge from the exploration of the situation to indicate some of the problems for future investigation and analysis.

In selecting this theoretical perspective I was aware of the choice to be made between an in-depth analysis of individual cases or small samples and the more superficial analysis of a larger sample. The advantages and shortcomings of what Meehl (1954) has called the 'clinical' and 'actuarial' methods in social science have been extensively reviewed in the literature. In practice the final choice of methods adopted in this study was taken in the light of several considerations. First, it was evident from the review of the literature (discussed in Chapter 2) that there was concern about the techniques that were part of the rehabilitation process and also the role of the disabled person in rehabilitation. Second, I was not concerned to obtain quantifiable data from a larger sample of respondents that was beyond my resources. With limited time available to undertake the fieldwork, I saw instead a research project that would excuse the small sample size, but also allow me to conduct an in-depth analysis of the sample. Third, I was also aware that by adopting an interactionist perspective it would provide me with an opportunity to understand the way in which patients and staff involved in the rehabilitation process were viewing and interpreting the situations in which they found themselves. Fourth, the limited nature of the study allowed me to undertake short periods of observation and interviewing at the unit, but still enabled me to collect sufficient information to provide the basis for a thorough analysis of the rehabilitation process. Fifth, I already had experience of interviewing disabled people from my earlier employment as a social worker. Consequently I felt most comfortable adopting this technique.

Participant Observation in the Unit

The data for the research were collected by two main approaches. Initially participant observation techniques were used as a means of gaining greater understanding of life of the rehabilitation unit, and also enabling a schedule of topics to be developed as the basis for interviews with patients and staff. This is a valuable procedure when the researcher is interested in understanding a particular organisation or substantive problem, rather than certain variables. The assumption is that the researcher does not know sufficient about the organisation a priori to identify the relevant problems and hypotheses and that these must be discovered in the course of the research.

The period of observation was arranged through contact with the Nursing Officer to the unit whom I wrote to and described my research intentions. I stated that I wished to learn about the work of a rehabilitation unit. It was agreed that I could undertake the observation and arrangements were finalised for me to spend one day a week in the unit over a two month period. At first I accompanied specific patients during their daily programme and in this way was able to familiarise myself with the work of the different departments and the rehabilitation personnel. Prior to the start of the observation phase I met with the Rehabilitation Officer who subsequently described my research outline to the unit staff at their weekly meeting. Subsequently in introducing myself to individual patients and staff I kept the formula as truthful as possible and consequently minimised pretence and distortion. The day periods of observation were more than sufficient to enable me to accumulate copious notes which I wrote up at lunchtime and each evening following the observation period. I varied the times of the observation to some extent to enable me to see the unit throughout its day and evening activities.

As an observer in the unit my experience followed Vidich's (1954) description of participant observation where he describes the value to researchers of making use of individuals who are socially marginal in the society being studied. He describes how even when the observer tries to avoid the marginal individual, he is often sought out by them. Vidich sees such individuals as a bridge to the meanings of the society. It is they who provide him with his first insights into the work of the society. This was my experience when very early in the observation phase a nurse offered to discuss the unit and clearly set out her views which were critical of some personnel and aspects of the rehabilitation process. This description of the unit gave me valuable information at an early point in my involvement in the project. Nevertheless as a 'disinterested researcher' (Voysey 1979) I was aware that what the observer sees depends largely on his network of relationships and I did not want to be lead into ways of seeing the unit conditioned by these preconceptions.

During the observation period I participated in, observed and recorded, as much of the behaviour that took place in the unit as possible. I recorded, for example, the formal behaviour of the staff and patients as they met together in treatment situations. I also noted the informal behaviour of patients and staff as they sat around in the ward or in the nurses office, kitchen or dining room. Because I was accepted on the unit I was privy to the attitudes and reactions of staff and patients, and some of those people, both professional and family members, who visited the unit. The technique of participant observation was particularly well suited to my study of the unit where I did not fully understand the dynamics of the rehabilitation process. As an observer I could perceive the unit through the perspectives of the various participants, and through my own participation in the unit's activities, but also by constantly stepping back to observe and analyse what I heard and saw. In the account of the unit and its work I have strained to preserve these perspectives. Firstly, to convey the perspectives of the individual patients and staff by allowing them to speak for themselves, and secondly, to move beyond the individual personalities and analyse the rehabilitation process from a wider perspective.

Obviously any method of research has its drawbacks (and these need to be understood). The important thing was to recognise the potential limitations and take these into account when undertaking the fieldwork. The period of observation can be too short and the full meaning of the situation may not be grasped in the time available to the researcher. This is particularly critical if the episodic nature of the fieldwork which takes an interactionist perspective means that some abnormal or temporary features are recorded as mainstream activity. A further criticism is the risk of bias when the researcher gives greater weight to the opinions of some individuals rather than others. There is always the risk that the researcher will be seduced and captured by particular actors, especially congenial ones, whose perspectives on the situation gain greater credibility as a result of their willingness to respond to the researcher's concern for data. Lastly the data produced even from a rigorous framework of observation may still remain subjective.

Patient-Staff Interviews

The second method used with patients and staff was a loosely structured interview using a schedule of topics to be covered. I had originally rejected the idea of a standardised questionnaire, as I felt these methods would not have been appropriate for this research. I was not so much trying to find an efficient way of collecting a lot of information that was routine and factual, as using the methodological framework of interactionism that would be more sensitive and more fully present the patients' and staff's perceptions of rehabilitation. I saw the person's experience of rehabilitation as a valid basis on which to describe the rehabilitation process.

I felt that quantitative techniques would probably be overplayed in the current state of knowledge about the rehabilitation process. A smaller more detailed series of interviews combined with observation was I felt potentially more productive. Naturally the skills of observing, interviewing and recording the minutiae of life in the unit and responses to the schedule of questions would be critical.

Following Stacey's (1969) advice to the budding researcher the schedule for interviewing was kept relatively brief. This was in order that the respondents did not become tired or irritated by too long a series of questions, particularly as some patients were inevitably preoccupied with their personal situation or physically tired after a day spent in the exhausting regime of physical therapy. Secondly, I also took seriously Stacey's comment that lengthy interview schedules tend to generate more data that can be analysed. This certainly applied to my situation where fieldwork was constrained by the time that could be devoted to it alongside the demands of my work role.

As far as the schedule of questions was concerned the main purpose was to generate 'talk'. This approach to interviewing is seen as particularly valuable where experiences, feelings, reasons and motives are involved. In this 'exploratory' research, where depth of understanding is more important than large-scale coverage, a more rigid and standardized set of questions might well have failed to ask the appropriate questions because their relevance had not yet been seen. Strict comparison between one interview and another was not attempted as this was less important than the need to gather information about all the factors likely to be relevant.

Criticism has been made of the methodological weakness of some research on disability because of small samples and the failure to use control groups. This research recognises these criticisms and attempts to highlight particular issues and problems in rehabilitation, but it recognises that it is dangerous to generalise from such small scale research. Rather the findings could suggest hypotheses that could valuably be investigated by a large-scale research project. If this research is seen as a feasibility study then the in-depth analysis of a small sample, using qualitative methods, is appropriate. The views expressed by patients and staff can then be developed into a framework that could be used to yield quantitative data in a larger study representative of rehabilitation that could be generalised to the service as a whole.

In order to interview as representative a sample of patients as possible it was agreed with the senior consultant to the unit, following approval by the Medical Ethics Committee of the Health Authority, that all patients admitted during a two month period would be informed by a registrar shortly after admission that a researcher attached to the unit wished to interview them. It was described that the researcher wished to learn of their views on their treatment and progress in the unit. Some patients declined to take part, while other patients who had initially agreed were later unable to, either because they were discharged early or were unable to participate in the interview situation. Other patients who had speech difficulties following a stroke or were emotionally distraught were not seen. In spite of these factors I was still able to interview fifteen patients who were representative of the categories of disability present in the unit during the fieldwork.

The second phase of 'patient interviewer' role developed naturally from the observation period, which had also enabled the researcher to draw up the interview schedule based on issues that emerged during the first phase. Each interview took approximately one and a half hours to complete, and often extended over more than a single session. The actual interviewing was carried out at various places in and around the unit, but usually on the ward in the evenings after the patient's daily programme had finished. One of the difficulties was ensuring that the place chosen for interviews would be free from the interruptions of other patients and staff, and be a place where the patient could feel comfortable and relaxed, and where they could relate their experiences and feelings in a private and confidential atmosphere.
During the patient interview period, patients and staff came to understand the purpose of the researcher's visits, and showed discretion in avoiding interrupting the interview.

The third phase of staff interviewing took place when most of the patient interviews had been completed. As in the earlier phase the interview schedule grew out of the research process itself and was not drawn up at the outset. The staff interview schedule in many ways reflected the same sorts of questions put to the patients, and in this way the patient and staff perceptions of common issues and situations emerged.

Prior to interviewing staff permission was gained from the Rehabilitation Officer to conduct the staff interviews. By this time in the fieldwork I already knew most of the staff quite well and permission was readily granted by the heads of the various departments for me to interview their staff. Again the staff were informed of my intentions at the weekly staff meeting. All the staff approached readily agreed to be interviewed and this phase of the fieldwork provided an opportunity to obtain data from staff representative of all the disciplines working in the unit.

As far as recording the interviews was concerned I had originally intended to use a tape recorder. Following two interviews using this approach I realised this would present difficulties as I had insufficient resources to have all the interviews transcribed in full. Consequently I made 'shorthand' notes during the interviews. At the beginning of the interviews I explained to the respondents that I needed to make notes in order to remind myself of what they had said. No patient or staff objected to this method. In fact some patients specifically asked me whether I had ample time to record their views and offered to repeat their answers if necessary.

Overall the fieldwork fell into three distinct phases. First, the observation phase which lasted for two months. Second, the patient interview phase lasted for three months, and finally the staff interview phase extended over a further three months. During the eight months of the fieldwork I spent on average one day a week in the unit.

Lastly, in order to gain further knowledge about the rehabilitation process and collect additional material a short visit to a national spinal injuries centre was arranged. Four days was spent at this centre and a small number of patients and staff interviewed. This fieldwork was not intended to be seen as a full-scale assessment of rehabilitation practice at that centre. Nevertheless it does provide some illuminating points that can be compared with the data gathered in the unit.

Summary

The theoretical perspective found most useful in conducting this study was an interactionist one. This perspective placed emphasis on the meanings and definitions held by patients and staff in the unit concerning the rehabilitation process. Participant observation and loosely structured interviews were the research methods used, first, to gain a greater understanding of the setting for the research, followed subsequently by interviews with patients and staff. A brief visit was also made to a spinal injuries centre to collect additional information on the rehabilitation process.

4 THE REHABILITATION UNIT: ORGANISATION AND PERSONNEL

The Location of the Unit

The unit is situated within a hospital that had its origins in the Second World War as a military hospital, and bears all the signs of its original purpose. It has the familiar appearance of an ex-military establishment, with rows of single storey barrack buildings which are now hospital wards, the whole being connected by long draughty corridors. Since its development under the National Health Service additional buildings have been erected giving the hospital a hotch-potch appearance. The hospital has a regional role with plastic surgery and maxillo-facial units. There are also district orthopaedic and paediatric units on site. Currently a major new building programme is nearing completion consisting of residential facilities for staff and a regional spinal injuries unit. During the latter phase of the fieldwork for this project the remedial therapy area of the rehabilitation unit was reconstructed. This was a welcome change for staff and patients who had worked in drab cramped barrack buildings for nearly thirty years.

The hospital is situated on the crest of downland that surrounds the southern boundary of a small cathedral city. The hospital is two miles from the city centre but feels isolated by its lofty position, and the agricultural land that divides it from steadily encroaching suburbs of the city. The site is hilly and exposed with fine views across old sheep pasture to the city and its cathedral. These attractions offer little to the disabled person whose immediate environment is a series of dreary barrack buildings in a setting which resembles a permanent building site. The elevation of the hospital and the limited bus service effectively cut the patient off from the local community and offer a far from satisfactory location for rehabilitation purposes.

The Physical Setting

The rehabilitation unit consists of several separate but interconnected areas. The approach to the unit is by a corridor which links the barrack-like wards and departments. The ward runs off the corridor to the right, being approached through double swing doors. To the left are the remedial therapy and workshop departments. Although the first part of the ward is officially called the hostel to all intents and purposes it appears to be a normal hospital ward with regulation beds, screens and the paraphernalia of the health care system. Beyond the hostel is a series of treatment rooms and the nurses' office. Further along this same area is the Ward which is again much like the hostel, but has greater facilities for more intensive nursing care, with hoists and other equipment for handling severely disabled patients. Continuing through the Ward one passes by double doors to the daily living bungalow. This has been constructed in domestic style on the end of the ward. The interior is also domestic in scale with kitchen, living room and bedrooms. Returning to the main corridor and turning left opposite the ward through swing doors, one enters the remedial therapy departments. Towards the end of the fieldwork period the old barrack building was extensively remodelled and now includes a series of offices and various therapy areas. Passing the office one enters a large gymnasium-like room used by physiotherapists. Taking the opposite fork one passes through the workshop area where both light work (occupational therapy) and heavy work (industrial processes) are situated. Again as with the daily living bungalow extended modern facilities have been grafted on to the original military services buildings which still bear the physical appearance of their former usage. Additional facilities such as speech therapy and psychology are situated nearby but in separate departments off the main corridor. A series of portable buildings house offices until more permanent accommodation is available.

The unit first opened its doors to patients in 1956 and was originally concerned, in the main, with the rehabilitation of patients with hand injuries following treatment by plastic surgery. The programme of rehabilitation at that time differed little from today with the remedial therapies providing the major component. However the unit has had a changing patient population. A description of referrals by the Rehabilitation Officer indicated that the focus of the unit had varied, reflecting both changing social conditions and developments in medical treatment. Following the period when hand injuries played a large part in the life of the unit the next phase saw an increase in patients with head injuries, mainly as a result of motorcycle accidents. The compulsory use of crash helmets subsequently reduced this referral category, but the growth of motoring with increased road accidents generated its own referral pattern. More recently the rapid increase in motorcycle sales, particularly to teenagers, has again resulted in referrals of young people injured in accidents, particularly head injuries. Alongside these traffic-related injuries the unit has been provided with a wide variety of referrals due partly to other types of serious accidents, for example in industry, and also the increasing numbers of patients who have successfully survived major medical crises which left them alive but disabled.

Referrals to the Unit

The intake of referrals is usually three or four a week and tends, in the words of the Rehabilitation Officer, 'to err on the side of the less severe'. The unit nevertheless has patients referred with a wide range of disabling conditions and is not highly selective. The only rehabilitation work it does not undertake, in the words of the official description of the unit, is that of the purely psychiatrically disabled. In practice back-pain sufferers, stroke and post-surgical orthopaedic patients form the major groups of referrals to the unit.

Discussion with unit personnel indicated that individual consultants are selective about the sort of problem considered suitable for the unit, and this was a major influence on the patients admitted. One consultant was seen to be interested in patients who had psychiatric symptoms, and in the words of a remedial therapist 'admitted nutters'. Another consultant seemed to be concerned with patients who presented social problems in addition to disability. Although some staff did not consider these types of patients suitable they nevertheless went on to say that the unit should not be over-selective. Patients with psychiatric or behavioural difficulties appeared to be universally unpopular with a wide range of informants, although definitions of psychiatric or behavioural problems tended to be stretched to cover a very wide variety of normal behaviour that one might expect to witness in people whose lives had been shattered by injury or crippling disease. In describing the ideal admission staff seemed to paint a picture of the patient with a clearly defined medical condition, not too severe and without any over-lying emotional or psychiatric problems which might test the staff's ability to relate to the patients' psychological needs or behavioural difficulties in adjusting to life with a disability.

Referrals to the unit come from general practitioners via the Rheumatological Out-patients Clinic, or to the consultants at the unit directly. Local community occupational therapists involved at the GP's request can also seek assistance from the unit and constitute another source of referrals.

Catchment Area

The unit does not have a fixed 'catchment area', although in practice the majority of patients come from the health district or region. The catchment area in fact tends to be regional rather than local, with some patients living forty miles or more from the unit. In unpublished statistics it can be seen that the proportion of admissions from within and without the health district balanced at around fifty per cent.

Patients treated during 1977

Number of admissions from the Health District	103
Number of admissions from the Districts in the Health Region	94
Number of admissions from outside the Region	11
	200

These figures indicate that the unit has a major role in regional terms, but also offers facilities to patients who live outside the region who need the specialist help available. The large catchment area also raises questions about the patients' links with his home, access for relatives, and the effectiveness of staff links with local services.

Attendance and Duration of Stay in the Unit

Patients may attend the unit on a daily basis or live in the hostel, which is open five days a week and is for patients who can attend to their own personal needs. Patients needing more assistance may be admitted to the acute beds which have 24 hour nursing cover. The duration of stay in the unit can be from one week to six months or more. In the data referred to earlier an analysis of referral groups and duration of treatment of some 190 patients, seventy-five per cent of patients had completed treatment within eight weeks, with rheumatoid disease and fracture groups completing treatment often within four weeks. On the other hand patients with head injuries and spinal injuries might spend in excess of six months in the unit. Length of stay on the unit was not always related to treatment, but could often be influenced by lack of services in the patient's home area (typically for some severely disabled people who had completed their rehabilitation but could not return to the community because they required long-term accommodation).

The Patients' Routine

Following admission staff plan a programme for the patient which usually means the majority of time is spent in physiotherapy. As the patient's physical side improves the balance of the programme alters with more time given to independence training in the daily living bungalow, and time spent in either the heavy or light workshops. For older or chronically sick patients leisure and recreation activities may take the place of workshop activities. The programmes are organised between 9 a.m. and 5 p.m. each day except Mondays when programmes start at 10.45 a.m. as patients will normally have spent the weekend at home. The underlying principle running throughout each person's daily programme is that of work interspersed with the customary lunch and tea breaks.

Departments and Personnel

The unit has a number of separate departments each concerned with a particular aspect of the rehabilitation programme.

Medical Staff

The unit was staffed by three consultants and two registrars. The consultants all had additional appointments outside the unit. The registrars were resident and served the unit and a number of other wards in the hospital. Control of beds and admission to the unit was the responsibility of the consultants. Although the consultants spent the least amount of time on the unit they had a major role in making diagnoses, outlining the direction of treatments and specifying when patients should be seen again and reviewed. The registrars took most of the day-to-day medical decisions and were frequent visitors to the unit.

From the comments made by one consultant there were indications that tensions existed between medical staff and remedial staff. Although the consultants had clinical control and hence considerable power on decisions in the unit, it was clear that the remedial professions were seen as the main practitioners of rehabilitation.

Physiotherapy Department

The physiotherapy department filled a key position in the rehabilitation unit with physiotherapists heavily involved in the early stages of most patient rehabilitation. The physiotherapist performs the exercises with the patients in order to achieve physical independence as quickly as possible. The unit had a senior physiotherapist and two basic grade physiotherapists. A Superintendent Physiotherapist was also in post and she additionally had the position of Rehabilitation Officer, and played a co-ordinating role on the remedial therapy side. The main location for the physiotherapy sessions was a large gymnasium-like room that had recently been constructed in the latest round of development.

The Industrial Therapy Unit

The Industrial Therapy Unit is based in the heavy workshop and contains machinery such as lathes, drilling machines and woodworking equipment. The unit is staffed by a manager who has a production engineering background and a team comprising industrial staff and occupational therapists. The range of activity is wide and fulfils a number of purposes. For example, machinery is used for remedial purposes in helping patients to undertake repetitive movements, such as knee extension after a cartilage operation. Patients are assessed as to their suitability to perform specific industrial tasks, covering such aspects as their powers of concentration, capacity to follow instructions, posture at machines and so on. Other activities centre around introducing patients to daily work habits for those who have lost all contact with work routine, and finally there is the education function of enabling a patient to relearn an old skill lost through disability.

The Light Workshop and Daily Living Bungalow

Associated with the heavy workshop is the light workshop, which is, in spite of its name, not an industrial setting but an occupational therapy department. The light workshop has a sedentary atmosphere in contrast to the factory-like regime of the industrial unit. This workshop is used as an assessment and treatment setting mainly for patients with brain damage and upper limb disabilities. A range of assessments are undertaken including tests for perception, memory and concentration with remedial activities such as basic language and writing skills, typing, printing and remedial hobbies. Some of the traditional cane crafts are also practised. This workshop is staffed by an occupational therapist.

A further site for occupational therapy activity is the daily living bungalow (DLB). The bungalow with its specially designed equipment provides a daily treatment programme for patients on the unit, and also serves outpatients. The DLB is used in order to both assess and train the patient to cope in a domestic scale setting. The disabled person's use of his residual ability to achieve independence in personal care and domestic activities forms the major part of the programme in the DLB. Patients are taught to achieve personal and household independence using equipment in circumstances that would mirror more closely the conditions in their own homes. The bungalow is also used for work with families in order to train them to cope with a disabled family member. An extension of this function is the residential use of the bungalow when the patient and his family can 'live in' for short periods not only to facilitate a realistic appreciation of the patient and the demands he will make on the family and helpers, but also to test out his capacity for coping with personal independence at home. The DLB is staffed by a senior occupational therapist and a team of basic grade occupational therapists.

Speech Therapy Department

The speech therapy department has a series of purpose designed rooms adjacent to the rehabilitation unit. It provides a speech therapy service to the unit and to other parts of the hospital, together with out-patient clinics in the district and region. The main focus of the work in the unit is the assessment and treatment of patients with brain damage, where communication disorders can further handicap the patient. The department is staffed by a Chief Speech Therapist and two senior therapists.

Other Services to the Unit

The unit has the services of several specialists on a part-time sessional basis. The social worker has a half-time appointment to the unit and the main emphasis of the work is the assessment of social factors as a preliminary to casework with the patient and family. A further important aspect is liaison with other agencies particularly where patients are admitted from a wide geographical area. The psychologist works in the unit on a sessional basis mainly for the assessment and evaluation of psychological attributes and functions. The assessment of intellectual impairment resulting from brain damage, and the assessment of residual skills and abilities and improvement during rehabilitation are major areas of concern. The psychologist is also involved in non-medical treatment techniques such as behaviour therapy, particularly in the context of patients' psychological strategies for coping with disability and adjustment to rehabilitation procedures. The unit also calls on the services of a Disablement Resettlement Officer (DRO) who advises and assists disabled people to enter or retain employment and also advises employers on the job which could be done by disabled people.

The Ward

The ward is a twenty bed facility and provides the residential element for patients who are admitted to the unit on an in-patient basis. The role of the ward is different from one in a general hospital in that the majority of patients are not sick, although they may have medical conditions that require monitoring or treatment, and that they are away from the ward for much of the time attending the rehabilitation programmes, returning only for meals and at the end of the day. Some patients early in their treatment need rest periods during the programme and these are spent on the ward. The main aim of the ward is to support the patient, yet at the same time reduce the total care received to enable the patient to become an independent individual again. The nurses continue the patients' programme when the remedial departments close and supervise patients' dressing, encourage walking and any therapeutic measures that can be continued without special equipment. The ward is also the patients' 'home' during his stay on this unit and this gives the nurses an opportunity to observe the patient when he is relaxing after a day's activity. The ward has its closest relationship with the daily living bungalow as both are basically concerned with the same thing - getting the patient to use residual-function in personal areas, such as dressing using the weak side of the body, or leading with the good side when transferring from wheelchair to bed or toilet. The nurses also have the closest links with relatives as patients are usually visited in the evening after programmes have finished. The ward is staffed by a sister and six trained nurses and four assistants. There is also a part-time ward clerk.

Coordination of the Rehabilitation Programmes

Rehabilitation is in some ways unique within the health care system because it requires such a wide spectrum of input from supporting specialists. To work effectively it has to be a truly interdisciplinary effort. In order to coordinate the work of such a large team of staff from different disciplines a weekly meeting of all staff was held. This meeting took place on Monday mornings from 9 a.m. to 10.30 a.m., and comprised of all the personnel involved in rehabilitation. With ten or more separate professions represented this meeting could number twenty or more staff. The meeting was chaired by a consultant, or senior registrar in his absence. The main function of the meeting was to review the treatment and progress of each patient. In addition to the review of treatment and progress the meeting fulfilled other functions. One of these was keeping staff informed about the unit, and included such details as official visitors and admission of new patients. The underlying purpose of these weekly meetings was to maintain open communication between the different disciplines and to foster the sharing of ideas.

In addition to this full weekly meeting a further smaller meeting with disciplines represented took place on Thursday afternoons from 4 p.m. to 5 p.m. The purpose of this meeting was to examine specific problems of patients and explore possible solutions. At neither meeting did patients or their relatives attend, and the meetings were described by one observer as being convenient for staff as they took place either when patients were still returning to the unit from weekends at home or only drew on representatives from different departments and this avoided interrupting the patients' programmes.

Summary

This chapter has described the unit, its formal organisation and working practices. The unit is situated in a hospital and is based in buildings that have been adapted from earlier military purposes. The unit has both a local and regional catchment area and takes a wide range of referrals involving physical disability. The referrals tend to reflect the interests of the consultants to the unit who are responsible for admissions. Patients in the unit are treated by a multidisciplinary team with a strict regime based around a programme of remedial therapies.

5 THE REHABILITATION UNIT: THE PATIENTS' PERCEPTIONS

This Chapter deals with the patients' everyday perceptions of the Unit and their rehabilitation programmes. In the review of the literature in Chapter 2, the point was made that studies of rehabilitation that take account of the disabled persons' views and perceptions are a recent development. This Chapter intends to extend that development and presents the views of fifteen patients collected by means of a loosely structured interview. As was mentioned earlier, in the description of research methods chosen, the main purpose of the interviews was to generate 'talk', and with this in mind the intention of the researcher was to say as little as possible during each interview, except to elaborate on what respondents said for purposes of clarification. Throughout the Chapter preference has been given to what the respondents themselves had to say. Their situation is better described in their own words. Consequently, interpretation and comments are kept to a minimum, except in the final discussion of the Chapter. The statements by the respondents are sometimes edited to make them more readable, but other than this they are presented as spoken.

Following the period of observation it was decided that seven areas were key to the understanding of the rehabilitation process from the patients' perspective. Although these areas appeared to be of importance it is recognised that the interview schedule was based on a brief period of observation, was inevitably selective due to time constraints, and may have overlooked other equally important areas critical to the rehabilitation process.

The first part of the discussion in this Chapter is concerned with how the patients saw their admission to the Unit, and the various reasons for being admitted to a rehabilitation centre. The second part focuses on the rehabilitation programme and the patients' involvement in the development of the programme. The third area examines the patients' understanding of their progress in the programme. The fourth area examines the relationships

(cont'd on p50)

Figure 2 Personal Characteristics of the Respondents

Name	Age	Family Composition	Household Composition	Last Occupation	Disability
Mr A	59	Married	Wife	Mechanic	Multiple Injuries
Mrs B	45	Married	Husband & 2 Daughters	Housewife	Multiple Sclerosis
Mr C	18	Single	Father, Mother & 2 Brothers	Wood Machinist	Head Injuries
Mr D	20	Single	Lives alone	Computer Programmer	Flexor Tendon Injury
Mr E	30	Married	Wife	Chef	Amputation of Right Leg
Mr F	23	Single	Lives alone	Forester	Multiple Injuries
Mr G	28	Single	Lives alone	Bank Manager	Spinal Injury
Mr H	20	Single	Lives alone	University Student	Hand Injury
Mrs I	53	Married	Husband & Son	Housewife	Rheumatoid Arthritis
Mr J	68	Married	Wife	Joiner	Cerebro-Vascular Accident
Mr K	21	Single	Father & Mother	Clerk	Head Injuries
Mr L	27	Single	Father & Mother	Aircraft Fitter	Head Injuries
Mr M	37	Married	Wife & 2 Daughters	Disabled Workshop	Spinal Tumour
Mrs N	54	Married	Husband	Housewife	Multiple Sclerosis
Mr O	32	Married	Wife, Son & Daughter	Shipyard Worker	Muscle Wastage

between patients and staff and focuses on issues left unresolved for the patient. The fifth area looks at the families' relationships with the patients, and also their involvement with the Unit. The sixth area is concerned with employment matters and the patients' views about their future job prospects. Lastly the patients' perceptions of the future following discharge are explored.

Admission to the Unit

As a way of starting the patients to talk about their rehabilitation they were asked about their entry to the Unit. In asking this question I was curious to discover how clearly they saw the reason for their admission and what they hoped would be achieved by rehabilitation.

For some patients their admission was perceived as helping them to overcome physical difficulties caused by their disability. Overcoming these difficulties held out the hope of leading a life that more closely approximated the life they had experienced before the onset of disability:

> I'm here so they can get me back to normal, nearly as I was before. As perfect as possible.
> (Mr C)
>
> They're doing all they can to get me mobile again. I've had this slight stroke you see and I've lost the use of my left side. It's gradually coming back. The physiotherapist is doing all she can to get me mobile again.
> (Mr J)
>
> They're trying to get me into a regular routine again. It's mainly my eyes. I can't concentrate for more than a few minutes. I even have to use a ruler to follow words when I'm reading. My balance and coordination

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*During the period of the fieldwork the majority of patients in the Unit sustained traumatic injuries as a result of road traffic and industrial accidents and other forms of accidental injuries. These injuries which mainly affected men, meant that the majority of patients interviewed were men. This predominance of male patients was not a constant feature of the Unit. At other times during the fieldwork the ratio of male to female patients was more evenly balanced. Patients are referred to as 'he' for convenience throughout the text.

> are poor too. I'd like to get fit again,
> but I don't know how long it will take.
> (Mr K)

Other patients had clear understanding of the specific reasons for admission to the unit:

> I was depressed and my arthritis flared up again. I had not been able to walk very much and had to have injections to kill the pain. I'm mainly here for physiotherapy. They're trying to get me mobile. Dr. .... said I'd be a lot better after spending a period here.
> (Mrs I)

> I'd been in a lot of pain with my multiple sclerosis. I had a car accident last year. I wasn't badly injured but it affected my multiple sclerosis. I broke my arm and could not use the Zimmer Frame. I asked to see the consultant because I thought I would benefit from a spell here.
> (Mrs N)

> I came here to be nearer the scene of action. I was in Stoke Mandeville and was ready for discharge. I'm getting a flat and needed some time to finalise things. I also needed some fine tuning before I move in. I wrote to the consultant myself and explained it and he offered to help.
> (Mr G)

One patient saw things very differently. Her admission being a mixture of punishment and release from a restricted home life for a few weeks:

> My daughter told the Welfare I wasn't doing anything at home. I was getting lazy she said. She's got me here to make me work. My daughter is eighteen and does lots of things at home. I'm not allowed to do anything. I've also come to get some help with my walking. If only my daughter would let me walk more. She's always going out and doing things.
> (Mrs B)

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*In reporting the respondents' viewpoints some sampling has taken place. Answers to some questions were either too brief or superficial and added nothing further to the understanding of the rehabilitation process. Other examples, where a limited number of responses are used, include questions on family relationships and employment which were not seen as relevant by all respondents.

Two patients had both remembered being given information about their admission and why rehabilitation was necessary:

> I had a traumatic amputation. I was in the infirmary, then I came here. I knew I was going to spend a long time in hospital being tidied up. In the Orthopaedic Ward they said 'we're putting you back together again. You'll be prepared for an artificial limb'. They're teaching me to bandage my leg. I'm building myself up in physiotherapy.
> (Mr E)

> I was in the general hospital, but they didn't seem to know how to help. I was raring to go but nothing happened, Dr. explained what treatment I'd get. I'd have intensive physiotherapy. I'd get tired and exhausted by the end of the day. It's everything I've been waiting for.
> (Mr F)

Two other patients were less clear about their admission to the Unit and expressed some confusion about the purpose of their rehabilitation:

> I'm still not clear what it's about. I spend most of the day in the workshop except for an hour in physiotherapy. The people are nice enough. I don't get any trouble or get moaned at. I'm not clear what they want. I suppose they're sussing me out.
> (Mr L)

> It surprised me coming here. The surgeon suggested I come here, but didn't really explain. Something about muscle wastage, it needed building up. I think that's what they're aiming for. I'm a bit 'out on a limb' here. I don't think the doctors are too sure. They've not sat down with me and discussed it.
> (Mr O)

Four patients gave very brief answers to this question: transfer from another hospital (Mr A), to get finger back to normal (Mr D), transfer to Unit to be nearer home (Mr H), treatment in Unit prior to transfer to another hospital (Mr M).

The Rehabilitation Programme

In order to find out about the patients' perceptions of the rehabilitation programme they were asked about their involvement in the initial stages of their own programme. I was also interested to discover whether the programme made sense to the patient, particularly the activities they engaged in each day.

Most patients interviewed readily complied with the staff in the operation of their programme with many feeling satisfied with the arrangements. Other patients although accepting the help offered, did not fully understand why they had to undertake certain activities. Some patients voiced doubts about not being asked to contribute more after the initial period of residence in the Unit. It was clear that the majority of patients had little opportunity consequently to modify the direction of the programme, except for those patients who staff saw as highly motivated.

> The programme's alright. I'm doing walking exercises between bars in physiotherapy. They're also showing me how to use a leg bag (urine bag) and how to empty the catheter. I've also got to slim. I'm four stone overweight. I'm on a diet. Yes, its very good I'm quite satisfied.
> (Mrs B)

> It's been alright from the start. I've had good talks with the therapists. They seemed to know how I felt. They've recognised this and responded accordingly. The programme has helped me develop a positive state of mind.
> (Mr F)

> My programme's basically exercises. You've got to do them. They tell you there are things you'll be able to do yourself. I'm getting intensive treatment. They didn't do that at the general hospital. They said there'll be an improvement after the exercises.
> (Mr J)

> Yes my programme makes sense to me. Four of them sat round and asked me questions. They worked out the programme and discussed it with me, then I had a chat to the nurses. They'll tell you if you ask questions, but they don't explain things unless you ask.
> (Mr A)

> I can't understand why I have to spend so long in the workshop, yet I only get a short time in occupational therapy. OT is helping me on a larger scale with my problems. I'd like to do something where I could use my imagination more. I've just been put on a job making wine racks, I wasn't asked.
> (Mr K)

> They ask you these questions and write down the answers. After that you're not included. They've discussed it, now you do this! If they'd say you need to do this, but you can't do that. You need help to rebuild your life, but you're just left dangling.
> (Mr O)

> They threw everything at me that first week. I didn't know which way to turn. I wished they'd have sat down and explained it to me.
> (Mrs I)

> They're fairly helpful. I'm getting intensive therapy to get the fingers moving again. I sometimes wonder what the benefit is, but I tend to accept what they say. If you ask they'll tell you what they're doing.
> (Mr D)

> Somebody obviously worked hard at designing my programme, but there's a lot of ordering around. It's very regimented too. It's imposed discipline. I would have thought they'd be looking for self-discipline. They should be teaching patients to look after themselves. The assumption here seems to be we'll organise you for a spell, then you leave and live as you did before. I don't know if the programme helps. When you've acquired a disability life's very different.
> (Mr G)

Six patients described their programme as satisfactory and willingly accepted the arrangements that had been made for them. They had no thought about their own potential role in planning the programme or questioning staff about the balance or direction of the programme.

Making Progress

Progress is a difficult area in rehabilitation. Professionals have their own conceptions of progress - for example the therapist measuring progress a patient makes in terms of increased mastery of specific physical activities, or the nurse's perspective of the patient making less demands and able to take over aspects of his own personal care and requiring little intervention from the nursing staff. The patient's perspective can mean different things although it was to be expected that greater personal autonomy over everyday activities would be significant. I asked the patients what progress they had made during rehabilitation.

> I've made a lot. I was unconscious for three weeks. First I was in a wheelchair, then on a frame. I'm walking now. I lost my speech as well, but it's getting better as well, although my memory's still bad.
> (Mr C)

> I'm walking again. I was immobile when I came here. Dr. .... said - 'we're going to get you walking again' - and he did! The doctors have pushed me very hard. It even got Sister worried. She thought they were pushing me too hard.
> (Mrs N)

Similar themes emerged from the responses of other patients. But for others physical improvement was only part of their perception of progress.

> It's evident I've made considerable progress, in terms of hand movement, but that's not the most important thing. Losing your thumb and part of a finger, what does that mean? Rehabilitation has got my hand moving, but not in other areas. That doesn't help me. I would have liked somebody to work with me. I don't think the Unit can help my problem of what I'll look like.
> (Mr H)

> I've seen a lot of progress. I couldn't stand up when I came here. I can stand now on my own and walk with a stick. I'm worried about this arm though (left-sided hemiplegia). I hope it doesn't affect me too much. I used to be very active - the crib league and gardening - I'd like to do that sort of thing again. They tell me I'm improving. I hope so.
> (Mr J)

Another patient who was highly motivated constantly monitored his own progress. He was liked by staff and had a positive relationship with therapists and nurses.

He received considerable feedback from staff who were interested in someone who showed commitment to the programme.

> I've made good progress here. I've got more arm and leg use, and I'm making a saw with my foot. It's helping my balance. I came here with a very positive attitude. I was convinced I'd get better, even though the doctors keep telling me it'll be a long time. I've put all my efforts and will to that end. The staff know that.
> (Mr F)

In spite of enormous effort that was recognised by all around him this patient still had doubts.

> You just don't know about time scale. Recovery could go on for years. Each injury is different and I haven't made as much progress as I expected.
> (Mr F)

Similarly two other patients had made an initial improvement that they felt had not been maintained and they raised doubts about how much more progress would be made.

> I think I've made progress. The main thing is how I feel in myself. I don't get so frustrated now so that must mean progress, but I think I'm slowing down. I've not improved so much recently.
> (Mr K)

> I did improve at first. I haven't had double vision since Christmas. I don't think I've made any more progress. I've not improved since then. I don't really know if I'll get any better.
> (Mr L)

For other patients the unit enabled them to see themselves positively as a result of undertaking everyday activities that had been denied them at home for a variety of reasons, either because of enforced dependency or firmly established roles within the family.

> I've moved from the ward to the hostel now. I can make coffee now. I never tried that at home. The wife didn't like me doing it.
> (Mr A)

> Since I've been here I've done washing and ironing in the bungalow, (ADL bungalow). I've made a cake and used the washing machine. I'm never allowed to do that at home.
> (Mrs B)

Patient-Staff Relationships

This section is concerned with the relationship that existed between patients and staff, particularly where that relationship could be used to assist the development of the patient during the rehabilitation process. The communication of information is of crucial importance to the patient, since he needs this information in order to make sense of his situation, but also to learn what adaptations he needs to make to his lifestyle. Consumers of professional services often feel that they have difficulty getting satisfactory replies to their questions. Professionals are sometimes seen as unsympathetic and unable to communicate their knowledge effectively. There is also a strong tradition in medicine of giving patients only sketchy information about their condition. Patients are not seen as people who are entitled to know about matters that may affect them for the rest of their lives. The other area of difficulty is giving bad news. Sometimes, again for a variety of reasons, professionals feel that the true situation regarding a person's condition is often too bleak to reveal. This results in their information being indirect and vague with critical areas (for the patient) skated over.

These issues were explored by asking patients what opportunities they had to talk with staff about their situation, and whether there were staff they could identify who were willing to listen to their concerns.

Several patients felt they could discuss their problems with members of staff, although these statements were qualified as some staff were easier to relate to than others. Patients also worried about initiating conversation about topics they felt staff could not be interested in hearing. Other patients felt that staff communicated their criticism of them and they naturally avoided discussion with staff:

> I talk to ward staff when they're dressing my limb. I talk to the physiotherapist a lot about progress. I want to know if they're satisfied with my progress. They're in the know so I ask them - I don't have any guidelines to go by. Am I doing well or doing badly? They don't seem to mind listening to me. But I'm sure they don't want to hear about all your little home problems. I don't make much fuss.
> (Mr E)

> I'm worried about how long I'll be here. I don't know when I'll be able to drive again. The one thing I love is my car. The nurses said I wouldn't be able to drive for two years. I haven't tried to talk to the staff. Anyway I don't think they'd want to know about my worries.
> (Mr L)

> I don't know what the future will be. I wish they'd come out and say so. You don't know how far you can go. You fire questions, hope to get an answer. I just wish they'd admit it if they don't know what's wrong with you. Talking with other patients it's the uncertainty that really worries them. Uncertainty, it's a bugger! Patients must be told, not kept in the dark. Probably they (staff) don't know.
> (Mr O)

> I think they're (staff) interested. I talk about my husband and daughter. I carry some photographs around in my bag, but I've not got them to look at them yet. One of the men (male nurse) is very good. I can talk to him. He'll talk about the family.
> (Mrs B)

For some patients their relationship with particular members of staff created problems that must have undermined their progress:

> The physiotherapists have helped me to do what I want to do. They're right to let me decide I'm mature enough to know what I need to do. On the ward though, I get little lectures. It's done with the best of intentions but you don't talk to people like that, we're not old ladies. The senior nurses are better, but the assistants order you around. One got very upset when I

> refused to do something that was impossible for me. I also had trouble over the drugs. When I came here I had my own supply. They took them off me. You ought to be able to keep your drugs. You need to have that responsibility.
> (Mr G)

> If you're late for your programme some of the nurses shout at you as if you're a kid of two. The physiotherapists and OT's have been quite good to me and helped as much as anyone. I think some staff just have an extreme aversion to people with my sort of problem.
> (Mr H)

For other patients the way team members spoke to them conveyed a message that they were incompetent or inferior in some way, including Mr O quoted above:

> In the workshop after something has been described to you, you feel about 3 years old in the actual way they speak. It might be just me but there's a couple of other people, patients, have said the same thing.
> (Mr K)

> The doctor said if you were a professional footballer you'd soon be out of here. He was implying that I was just malingering. I've got a job that's just as important that I get back to work. A student physiotherapist made a similar snide remark when I wouldn't do an exercise fast enough. She implied I was malingering too. It seems anything they can't see on an X-Ray, it must be in your head.
> (Mr O)

For one patient committed to returning to his job which was still open to him, the blunt statement that could have undermined his commitment to the rehabilitation programme was highlighted by his reaction to a remark by a doctor:

> He came out with a crack I didn't like. Had I thought about early retirement? It took the wind right out of my sails. Oh blimey! I'm trying to get myself better and get back to work and they come out with early retirement. I was disheartened that day. I could have packed my bags and gone home there and then.
> (Mr A)

Another patient who had been admitted to the unit specifically to deal with her mobility problems, resented an insensitive and inaccurate remark made by a social worker:

> The social worker said to me, you'll have to face the fact you might not walk again. That upset me, I was crying. I talked to Sister. She asked a nurse to get me a frame. I walked across the ward. I walked further yesterday. I proved I could walk again. I'm a strong willed person, I'm going to fight it every inch of the way. (Mrs N)

Trying to get information in order to plan the future was a theme that ran through many patients' accounts of their rehabilitation. Mr K quoted earlier was particularly concerned about difficulties in this area:

> I've asked several times now. My main worry is my sight. Will I be able to think about work again after I leave hospital? One way and another it's just been skipped around. The only thing I can think of is that nobody knows if my eyes are going to get better. But even if they tell me something I don't want to know I wouldn't get upset now. It's over a year since the accident. I've come to accept things. I'd just like to know, after all it is my body. (Mr K)

The Family Relationships

The role of the family is important in the life of the disabled person. The family can be a support to the patient and provide the reassurance that he/she is still an important person and is loved by his family. On the other hand the family may resent the patient's new status as a disabled person. Feelings of hostility may be mixed up with the guilt when the patient's needs are great and the family is asked to shoulder the burden of caring. Much has been written about the impact on the family of one of its members becoming disabled. The disability is seen to 'spread' and disable the able-bodied members of the family. Certainly the whole family structure can be altered by one of its members becoming disabled with changes in roles that have probably become firmly established.

The questions in this area were concerned with how the family had reacted to the patient's disability, and what problems this had generated. Nine of the patients had close family links and felt they could answer this question.

Those patients with a long-standing disability tended to have worked out patterns of family life that enabled their needs to be met, although in some cases, in a restricting manner:

> My husband needs a break every so often. He just can't cope with me when my MS (multiple sclerosis) is bad. He's very good. He does the cooking and helps with shopping, but he's got a nervous disposition and it gets him down.
> (Mrs N)

> I've got a good family. We do things between us. It makes all the difference. The family always rally round. Originally they all jumped up to help when my arthritis got worse. They wouldn't let me do anything. Now they let me be independent. I need help with a lot of things, but I try to do it for myself first. I'm lucky the family all live close by and will offer to help if I need it.
> (Mrs I)

> My husband's very good. I think he just accepts it. I've been in a wheelchair for twelve years, since my little girl was two. They do a lot of things for me. My little girl gives me a bath and washes my hair.
> (Mrs B)

But in spite of this help and support Mrs B felt restricted by her family who obviously found her a source of friction at a number of levels, particularly with her eldest daughter who had been instrumental in arranging her admission to the Unit.

> I'm never allowed to do things at home. My daughter says I'm lazy. She's sent me here to make me work. I'm a housewife but I don't really do the cooking. My daughter says, 'go into the living room and keep out of the way'.
> (Mrs B)

Similarly in her relationship with her husband strains in the marriage were apparent, with her dependence and limited abilities generating conflict. One particular area of concern was her feelings about her sexuality since she had a catheter inserted to deal with a bladder problem:

> I was a bit against it at first. I didn't think he'd like it, I think it puts him off. He says it's not the same as it used to be (sexual intercourse). 'You don't come now do you'. The sister suggested I get some cream. My daughter got some from Boots. I think it's better. Sister suggested he put some cream on himself. He tried it once, it was much better. I went home last week-end but he didn't have anything to do with me. It might be better next week-end. He goes out for a drink and comes back late. He says he's too tired when he comes to bed. He says he's got to get up early for work.
> (Mrs B)

Another patient who had been admitted for investigation also reported difficulties in his family relationships:

> My wife's a worry. She gets frustrated, you know, sexual. I can't do nothing with all this around me, (in-dwelling catheter). I've written it off, (sexual intercourse). We're happy enough together, but once in a while she gets fed up. I spoke to the male nurse. He mentioned it to the social worker. We had a long chat. I got it off my chest.
> (Mr M)

One of the younger patients whose disability had resulted from an accident had come to realise that his previously close and enduring relationship with his girl-friend no longer meant so much to each of them. The extent of his head injuries and the consequent memory loss created a barrier between them that neither had been able to overcome:

> I was going out with the same girl for over two years when I had my accident. I just can't remember now what we did, what she liked. The hospital gave me four days to see if I could remember May on my own. She was there all the time. In the end I had to ask who she was. When I went home she used to ring the hospital every night and come and stay when I went home at week-ends. She used

> to get upset. She'd be talking about things we'd done. I just didn't know. That used to get her depressed. We decided to give it a trial without seeing each other. At first she used to ring each night. She rings occasionally now. It's going on like that. I'm not sure about the future.
> (Mr K)

An older patient with a good relationship through many years of marriage to a supportive wife had not been able to talk to her about his fear of not working again:

> She copes well, she manages me well. She's just thankful it didn't affect my brain. She thinks like me, I'm going to get better. Like me she thinks I'm going back to work. I've not told her what the doctor said. I'll have to sometime. I don't know how she'd take it.
> (Mr A)

A younger man who had a leg amputated following a road accident spoke warmly of his wife's support and commitment to helping him adapt to living with an artificial limb. She had provided some of the inspiration needed to work at his rehabilitation programme.

> She's accepted the disability wonderfully. She's given me lots of encouragement, and got a lot of pleasure from seeing the progress I've made. She insisted on seeing the wound dressed. Now she's learning to bandage the wound. It's helped me enormously. I haven't had to hide anything from her.
> (Mr E)

For some patients disability meant more restricted lives, with fewer opportunities to lead active social lives. The realisation that these changes would take place had begun with the falling off in contact with friends during their stay in the Unit, which were portents of the future. A patient who had suffered severe head injuries following a motorcycle accident had been told he might not ride again. He'd lived in a remote country area and had depended on personal transport to maintain his social life:

> My mum and dad and two brothers are at home, but I won't have a bike (motorcycle) to get round on. I won't be able to go

> out with my mates now. I just won't see people I used to see before. I'll grow further apart from them. I'll be stuck at home.
> (Mr C)

Lastly disability could also mean the inability to participate fully in family activities with the threat to relationships implied by this patient's response:

> I'm a married man with two children. It's affected me. We can't do the things we used to do. My wife likes ice skating but I have to sit on the side now like a dummy. It's a disappointment for the children too. They say 'dad can't do it now'. It's put a barrier between us.
> (Mr O)

Employment Prospects

The importance of employment was a concern voiced by many of the patients in the Unit. Work with its importance, both in terms of the person's lifestyle and his status in society, was something that patients had become aware of during their stay on the Unit. Most disabled people, however seriously impaired, would wish to work. By saying this disabled people wished to be valued in the same way as the able-bodied person. Work brings with it important consequences, both in income that enables the individual to acquire access to material things that make life more comfortable, and in reflecting the personality and interests of the individual. Work is also a major determinant of a person's status in society, and consequently the esteem he is held in by his family, friends and community. The risk of unemployment with the deprivation of normal expectations is something familiar to many disabled people. The link between disability and unemployment has been well documented. With a significant proportion of disabled people unemployed this was a future that patients in the Unit feared.

For ten patients, all men under retirement age, work was a preoccupation. They were concerned both about maintaining their current job or finding new employment after discharge from the Unit.

One patient who had entered the army on leaving school and had worked as a mechanic at a nearby army barracks had found his employer concerned and supportive. His job was being held open for him and he received full pay whilst in hospital. His captain had been to visit him twice and a car had been provided to bring his wife to the hospital to visit him. Although his employer showed positive concern, he was less confident about the future. His multiple injuries had resulted in physical impairment that caused him to question whether he could effectively carry out his duties in the future:

> One leg's shorter than the other, my pelvis has been damaged and I've got a plate in my elbow. I can't bend over for any length of time because of the pain in my chest. Getting back to work is my one intention, but I'm never going to inspect or examine vehicles again. I won't be able to crawl under vehicles, and I can't use the accelerator or brake now. Work's my hobby. I joined the army as a boy apprentice, I've been with the army ever since. My father was in the army too, I was born in the army.
> (Mr A)

For another patient work held out one of the main opportunities to regain something approaching his existence before his accident which had resulted in a spinal injury. He was fortunate that, as a bank employee, he could undertake many of his previous duties from a wheelchair. Nevertheless, he still had nagging doubt about his continued employment and the risks to his future lifestyle if his employment was terminated.

> I worked at ..... Bank before the accident. With the label tetraplegic I think they thought I was a vegetable. I've already seen the bank's medical officer and my division of the bank is receptive to me returning to work, but head office is less sympathetic. I know there are problems with a tetraplegic working, but if I can get back to work I know I'll be O.K. The alternative looks like a low quality life.
> (Mr G)

Although employed as a chef originally, following an amputation one patient had niggling doubts that his disability might restrict his employment in the future. He had been told his job was being held open for him. This had encouraged him, but an examination to follow caused him anxiety.

> I've got to go before the medical board. I may be a work hazard, you know, slipping or falling in the kitchen. I might have to do a different job. I just hope it won't mean a cut in pay.
> (Mr E)

A patient who was recovering from head injuries, following a road traffic accident had considerable doubts about employment in the future. He had been working as an aircraft fitter in Germany at the time of the accident for a firm with its headquarters twenty miles from the Unit. He had since lost his job and had started to press the staff in the Unit. He had recently had a visit from a Disablement Resettlement Officer (DRO), from the Department of Employment.

> The foreman (Heavy Workshop) and the psychologist are trying to get me on a refresher course. But will it come off, I don't know. One or two official people here might say 'no, we don't think he's that good'. I've just got to sit and wait.
> (Mr L)

Mr L had already begun to receive confirmation that the 'officials' did not think he was suitable to return to work in the aircraft industry.

> The DRO suggested an Employment Rehabilitation Centre, (ERC). Portsmouth and Bristol were mentioned. He gave me some leaflets. He said there might be some difficulty getting work. There's not much about now. The foreman said the same. It'll take some time. I just don't know what will happen to me job-wise. I do want to work. I want to keep my mind active.
> (Mr L)

For another patient, recovering from head injuries caused by a motorcycle accident, a depressing future looked likely with a placement in a workshop in a village for disabled people. He had already attended an ERC - following discharge from hospital, but since he had been transferred to the rehabilitation unit. At the time of the interview he was having difficulty with speech. His memory was also poor for some past events.

> I was working previously. They held my job open till October but I've lost it now. They're trying to place me at the disabled workshops, but I'd like to go back to my own job or try bricklaying or something.
> (Mr C)

For patients whose injuries were less serious and who had well-defined skills in jobs that could be undertaken by a person with physical impairment, the future looked brighter. One patient had been made redundant then obtained a new post only to find himself hospitalised due to a tendon injury caused by a corkscrew when opening a bottle. His work as a computer programmer was something he was keen to resume quickly, and so avoid the risk of further unemployment.

> I'd been unemployed then this happened. It affected my work, but they're holding my job till I'm well again. I want to get discharged and get back to work. I'm bored here. It's tedious on the ward. I want to get started again.
> (Mr D)

Another patient who also had a job to go back to was nevertheless worried that his disability would affect his employability in the long run:

> I'm not sure about my job future now. Climbing up ladders in ships puts pressure on me. I'll have to reduce that part of my job. It's causing me concern the not knowing.
> (Mr O)

Two patients had similar concerns, that they were reaching the end of their period in the Unit without any concrete job proposal or retraining arranged:

> I haven't had any guidance. They've not helped me sort out what I'm going to do in the future. I need someone to

> look at my occupational history. Someone who can help in that way.
> (Mr H)

> It was a very physical job. That's all over now. I could fall back on my design training, but I'd need more training. There's been some talk about seeing the DRO. I'm very concerned about occupation in the future.
> (Mr F)

Lastly one patient had been offered help to look at his future employment needs, but still had many problems resulting from head injury. He was keen to make progress, but lacked confidence when employment options were offered.

> I was asked to see somebody from the Job Centre with the view to going to an ERC. I just didn't feel ready. It was all arranged for me by the social worker. I feel she was pushing me too quickly. I'm not ready to start looking at employment yet. I still need a lot of help to get about so how can they think of employment. Work's going to be difficult anyway. I knew that from what they told me.
> (Mr K)

The Future?

The final area of questions concerned how the patients saw their future following discharge from the Unit. A particular area of interest here was how the patient perceived that disability would affect their lives. The patient has to balance on one hand, managing a problematic situation where he attempts to limit the extent the disability affects his life, and at the same time accept that limitations such as reduced functional capacity may be present. How much had patients begun to lower their expectations about their future activities and abandoned unattainable normality, and replaced it with a reconstructured normality based on the experiences of what was possible to achieve in living with a disability?

For some patients the future held out fear of re-entering a world where their reduced capacity would inevitably bring problems. Also a world where many of the support and networks established before disability would no longer exist. The one factor that seemed to be present in most interviews was that of uncertainty. The future for most patients was unclear both in terms of their personal progress, but also in areas such as social and community life and employment as can be seen from the following extracts.

One patient recovering from multiple injuries had doubts about whether he would be able to resume his employment and expressed feelings that indicated he was still unable to resolve the uncertainty that was constantly in his thoughts:

> I try not to think about it. I dread thinking about it. It's my one ambition to get fit and get back to work. I've got one leg shorter than the other, but a new boot's been made with a built up sole. Once I can manage that and flex my foot, I might be able to drive again.
> (Mr A)

For another patient severe head injuries with some loss of vision meant that he would be dependent in the future. The loss of memory following his accident also posed problems:

> It'll make me a great deal more dependent and I don't like that. I'm not able to get about on my own. I can't even go for a walk. I can't see traffic. How could I think of employment if I can't go out without help? Six years of my life have been wiped out. I suppose it's a chance to start again. What worries me is I don't like asking. I don't like putting people out.
> (Mr K)

A patient who had already completed his rehabilitation programme recognised that disability would now have a major influence on his life:

> I'm extremely disabled. It colours your entire outlook on life and what you can do in the future. It'll cause major problems and I know it'll be expensive. If I can get back to work that will make the difference, otherwise life will get worse.
> (Mr G)

Mr G already identified with his new disabled role to the extent of seeing himself as someone who could make a contribution in assisting other disabled people:

> I've made friends with people in wheelchairs. I'll contact disabled organisations and see if I can help. We can all reciprocate and help each other. (Mr G)

A patient whose disability had resulted from a suicide attempt recognised he was not seen sympathetically by some staff, particularly the nurses on the rehabilitation ward. His forthright opinions also made him unpopular and this appeared to have isolated him further from staff. He recognised that he needed guidance on planning his future, but he had not received the help he needed. He was cynical about the Unit's willingness and ability to help:

> My life's been interrupted, but life was pretty sour before the injury, I need someone to look at me, somebody who could help. People haven't asked or discussed these things with me. There's been some discussion about benefits, but areas like managing myself haven't been dealt with. (Mr H)

Almost at the point of leaving the Unit, two patients anticipated some of the difficulties they might face when they were no longer part of an environment that took account of their disability:

> Leaving here's going to be difficult. It's O.K. here, we're being watched and helped. When you go out into real life it'll be a different kettle of fish altogether. You're here for a period of time; then bang goes your lifeline. You think at first that coming here you'll be normal again. If only they (staff) would come out and say 'you'll be able to do these things, but you won't be able to do that' - it would help you begin to restructure your life in the future. As it is you're left dangling. (Mr O)

> I think I'm prepared for the fact that things may not work out, or that people will not be as kind as they are here. I also know now that recovery can go on for years.

> I can't do a lot of things. I made a lot of progress at first, but I'm on a plateau now. The trend looks downwards. I'm not making any more progress.
> (Mr F)

Lastly, for three patients with progressive conditions the future was predictable. They all had long experience of the limitations of disability and were resigned to further restrictions:

> I don't like to think I'll be too disabled. I hope all the time I'm going to get better, but I know I won't. I've been in a wheelchair too long. The family will do things for me, but I'm not allowed to touch anything in the house. I just have to accept it.
> (Mrs B)

> It'll be very much as before. I shall have to come back here from time to time. I know increasingly I won't be able to do the things I want to do. I've looked at it and accepted it. It still comes hard particularly when you were once active.
> (Mrs I)

> I try not to think about it. It takes a long time to get back to square one (following the recent flare up of multiple sclerosis). It'll be three to four months at least. I'm looking forward to leaving here so long as I can do some things for myself.
> (Mrs N)

Discussion

The aim of this Chapter has been to focus on the patients' perception of the rehabilitation process. The areas chosen for investigation were ones that seemed important by the author following the period of participant observation. The evidence suggests that the overwhelming feelings for many patients were of not knowing what the future would hold for them. Although the perceptions are at times muddled and inconsistent they nevertheless communicate tellingly the feeling of isolation and uncertainty many of the patients felt during their stay in the Unit. Such feelings were shared by others and increased markedly towards the end of their stay, as they prepared for discharge. Most often patients interviewed were striving to make sense of what had happened to their bodies, and searching for milestones that could be used to measure their return to a non-disabled or less disabled state. Of course the future for many of them was uncertain. The impairments to their bodily process were still present and disabling, and the lack of information available to them, allied with limits to professional knowledge, further exacerbated their difficulties. The process of rehabilitation in the Unit, from admission through to discharge, appeared to be permeated with doubt and anxiety. This was partly as a result of the patients' lack of knowledge about their condition, and partly the ethos of the Unit. This kept the patient firmly in the 'sick role', and offered him little opportunity to relate directly and frankly with staff, in a relationship of equality that would facilitate a genuine sharing of information about his situation.

First, admission to the Unit was seen by most patients as offering the help they needed in order to re-develop those abilities they had taken for granted before becoming disabled. This included the physical therapies to increase their levels of independence, or the provision and mastering of compensating aids such as artificial limbs, to restore functional activity to previous levels. For patients who were uncertain about their diagnosis, the purpose of admission to the Unit was less clear. The lack of clear communication by the referring consultant, or at least the patient's lack of understanding, was an important factor in the patient having misconceptions or confusion about the purpose of rehabilitation, and made it more difficult for the patient to feel enthusiasm for his programme.

Second, the construction of the rehabilitation programme tended to be 'directional' on the part of the staff, particularly where the patient was unclear about what they wanted to, or were expected to achieve in rehabilitation. It appeared that a patient joined a programme that was already determined before he arrived, and that he was 'slotted' in to the activities on offer. The opportunities for any deviation from the set programme were minimal because the activities were well developed, and relatively unchanging, irrespective of the individual patient's needs. This approach meant the patient's opportunity to contribute or subsequently negotiate modifications was severely limited. The risks were of influencing the patient's expectations about his own abilities, and creating a sense of helplessness early on in the programme which would persist and would have been difficult to overcome as the patient adjusted to his role within the Unit. The exceptions to this situation were some few young and highly motivated patients who found ready allies in the remedial therapists, and to a lesser extent nurses.

Third, measuring progress in the rehabilitation process is a complex matter. Progress is often a social judgment which depends on the opinions of patients and staff. The patient's perception of progress is also influenced by the feedback he receives from the different staff in the Unit. The patients tended to see their progress in terms of increase in functional ability, although this was not necessarily their only criterion. Other factors, such as physical appearance and opportunities for new role relationships based on their increased competence in everyday tasks were also areas of concern. The difficulty for the patient is that each discipline has its own judgments about what constitutes progress, but these judgments may not be the most significant to the patient. It is also likely that no professional judgment is offered on the less tangible areas of progress related to adjustment and self-concept, which are just as critical for progress as the more obvious and often measured activities such as bodily exercises.

Fourth, the relationships that existed between patients and staff on the Unit were critical for the effectiveness of the rehabilitation process. Relationships with the emphasis on creating positive caring attitudes towards patients is an important factor in establishing and maintaining effective treatment programmes. These sort of relationships were not apparent in the Unit. From the comments of patients many found their relationships with staff were unsatisfactory for a number of reasons. Firstly, patients often felt that staff were not open and frank with them about their situation. Even when patients realised that staff did not have the concrete answers they were searching for, they nevertheless would have appreciated more discussion to try to reduce uncertainty. Secondly, patients in a rehabilitation unit are invariably sensitive about their situation. Here the tactless remarks, unwarranted criticism or cynical aside by a member of staff, could hurt the patient and make him feel inferior. Lastly, patients often remarked on the manner in which they were asked to undertake activities within the Unit that indicated that they were no longer responsible adults, but in fact children. Staff were not always naturally therapeutic in their relationship (and this resulted in patients feeling uncomfortable in relating to staff), nor attempted to enter into a dialogue about the patient's disability. Some of the traditional features of communication within a hospital that placed the patient in the 'sick role' with its submission to the greater expertise and power of the professional fitted uncomfortably in a Unit committed to improving the ability of the patient to manage himself.

Fifth, the patient's relationship with his family and their involvement in his treatment was an important factor in the rehabilitation programme. When disability strikes every member of the family is affected, and this knowledge should underpin the practice in a rehabilitation unit. It was clear from the interviews that many patients had difficulties in their relationship with their families, particularly spouses. Problems concerning dependency and how this affected roles and expectations within the family were apparent, particularly where patients had chronic illness, and provided with long-standing support by relatives. For other patients difficulties in relationships and ability to meet sexual needs of their partner were apparent. For some patients the onset of disability had seen a contraction in their range of relationships. These could be close personal relationships with another person or the looser relationships of friends. The social isolation that faced these patients was apparent and they voiced their anxieties about their future life-style. Although the Unit invited relatives to discuss matters with the staff these seemed to be gestures at family rehabilitation. The full involvement of the family with substantial help to either support their caring commitment, or overcome or reduce their opposition to rehabilitation goals was needed. It was certainly clear that patients and their families were not getting the level of counselling and support needed, particularly in areas of marital relationships, and unnecessary dependency roles within the family.

Six, employment was an important talking point for those patients of working age, who almost unanimously held on to strong hopes of being able to work in the future. Most of these patients had either lost their previous jobs, or were hoping to return to work, although with the knowledge that their disability may mean a change in responsibilities, with the possibility of a reduction in income. Those patients with employment who were nearing the end of their rehabilitation in the Unit had been visited by the Disablement Resettlement Officer, and had been tested in the workshops using work assessment measures. Again what concerned the patients was uncertainty; the lack of any clear indication of whether they would be able to work in the future. It was possibly unrealistic for them to expect staff to offer very concrete advice, but of more concern was the way in which patients worried and in some cases were preoccupied with their employment prospects. There was no clear evidence that staff were sensitive to these concerns, and many patients found no one among staff who could answer their questions satisfactorily, or more realistically listen to their worries. The major importance of work in the lives of these patients was something that needed more recognition, and counselling should be provided to help support the patient until more concrete information was available.

Lastly, the future for the patient is something that is often impossible to predict during rehabilitation. The patient makes progress in certain areas, particularly functional, that indicates to staff that he is now able to manage independently, or with the help of a supportive family or community services. It is also important to remember that demands for new admissions will result in pressure to discharge patients so that his bed can be made available to another disabled person awaiting rehabilitation. For patients on the Unit the anxiety about what the future would be like was strongly expressed. Most patients recognised that their disability would affect them in the future, both in their personal and working lives. Although most patients had been home for week-ends, many still felt they were not prepared for the future. Preparation for independence needs to begin on admission to the Unit if the patient is not to become institutionalised into the dependent role. But there was little evidence of a coherent approach to this area. Patients were leaving the Unit with feelings of doubt about themselves increased by the way the Unit had responded to them. Instead of increasing their mastery and positive feelings of self-help, patients had been 'managed' in a directive way which offered only limited assistance for living an integrated and independent life following discharge.

In conclusion the main themes to emerge from the patients' responses was a rehabilitation unit geared up to meet the patients' functional needs by the use of physical therapies, but less aware of the psychological and social needs of patients. The latter needs were voiced strongly by some patients, but staff were also often unable to respond due to their inability to perceive the difficulties patients were experiencing. Some staff also felt themselves to be at the limits of their knowledge and avoided involvement in painful areas that they could not handle.

In addition to these difficulties were their feelings about the nurses in particular. Many patients voiced strong criticism of their handling by nurses. These usually centred around feelings of humiliation as a result of the nurses attempts to 'manage' patients who did not comply, often quite understandably, with the demands of the ward or Unit. This latter area had significance for how patients saw themselves. On one hand participating in therapies to increase their independence and coping skills, and on the other hand being treated in a dominating manner which resulted in patients resisting the nurses' efforts to help them more generally.

6 THE REHABILITATION UNIT: THE STAFF'S PERCEPTION

Whereas the previous Chapter focussed on the patients' perceptions of the rehabilitation process, this Chapter deals with the staffs' views and perceptions of that process.

The interviews with staff took place following completion of the patient interviews. It was during the latter stage of the fieldwork that some of the important issues became clear and the interview schedule used with staff reflects this increased understanding. During this period of the fieldwork I was able to visit the hospital on a weekly basis and interview members of staff who represented all the disciplines working in the Unit. The interviews with staff included the nurses working in the ward and hostel and also the medical registrars. In the rehabilitation departments I was able to interview the physiotherapists, occupational therapists and workshop staff. In addition the occupational therapists based in the daily living bungalow were interviewed. The supporting staff included the psychologist, social worker and speech therapist who were also interviewed.

The format of this Chapter follows closely that of the previous one. The first part is concerned with the staff's understanding of the purpose of rehabilitation and the patients' participation in the rehabilitation programme. Secondly, the staff's views of the patients' progress are explored, including their ideas about its measurement. Following this is the closely related topic of the staff's views of patients who are perceived as unsuitable for rehabilitation. The fourth section examines the extent of relationships between staff and patients, including discussion of issues that patients find difficulty in raising with staff. The fifth part concentrates on the staff's perceptions of the patients' readiness and ability to return to their own homes. Lastly there is an exploration of the coordination of programmes within the Unit, and the level of cooperation between the different disciplines.

The Concept of Rehabilitation

As a way of encouraging staff to talk about the Unit and the rehabilitation processes they were asked the question, 'how would you describe rehabilitation?' I was concerned to discover what perspective they took on the broad question as it would begin to indicate both how they saw their role in the Unit, and how they saw the patient. One group of staff gave replies which were brief and succinct statements that saw rehabilitation as a body rebuilding exercise in readiness for some form of near-normal life in the community.

> It's getting a person back to as normal a life as possible. Obviously they won't be 100% fit, but it can be a gainful life - working and being a useful member of the community.
> (nurse)

> It's the common aim of getting them home. Encouraging, supporting and training them to lead an independent lifestyle.
> (nurse)

> It's treatment that enables the patient to have a normal lifestyle in all areas. We're making patients fit for life again.
> (occupational therapist)

For other staff this was a restricted view of what rehabilitation could achieve. They saw the patients' viewpoint as being significant too:

> I think it's working with people on what they want to achieve. They set their own aims anyway. They're not always realistic, particularly if they've got head injuries, but they can achieve their maximum potential.
> (occupational therapist)

> I think it's to help people achieve the goals they've set their mind on. We help them achieve that. They've got to accept life, though, as a handicapped person.
> (nurse)

> I can't define it. It's basically a problem solving activity, where the patients define the problem. It's irrelevant to try to put them in a pigeon hole. I don't think I can give it a definition.
> (psychologist)

Two staff saw further dimensions to the question that needed to be taken into account when trying to describe rehabilitation:

> It's about improving the quality of a person's life, both physically and mentally. It's having an idea about the optimum the patient's capable of within the limits of their disabilities. I try to find out what the patients' aspirations are. There's plenty of pat answers but it's much more difficult to explain what you try to do. We have to be aware of so many limitations the patient has.
> (doctor)

> It's a wide open thing. I hope to look at all aspects of the person, not just their home and work, but their leisure and hobbies. I think about when they go back to their family, it's important to look at the family. We have to retrain them sometimes to accept a 'new' or 'changed' member, especially the younger patients.
> (occupational therapist)

Having established how some staff saw the rehabilitation process it was then important to examine the patients' role in rehabilitation. Treatment in hospital tends to be formulated along the lines that staff see as important. Hospitals are designed to dispense treatments that assume the passivity of the patient. The goals and solutions to problems are those of experts who have authority over the patient and control and dictate the treatment programme. This approach can deprive the disabled person of his right to self-determination and can undermine how the person sees himself as a coping individual. There are also stereotyped views of disabled people held by professionals, which tend to see limitations in one area, say an amputation or spinal injury, resulting in problems to the person in other areas of their life and that person being seen as 'helpless'. This view of the disabled person reduces his potential to maintain some control over his situation and negotiate with the experts in order that all the options remain open to him. In order to discover the staff's views on these issues they were asked, 'What involvement patients had in planning their rehabilitation programme?', and secondly, 'whether the patient could re-negotiate his programme subsequently?'.

For most staff a disciplined approach based on a programme designed by remedial therapists was seen as necessary. This approach did not indicate much opportunity for patients to be consulted or involved in the planning or direction of the programme. The following extracts are typical of the staff responses:

> The programmes have to stay as planned, otherwise a lot wouldn't attend the sessions. It has to be firmly regimented. The patients usually stick to what they're doing. Very few ask to change. It's strange at first, but once they get used to it they seem to accept it. There's no serious problem of .... 'I'm not going to go to ....'.
> (nurse)
>
> They're given little choice. Things they don't like doing they need to do for their own good. Some wouldn't want to go to the programmes if not.
> (nurse)
>
> They're not given any choice initially. The patient accepts what is initially. The patient can ask for the programme to be changed. It can be, if the reason is a good one.
> (occupational therapist)
>
> In the beginning it's structured. The therapists know best, which muscles need exercising. If they don't like it they default or go missing. If it's the workshop and the person hates it, they can give them a change.
> (nurse)
>
> Programmes are 9-5 p.m. They've got to be structured in every possible way. They're allowed their freedom in the evening.
> (nurse)
>
> We just tell them what their programme will be. They don't have any say in it. If we think something's beneficial they've got to accept it.
> (physiotherapist)

> I take over the patients when they reach the first stage. I push them hard. I work them as hard as they will allow me to. It's diversionary for many, they've no chance of working in the future.
> (workshop manager)

> There's an expectation about what a patient will do. We don't have too many problems over here. It's a vital part of their programme and if they won't take part there's no point in coming. If there was a clash on this it would cause difficulties, but that hasn't happened.
> (occupational therapist)

> I tell them if they don't pull their weight. They need to know they're doing it for their own treatment, not just for me.
> (occupational therapist)

One member of staff recognised that there were difficulties facing patients, but that the approach taken in the Unit was not necessarily helpful to the patient long-term:

> The patients are usually amazingly co-operative. The doctor said, I've got to come here, you know best. It's the medical model. They pass over responsibility for getting well to the professions. It's difficult for patients who've been ill for some time. They're not prepared to take up responsibility. We ought to be providing facilities for them to take control. There's room for negotiation. We don't need to be that inflexible.
> (occupational therapist)

One member of the staff introduced the idea of greater patient involvement:

> I suggested we should ask Mr. .... how he felt about the decision to discharge him, but the others present at the meeting thought this suggestion a bit odd.
> (psychologist)

Another member of staff indicated that opportunities to influence the rehabilitation programme were dependent on personal factors that favoured some patients more than others. It was also clear that some activities were recognised by both staff and patient as having little therapeutic value:

> If the patient is able to communicate with staff and is popular they can negotiate over their programme. Any change in their programme does depend on their popularity. Some patients understand that and know how to negotiate. Others can't and don't understand how to get things changed. It's particularly difficult with the workshop. They are sent there for diversionary reasons because there's no more time for other therapies. The referrals are inappropriate and staff know it and they don't give the person help. The patients pick this up and feel badly about it.
> (doctor)

Patients Who Make Progress

The next area explored concerned patients' progress in rehabilitation. It was apparent from the observation notes that the word 'progress' occurred frequently in staff discussions and remarks about patients. I was interested to discover whether some patients are seen more positively than others in their progress in their programmes, and also how staff measured the progress patients made. Staff were first asked the question: 'Could you describe the patient who makes progress in rehabilitation?' For many staff progress in rehabilitation was perceived in terms of the patient's motivation including attitude towards treatment, returning home and some pre-disability lifestyle:

> It's somebody working to achieve something; wanting to go back to something. It's got to come from the patient. Somebody really determined will be more likely to make progress.
> (nurse)

> The one who's determined. The one who listens to what they're told and what's asked of them. Patients who don't go ahead and try to do it their way.
> (nurse)

> It's the younger patient, rather than the older ones. They've got to be motivated, you can't flog a dead horse. Even some of the younger patients are not always motivated to do exercises.
> (physiotherapist)

> They've got a home, something to go back to. There's stable relationships within their life; a job open to them; one they've held for a while. Something that's within their reach, it's attainable. They're usually mentally stable, positive and constructive. They cooperate in treatment and are well motivated. These are the people who can respond well to rehabilitation.
> (occupational therapist)

> It's the motivated ones. They've got some reason to live .... a family or a job waiting. It's difficult to generalise but the older ones, or those who have other problems are difficult. We get a lot who are difficult .... they're too old, they don't have a family, they can't cope on their own.
> (occupational therapist)

For other staff motivational factors were less important. They saw the patient's clinical condition as the factor important in predicting progress.

> It's head injuries, they're usually younger. They've got a better outlook on life. They've more friends and parents to help. CVA's make some progress, but not in the long run. They have hopes that can't be achieved. For example, they won't accept wheelchair independence, but won't walk either. Hands also make good progress. We only keep hands a couple of weeks.
> (nurse)

> The rewarding ones are the head injuries, hand injuries and CVA's. With head injuries you do see progress over a reasonable length of time. At the end of six months you see a "waking up" process. CVA's are slower but there's an upward recovery.
> (occupational therapist)

> CVA's and head injuries make most progress. Well eight out of ten. It's people with physical things rather than backs. If they're extroverted it's better. Introverts turn back into themselves. They've got to want to get better, to come to terms with disability. If they're depressed and can't accept disability or if the family won't let them do things. If they lay back and let other people do it. Like backs that have gone on for years ... it's a way of saying, I can't cope with life.
> (nurse)

Having established what some staff saw as patients who made most progress, I went on to ask staff 'how progress was measured in patients they worked with?'. For some staff measuring progress was simply observing a patient taking more responsibility for personal care areas:

> It's obvious their attitudes change, they try to do more for themselves. Suddenly they've done something .... they can dress themselves ... they've achieved something.
> (nurse)
>
> It's personal care ... dressing, feeding, being continent. They can survive without speech, but they need to be able to do daily living things.
> (nurse)

Remedial therapists tended to agree with the above viewpoint put forward by nurses, but mentioned specific techniques for measuring progress:

> It varies from patient to patient. We chart their goals each week ... like putting on a shirt. The chart would show that. They come here (ADL Bungalow) unable to dress themselves. We send them out able to do it with or without aids. Progress can be slow. You can't make written records of every little detail.
> (occupational therapist)
>
> For instance hand injuries do more. You can observe them and compare one activity with another. They tell me what they can do and I watch them. With head injuries and CVA's the assessments show what progress they've made.
> (occupational therapist)

A member of staff in the heavy workshop had a similar approach, although a judgment at odds with the views of his colleagues was noted.

> With hand patients you can measure the finger movements. You can observe them carrying out some specific task, for example, using a sandbag machine with no pain. You then move them on to some harder task and measure that.
> (workshop manager)

> Progress is an attitude of the mind, you can't pin down a particular type who makes progress. Some are unsuitable ... head injuries, teenagers particularly. They don't realise why they're here.
> (workshop manager)

For other staff improvements in ADL and physical functioning was insufficient to demonstrate progress:

> It's very difficult. What staff see as progress is not necessarily what the patient sees. It's how the patient sees it that matters. It's something that's demonstrably important to that patient. Doctors fall into the trap of feeling good about some clinical change that the patient is not concerned about. For example, a doctor sees a change in the patient's blood chemistry as progress.
> (doctor)

the doctor went on to clarify measuring progress, and put it into a wider context:

> It's helping the person; say a roofer who's fallen off a roof at work, he's got to adapt, take a different job because he probably wouldn't get employed again because of coordination problems due to head injuries. He'll probably have to accept a lower income. You have to explain this to him. You have to explain it probably would happen anyway as he gets older and is less physically able.
> (doctor)

> It's the emotional and social aspects that are important. They often zoom ahead physically after those personal areas have been dealt with. Physical progress can be denied if the patient doesn't see himself as he was before. They block off ... it's too personal or too intimate to consider. The social worker measures progress through the responses of the patient.
> (social worker)

Lastly a view that indicated the member of staff had clear ideas about the measurement of progress but felt other staff didn't always share his concerns:

> First you've got to define the problem in objective terms. Then it's measurable. You agree with the patient on some goal.

> How do you know treatment is complete unless you measure things. It's the patient who should set the goals. I'm here to help them. You've got to put the question to the patient ... 'what do you think your problem is?'. This is against the medical view, they say, 'we know what's wrong with you', I see around forty percent of the patients who come here. Less than half have any goals to work to. It's basically lazy staff.
> (psychologist)

Unsuitable for Rehabilitation?

It became clear that the question about progress indicated that some patients, particularly the highly motivated ones, and others who were thought to have the best chance of demonstrating improvement, might be those patients who received the concentrated efforts of staff and benefited from the optimism about their potential success. By implication other patients did not make progress and, as one staff member stated, were 'unsuitable' for rehabilitation. The staff were asked the question: 'Are there patients who are unsuitable for rehabilitation?'. The nurses were unanimous in their views that some patients were admitted to the Unit too early after becoming disabled:

> Some patients come too early, particularly head injuries. They need to go off and come back later when they've settled down a bit. Others reach a plateau and there's no movement. You need to send them off too, for six months and then take them back.
> (nurse)

> It's the patient who doesn't show any improvement in the first month. You've got them too early, or if it's not too early they're the patient who'll never do it. We tend to hang on to strokes too long when they're not making progress. Improvement might come in six months' time, but sometimes the brain is too damaged.
> (nurse)

For some nurses the patients unsuitable for rehabilitation were identified as the patients whose problems were inappropriate behaviour, primarily psychological, which some staff felt the Unit was not able to help:

> Aggressive head injuries, they need to go to a psychiatric hospital. The patient's got to be able to fit into a small group. They shouldn't need attention on a one-to-one basis. The others are patients with disruptive behaviour who won't go to their programmes or listen to advice.
> (nurse)

One nurse added to her previous statement and identified further problem areas:

> It depends on their personalities. Very aggressive patients are difficult. CVA's who've drunk and smoked heavily are a problem. Some patients are unpopular. They're aggressive and don't cooperate. Some have psychiatric problems. They get depressed or drink too much.
> (nurse)

> They're patients with behavioural problems. They need to go to a psychiatric unit till their problems are sorted out. Other patients get neglected while you're sorting that type of person out.
> (nurse)

The views of two remedial therapists were in accord with that of the nurses:

> They're unsuitable if rehabilitation isn't applicable and can be of no help to them. If the patient has a large psychological overlay in a unit geared to physical treatment.
> **(occupational therapist)**

> They're unsuitable if there's psychological overlay. You don't usually get on very well with those.
> (physiotherapist)

Other factors were seen as reducing progress in rehabilitation and indicating patients may be unsuitable:

> It's the ones that want to be rehabilitated. Quite a few have got used to people doing things for them. The family has got to want the person rehabilitated. The family sometimes wants the person to

> be an invalid. The family does everything for them. They're not suitable for rehabilitation.
> (occupational therapist)

> There are some patients who we know it will not be worth treating. It pays some patients to be ill, for sexual reasons, to get out of working, or waiting for compensation. Others are keen to get on and we can push them. They fight hard to get back to normal.
> (doctor)

Second were those patients whose disability had been caused by industrial accidents:

> It's those patients with 'compensation-itis'. Basically they don't want to get better.
> (physiotherapist)

> It's where the unions are involved or they're waiting for compensation.
> (workshop manager)

Lastly, two members of staff took a different view and talked about the response of staff, rather than the type of patient who was unsuitable. First a doctor:

> The staff have certain expectations of patients when they're admitted. The nurses like more passive patients who don't ask too many questions. On the other hand the remedial therapists like people who are active. You recognise that some patients are unpopular and don't get the help they need from some staff, and they get discharged earlier. They just don't get on with the staff. It's recognised by the doctors but there's little you can do about it.
> (doctor)

She also saw other factors related to the policy of the Unit having consequences for some patients:

> We treat patients like children. We take away their roles and tasks and slow down their progress. Then when they make progress and start getting demanding or upset staff it's seen as unnatural. For example the younger patients who go to the pub and get drunk. We 'expel' them because some staff can't accept it.
> (doctor)

The second member of staff, a nurse, felt the approach taken by staff in the Unit was inadequate to meet the needs of some patients. In expressing these views she stated that they were untypical of her nursing colleagues:

> Some patients don't have their needs met on this Unit. They have to get on with the programme even though their needs are not always met by these activities. We tend to see our role clinically, even though this may be a minimal part of patient care. We are not specifically trained to deal with the problems patients have in rehabilitation. We bring typical nursing attitudes to rehabilitation work. This works against the needs of the patient.
> (nurse)

She went on to describe an example of a patient who wasn't helped:

> A young girl was on the Unit. She was partially sighted and had mobility problems. She also had psychological problems, but that couldn't be dealt with on the Unit. She was transferred to a cottage hospital. She didn't get the help she needed.
> (nurse)

Communication between Staff and Patients

There have been many studies that have documented the dissatisfaction patients feel about the level of information they are given during hospital treatment. Poor communication between staff and patients can create major obstacles to treatment effectiveness, and leave the patient confused about his situation. Examples might be where no-one is willing to give the patient bad news, or where the patient gets double messages from different staff. For the patient with disability in a rehabilitation unit the need for information is often vital. The patient needs to know as much as possible about his condition as he often has to manage distressing aspects of that condition for a lifetime. He also needs information that can help him plan and construct a future that may mean a new and different lifestyle from that of his past. The ability to communicate skilfully and the establishment and maintenance of good relationships with patients is critical for the effectiveness of the rehabilitation process. In order to generate talk in this area I began by asking staff ... 'How honest and open they were able to be in their communication with patients?'.

For some staff the information they gave a patient was dependent on a personal assessment of the patient's likely response:

> You've got to make a mental assessment of the patient. Could they cope with being told things honestly to them, or do they need to be given information in a roundabout way. You've got to be careful what you say to them. The blunt information is left to the doctors or physiotherapists, like 'You won't walk again'.
> (nurse)

> It's a difficult thing, you use your discretion. If it's a favourable thing I tell them. If it's not, I tell them to see the doctors. That's the doctors' prerogative.
> (occupational therapist)

> It depends on the patient. Sometimes the patient isn't allowed to know their diagnosis, so we can't be frank with them. You're not frank with patients you don't like either. If it was a behaviour problem you'd confront them. You could be frank.
> (occupational therapist)

> You've got to be as honest as you can. It varies from patient to patient, but you've got to be honest to some extent. There are times when you have to do things more gently. You use your discretion ... with the terminally ill patients. Sometimes you're blunt, at other times more tactful.
> (occupational therapist)

Other staff said they took a more direct approach and were open and straightforward with patients:

> You've got to be very explicit. I would be with any patient. The more open you are with the patient, the better response you get. They know what they're trying to achieve then. I would tell a person they wouldn't walk again. It helps keep their motivation at a high level.
> (physiotherapist)

> We tend to tell them things on the black side. It gives them some of the impetus. Some take it badly. They don't want to hear what you've got to say, but it's no use pulling the wool over their eyes.
> (nurse)

But in spite of this tough approach there were exceptions for this member of staff:

> If they've got cancer they're not always told. We would tell the relatives but unless the patient asks point blank they're not told.
> (nurse)

Three members of staff spoke about their own practice in this area but also mentioned how they saw other staff's approaches:

> Patients always feel you're keeping things from them. I urge openness. It aids honesty by helping the patient clarify his situation and his anxieties. I see the patients who are upset. Sometimes they become obsessive. Is it a real problem or do they just want to get something off their chest? I also get the anger reactions when they learn things ... 'I won't walk again' ... It's the doctors who won't tell them what they want to know. Medically they're a law unto themselves.
> (social worker)

> You need to be honest with the patients about their situation. Not at first when it could devastate them, but later when they've adjusted.
> (doctor)

> Staff need to be good at their job in this area and have a broader view of the patient. They've got to be able to relate and understand the patients' wider needs. It's no good if they're just technically good, but can't relate to the patient. It's easy to undo the work of other members of the team by saying the wrong thing to the patients.
> (doctor)

> I get personally very involved with patients. I don't just see it as speech therapy. There are social and emotional things and relationships with wives,

> the sexual problems and feeling useless. My sessions involve a lot of emotional things. I see patients very differently from a lot of staff. The patients don't get aggressive here (Speech Therapy Clinic). I try to recognise how difficult things are for them. It's not aggression often, it's frustration and anxiety. They're people first, that should be the priority. They feel some staff treat them badly, like kids. That's why they're aggressive. I don't think some staff understand the complexities the patients experience.
> (speech therapist)

Problems that are not Discussed

An area closely related to the last section, and one that became apparent during interviews with patients is that of the problems that are not discussed. Areas of concern, particularly those of personal feelings about relationships and sexuality did not seem to be adequately dealt with by staff. During observations of staff at work with patients it was clear that some staff felt these were difficult areas to deal with and were avoided. This was because a member of staff may feel embarrassment and be unable to discuss the problem comfortably. It could also be because staff felt it would be too painful for the patient to express his feelings about intimate areas. The result was that discussions were avoided or the patient's thoughts diverted into safer areas. This occurred even when patients openly expressed concern about a particular matter.

In order to confirm these views staff were asked 'whether there were areas of concern to patients that did not get discussed?'. A number of staff rejected any idea that there were issues not discussed, others were not so categorical in their denial and indicated that one particular area was severely neglected:

> I think it does happen. Sexual problems don't get dealt with because the patients don't want to talk about it, and the therapist doesn't want to blunder in. It's not discussed because it doesn't come under any of our fields.
> (occupational therapist)

> The other area is women's personal problems ... menstrual flow. They don't like to discuss it. It tends to get missed out. If the patients ask we'll help.
> (occupational therapist)
>
> I think we go into the patients' problems too much. We ought to leave them alone.
> (speech therapist)
>
> Marital problems are a big factor here. They're not discussed at the team meeting. The patients talk to you, but you don't know what to say. I think the social worker may discuss it.
> (occupational therapist)
>
> I don't know what things don't get discussed. I don't know what other members of the team talk about. I know we don't always help with personal relationships and sexual problems.
> (occupational therapist)

One member of staff recognised there were problems but had doubts about intervening if the areas of difficulty lay outside her rôle as occupational therapist:

> We tend to shy away from these problems. We don'tdiscourage patients, neither do we encourage them. The patients also tend to be reserved and inhibited. If they want help it must come from the patient. We can't go blundering in point blank. If a family situation existed before the accident it's not really our business to get involved. There's nothing a therapist can do and we leave them alone. You can't ask about these problems in the same way as other problems, like dressing.
> (occupational therapist)

For the nurses, as a group of staff, there was some agreement on the difficulties they faced in discussing personal problems:

> We need more training in psychological problems, marital and sexual problems particularly. They are a problem for all patients, not just the young ones. We also need help on how to deal with depression and patients who're aggressive. These are the things that don't get discussed.
> (nurse)

> The nurse should be someone to come to when they've got a problem. Our roles are wider than others see. We could respond but it would depend on the nurse's willingness. The problem is that information is not always freely available to nurses to help them deal with the patients' problems.
> (nurse)

Leaving the Unit

At a point when staff, following a meeting where discharge was considered, felt the patient had reached a certain level of functioning, arrangements were made for his discharge from the Unit. Before that time the patient had usually spent several weekends with his family in preparation for eventual discharge. The decision to discharge a patient was taken when it was felt by those involved with his therapy and care, that nothing more could be achieved by his continued stay within the Unit. A further factor, only partly related to the patient's level of ability, was the pressure on doctors to discharge patients in order to meet the demand for new referrals. During the observation period several members of staff indicated they had doubts about the Unit's effectiveness in preparing patients for discharge. They were concerned about whether the Unit provided the appropriate experiences that the patient could carry over into their own homes on discharge. Another area of concern was expressed over the lack of follow-up, with the Unit discharging patients but having no further responsibility for them. In order to discover whether these views were commonly held by staff I asked them the question ... 'Do you feel patients leave the Unit able to cope with life in the community?'.

Some members of staff felt the Unit prepared patients effectively and saw no difficulties:

> It's very effective. We help the patient and the family to overcome their fears and to have confidence. We give them time and we're geared up to help. They go home for weekends and come back and discuss their problems.
> (nurse)

> It's not a problem. What's important is that the patient can cope in their own environment. We don't keep them here and then just send them back home and hope they'll cope.
> (occupational therapist)

Others saw things differently and felt there was a mismatch between the patients' needs and the approach taken in the Unit. Two of the nurses interviewed saw the patients' difficulties related to the length of stay in the Unit.

> Yes, most of them are here too long. It comes as a nasty shock when there's no longer somebody around twenty-four hours a day. I think we smother them too much. They get a false sense of security. Either they pull their socks up or end up in residential care.
> (nurse)

> We keep them too long. It's hard for them to leave. It's easier where people's demands are not going to be so great. We do quite well for ladies if they're just going to potter round the house when they leave. I don't think we're divorced from reality here, although we don't provide the magic solution.
> (nurse)

Other staff attributed difficulties to a wider range of factors including poor links with families:

> We need to work with the family more. There's no family counselling on a regular basis here. It's not just popping in for a chat when they collect the patient on Fridays. It's an important thing we're missing out on. What are we sending them out to? Are we prepared enough for what's likely to happen? What are we doing to them?
> (speech therapist)

> The basic problem is that we do things as professionals that we see as right but it may not fit the patient's needs when he leaves. We need to work with the families, that's very important. I think we often fail to understand the patient's family situation. It's partly a problem of the catchment area with a regional unit. Sometimes you have to discuss with the relatives and services on the phone.
> (doctor)

> I think we do badly. Problems of personal relationships are not always covered. We need more contact with the family. We need to get them involved in treatment. The other problems are the long-term disabled. They can't work, but we don't equip them with creative outlets. We ought to look more at the hobbies and interests they could pursue.
> (speech therapist)

This member of staff went on to describe work on an adjoining unit where a different approach to work with the family helped the patient on discharge:

> On the Burns Unit they have more contact with the relatives. They find it helpful to talk to the relatives and help them to do things with the patient while he's in hospital. Then when he goes home the family's already involved.
> (occupational therapist)

> I think sometimes we underestimate the family. We sometimes feel the patient won't cope, but we forget the power of relationships.
> (occupational therapist)

> There's problems of adaption following a period in hospital. It's an institutional system. It separates people from the community. Ideally rehabilitation would take place in the community and avoid the crisis of discharge.
> (psychologist)

> I'm not sure we deal adequately with this problem. They still have difficulties when they go home. Lots of things get overlooked while they're here. They come across more problems when they get home. We ought to be taking people into the community and test out how they manage.
> (occupational therapist)

> There's great danger in discharge. If we had more contact with their relatives there'd be less danger. We're professional people with middle class expectations of the patients. We say 'We can't send a person out to that', but people choose to live their own way. They have a right to be like that. We

> are dangerously judgmental and we ought to be aware of it. Disabled people can live in a variety of ways.
> (occupational therapist)
>
> I think some of the other disciplines are too positive. They say you can do that, but don't take account of life in the community. We're an artificial community here. We send people out, but are they ready to cope in the community? It's seen totally as a physical thing and although the therapists have clear ideas, are these realistic? There's also little work with the person and their family once they're in the community.
> (social worker)

Coordination and Communication in the Unit

Individuals of many disciplines have contact with patients during the rehabilitation process, and the team approach is customary. Consequently the efficiency of the rehabilitation process is closely linked with the quality of communication among team members. During the observation period conflicts between different professional groups were apparent. Some of these conflicts appeared to centre around traditional antagonisms about work patterns, for example between nurses and remedial therapists, while other sources of friction were attributed to the decisions or non-decisions of doctors. It was clear that significant tension existed between groups of staff and that the Unit had no obvious leader, or coordinator. Consequently staff found themselves working alongside each other, with demarcation lines and mistrust of other intentions in evidence. In order to explore this area of practice, I first asked staff ... 'How is coordination achieved in the Unit?'.

A number of staff identified the weekly team meetings as the mechanism for achieving coordination. Although for some staff this was not seen as satisfactory, particularly by nurses, who were critical of their opportunities to participate and influence decisions:

> There's not much coordination at this place. There's the weekly meeting where we all thrash things out. We get overrun by the others. It's one of us against all of them. They can stamp on us. We see the patient twenty-four hours a day, but they don't believe us.
> (nurse)
>
> It's the meeting where we all discuss. Everybody is supposed to be thinking the same way, but the strong get their views heard. The shy people just moan afterwards. In the end people go their own sweet way.
> (nurse)

Remedial therapists also identified difficulties within the meetings that did not achieve their potential:

> The weekly meetings are not achieving much. There's no medical leadership, nor is there leadership from the nurses. There's potential for it to be a fantastic rehabilitation unit, but there's underlying conflict between staff. It affects the coordination of the programme.
> (speech therapist)
>
> It's decided at the meetings, although it depends on the doctors. They can be obstinate. They have the power to overrule and their word goes. We get it quite often with one particular doctor. He'll give the patients the benefit of the doubt, even though he hardly ever sees them. We see them more often and see things differently.
> (occupational therapist)
>
> It's a team thing. We make joint decisions at the meeting. The doctors usually take our advice, although the physiotherapists and nurses often contest it. By the end of the first week with a new patient we've all made our own judgment and the direction we'll take.
> (occupational therapist)

The disappointment some staff felt with the weekly team meeting was only part of wider problems that were said to exist in achieving coordination:

> The problem is that patients are not assigned a member of staff when they're

> admitted. They need a central person to coordinate. The multidisciplinary approach doesn't work in the Health Service because of the role of doctors.
> (psychologist)

> Working together's important, but agreement on what's said at the meeting is difficult. No minutes are taken and it's left open to interpretation. The team approach puts a strain on members of the Unit.
> (physiotherapist)

> There is a problem of coordination. How do you keep in touch with patients when they're with several different departments? There's no record of the direction of therapy. The consultant wanted to use forms to keep in touch with the progress patients made, but people here don't like too many forms. It was a good idea, but the consultant's seen as mad on forms.
> (physiotherapist)

The need for leadership had been mentioned by some staff and it seemed important to question staff about overall responsibility within the Unit. The staff were asked the question ... 'Is there a leader who is responsible for coordination in the Unit?'. This proved to be a complicated area with leadership attributed to a number of people within the Unit. The consultants were seen to have a leadership role as a result of their clinical responsibilities. In addition the heads of different departments were also seen as responsible. Other staff saw the Unit as having no leadership, with all the consequences when clear direction is missing:

> There's no real leadership. It's very much lacking. The consultants only come up once a week to see their patients. Some of them are not orientated towards rehabilitation. They're more rheumatologists. We miss the direction of a specialist in rehabilitation.
> (speech therapist)

> It's a constant battle. The senior consultants rarely here. The medical people think they're leading, but they've still got too much power. There's a battle between the remedial therapists

> and the doctors.
> (social worker)

> The registrars don't have a specific role. They just deal with medical problems. The consultants are all different in their approach. It's difficult to say where they fit. They only play a minor role in leadership within the Unit.
> (nurse)

> The doctors don't have a traditional role here. They're more like psychiatrists or social workers. They're really liaison officers with a social welfare role. Although they influence decisions they're not terribly practical.
> (nurse)

Two doctors who had opposing views about leadership found themselves in a difficult position in the Unit, and seemingly did not want to see specific leadership in the Unit:

> There's difficulties on the Unit. There's a strong anti-doctor feeling. You may be in charge, but you can't necessarily get people to do things for you. There's a struggle for power going on against the doctors. It's not the nurses, they tend to agree with you.
> (doctor)

> No, I don't like the idea of single leadership. It leads to bossing people around. I prefer each head of department to work together, I think the weekly meeting is the right place. Staff can argue out their ideas and reach agreement. I think staff relating together is more important than a formalised management structure.
> (doctor)

Some staff saw the Rehabilitation Officer as having responsibility for coordination but harboured doubts about the effectiveness of this role:

> Yes there is leadership but it fluctuates. It can be the Rehabilitation Officer, or the Head Occupational Therapist or it could be the consultants.
> (occupational therapist)

> It's the Rehabilitation Officer, but we each have our own Head of Department, and they are the ones who lead us professionally.
> (occupational therapist)

> The Rehabilitation Officer has control, though she doesn't work with patients. She picks her information up from meetings. It would be better if there was a head on the ground rather than an office worker. She used to direct the programmes more, but her role has changed with her District responsibilities, and she doesn't spend so much time on the Unit now.
> (nurse)

> It's the Rehabilitation Officer, but she has other things to do as well so it's lacking very much compared with the past. It's also been affected since the medical registrar left, she did a lot more behind the scenes. She got involved with a number of staff, the other doctors don't. The final decision rests with the consultants, but they're not around very often.
> (speech therapist)

Staff were then asked 'Could you describe the level of communication between the different disciplines, and whether there were any major areas of disagreement?'. Many of the responses to this question focussed on the division that existed in the Unit between the nursing staff and the remedial therapists, although other disciplines also came in for criticism. First the nurses' viewpoint:

> We're not aiming for the same things. Nobody's clear about why the patients are here. It used to work, but we're not pushing people fast enough now. The Unit's become less structured. Patients had to be at their programmes or they didn't get another opportunity. Patients are often not at their programmes now. It's the O.T.'s and Physio's. they're too soft. They're not adult enough to deal with handicaps. Some are too immature. Sympathy's no good, they (patients) need to be pushed, it only makes our life harder if they're not.
> (nurse)

> The physios. are not as good as they were. They spend too much time on walking. People are walking rather than wheelchair independent. They get out of wheelchairs too quickly. The physios. are unrealistic. Walking means all now, the other problems are ignored. But problems aren't magically solved by walking. It needs a more practical focus. They forget other things like transferring, balance and getting out of bed.
> (nurse)

> We're looked on as the lowest of the low by the therapists. They don't think we've got a job in rehab., they just suffer us. If we were given a chance we could get involved in the activities, but it's very much us and them.
> (nurse)

The remedial therapists in return saw the nurses as the main problem:

> Conflicts are usually resolved if there's a good reason. It's often over a person seeing things one way rather than another. The biggest divide though is between the ward and the rehabilitation department. The nurses see things differently. The therapists see the patients as independent rather than dependent.
> (nurse)

> The nursing staff can be a problem. From five p.m. onwards they could carry on the work in the evenings, but they don't see it as their role.
> (speech therapist)

> It would be easier if the ward staff realised what occupational therapy was all about. They still dress people on the ward. They say there wasn't time, but the patients need to dress themselves.
> (occupational therapist)

A number of staff though felt that difficulties were caused by the approach taken by doctors:

> You have a patient who's referred for dressing. He's still being referred after six months. The doctors keep pushing it back on us. The consultant sees a patient once a week for five

> minutes, but we know the patient best. They haven't watched that patient, nor know anything about his level of recovery.
> (occupational therapist)

> We disagree over the length of time people stay. We're not pushing them enough. We keep people too long and it makes it difficult for them to leave. They don't have to think or face the pressure. It's the doctors who get involved and take away the patient's role. They always want them to stay longer.
> (nurse)

Discussion

The views of staff presented in this Chapter have revealed a number of areas of difficulty in the rehabilitation process, and indicates that there are individual and organisational pressures that affect the conditions in which staff practice in the Unit. Broad discussion of each of the areas used in the interviews are presented below. (Some of these areas are discussed further in Chapter 9).

First, the staff's perception of rehabilitation closely followed the patients' perceptions. Rehabilitation was seen as helping patients to return to the community to lead as independent a life as possible within the limits of their disability. The emphasis was on physical repair, although some staff interpreted the question more widely and indicated that rehabilitation encompassed more than servicing the body. These responses mentioned the need to consider the quality of the patient's life and the family situation, but also the patients' own views and what they wanted to achieve for themselves. These latter comments led naturally into questioning staff about the level of involvement patients had in their programme of rehabilitation. Did staff genuinely include patients in discussions and take their views, however badly expressed, fully into account?

Secondly, what opportunities existed for patients to discuss changes in their programme should they feel particular activities were unsuited to their needs?

The responses given to these questions suggest that staff in the Unit provide little opportunity for the patient to contribute to the programme. The patient plays a passive role and is a recipient of therapies that the staff have devised based on their knowledge and experience. None of the staff questioned seemed to consider the patients' involvement important, in fact, some were surprised by the very question. There seemed to be an unstated assumption that the patient would improve if they left the decisions to the staff. One member of staff was more perceptive and saw the dangers this crudely directive approach held for both patients and staff. She recognised that 'doing things to people' ran the risk of leaving the patient unprepared in terms of self-confidence and self-help skills that he could carry over into the community when he left the Unit. Likewise the question of patients changing their programmes mid-way brought little response from staff. Again this was an area that staff had appeared not to consider important and few examples existed of patients successfully achieving the changes they desired, even though some of the activities were of doubtful value and used basically to fill time, which patients were aware of. Where negotiation had proved effective, this was dependent on patients persuading staff to allow them to change activities. This was a questionable procedure in that less popular patients, usually those who were less articulate and demanding and often seen as poor rehabilitation material, were excluded from these opportunities, and patients who were popular with staff or admired for their commitment to their programme were treated more favourably.

The third area explored was the notion of progress. Staff frequently talked about a patient's progress or lack of progress. Some patients were seen as making progress, while others were seen to be impeding their own progress. The questions in this area were devised in order to discover how staff judged a patient's progress, and whether some patients were seen to make more progress, and what factors were thought to influence this situation. The responses of staff suggested that the patient who is young and highly motivated with supportive family and a job to return to was seen as likely to make progress. But this type of patient was always likely to make progress and probably less in need of the structured programme the Unit offered. The older patient whose progress was slow, and was less clear about his future, and the younger patient who did not comply with the routines of the Unit, were seen less optimistically, with staff giving less encouragement to them.

No clear picture emerged from interviews on specific tools used to measure progress. Most staff used ideas based on functional gains such as self-care achievements, although some measurement of the use of machinery in the workshop or manipulation of equipment in the ADL bungalow introduced a more structured element into this assessment. Again as in other areas of practice the emphasis was on physical gains with little mention of other areas that might have indicated that the patient was becoming more confident in adjusting to his new situation and learning ways of coping that would be transferable outside the Unit. Many of the gains credited to the patient were for achievements in the gymnasium or ADL bungalow which did not replicate any environment the patient was likely to find himself in when he was discharged from the Unit. Progress, was progress within a hospital, a location which emphasised dependency and recovery from sickness with little opportunity to take responsibility for more independent behaviour.

If staff are able to identify patients who make good progress in rehabilitation they are implying that other patients do not make progress and may even be unsuitable for rehabilitation. Again as in previous questions a wide range of responses from staff suggested that the patient who only makes slow progress and may be discharged from the Unit before he has completed his rehabilitation cannot be identified easily. Several different patients were categorised as unsuitable. In the search for the 'ideal patient' a picture began to emerge of those attributes that reduced a patient's chance of being seen as 'good material' for rehabilitation. Patients who had behavioural difficulties, particularly where these were seen as the province of psychiatrists, were mentioned most often. The staff were in common agreement that patients whose behaviour was outside the range they recognised as normal, presumably using subjective opinions, were unsuitable and should be transferred to a psychiatric unit. Broadly, staff were less inclined to try to understand the patient whose behaviour may have been indicative of the tremendous psychological impact that disability had on that person. The tendency seemed to be to categorise these patients rather than attempting to understand what they were experiencing by the use of counselling techniques. In a unit primarily focussed on physical therapy the denial of help for patients experiencing strong emotional reactions was inevitable, although deeply regrettable for some patients. Some staff recognised the problems facing patients and felt the approach in the Unit needed redirecting to take into account the needs of patients who could not necessarily respond to the demands of the physical treatments, and others who needed to be given more responsibility for their own rehabilitation and be less dependent on the goals set by staff.

The fourth area concerned communication between staff and patients. This was seen as important because of the risks both to staff and patient, if effective communication was not a feature of the relationship. The focus was on providing adequate and appropriate information for the patient in order that he could voice his concerns, but also feel involved in the direction of his treatment programme. The responses to the questions about communication suggested that staff did not have a consistent approach to communicating with patients. Some staff released only limited information, and then only if that information was felt to be positive and would not upset the patient. Other staff stated that they were blunt and straightforward in what they told patients, seemingly irrespective of whether the patient could cope with this crude approach. Some staff even saw communicating pessimistic information as increasing motivation. A very doubtful assumption. Other staff tended towards openness and honesty with patients, and recognised the importance of good communication in assisting the patient to work realistically on his problems. The question that remains to be answered here is what the patient experiences if he is on the receiving end of so many different approaches among the staff treating him. He will experience some staff reluctant to give him information about his development on one hand, and on the other, staff willing to share their understanding of his situation in a frank and open manner. Although a 'rigid party line' is not necessarily appropriate as this could leave the patient feeling staff had 'ganged up' on him, the different opinions must have been confusing, particularly to someone who was already often anxious and uncertain about his future.

An important dimension in the power of effective communication was the apparent lack of any close positive caring relationships between staff and patients, that could have been the main means through which patients could have been helped with their personal and family problems. The social distance and negative stereotypes some staff used, influenced the patient's willingness to ask for help and to identify individual staff who would listen to their concerns.

The area of personal relationships and sexuality was almost totally neglected and most staff in the Unit admitted to the inadequate help available due to a number of factors, including embarrassment, poor training or concern about hurting the patient's feelings. Other staff, particularly the remedial therapists, took a tougher line and indicated that discussing such matters would only increase the patients' worries, and that some things were best left alone. These approaches at best left the patients trying to work out their own situation, or at worst, left them desperately worried and concerned, with no opportunity to try and resolve issues that threatened their relationships, as some of them would be dependent on spouse and relatives to assist and support them when they left the Unit.

The fifth area was concerned with issues related to the patient leaving the Unit. This is a critical point in rehabilitation, as it is the stage in the process when the patient becomes a citizen again, and is no longer expected to exhibit those behaviours that were necessary while he was resident in the Unit. From the moment of his admission to the Unit the patient has been influenced and shaped by the attitudes of the rehabilitation team, who have to varying degrees rewarded passive and compliant behaviour, seeing this as appropriate to a patient making good progress in his rehabilitation. Suddenly at the point of discharge this is expected to change. He will now be expected to be an active independent person who no longer relies on the hospital and can live and cope with some degree of independence.

The concern of most staff was that the Unit did badly in this area; that insufficient work was done with patients to prepare them for discharge and particularly contact with the family to prepare them for the disabled person returning home. The way the Unit separates the patient from his home and community, yet expects him to re-enter them without preparation and support was identified as an area needing more consideration. In addition the environment of the Unit and its practices were also considered by some staff to create additional problems for the patient. It was recognised that the Unit because of its location and symbols of medical treatment and therapy had the effect of institutionalising the patient, even when his stay was short. This left the Unit with a double task both of rehabilitating the patient, and also overcoming the effects of the institutional processes which actually worked against the goals of the Unit. The 'crisis of discharge' as described by one member of staff was in fact a greater problem because of the environment and the system of treatment the patient had expressed since admission.

The final area explored through the interviews with members of staff concerned coordination and communication in the Unit. The Unit had twenty-five members of staff of eight different disciplines working with patients during this period of research. Although in practice the number working with patients was actually much smaller, nevertheless the need for a high level of cooperation and some means of coordination was important, both for the patient who required it in order to be treated appropriately by each member of the discipline working with him, but also by staff so that they could work in harmony with each other, and share their perspective on the patient and understand something of the other disciplines' contribution. Poor communication leaves the patient muddled and confused, but also reduces the efforts to interpret rehabilitation practice broadly for the benefit of the patient and staff alike. Communication problems in the Unit resulted in examples of patients being treated inappropriately, sometimes with distressing results that could easily have been avoided if a mechanism had been used to relay information to all those involved with a patient, and if there were some similar means of communicating and receiving feedback on actions taken.

The weekly meeting was seen as the main vehicle for discussing patients and communicating treatment approaches among members of the rehabilitation team. Very few staff found this forum to be adequate, and various complaints about the ineffectiveness of the meeting were voiced. The main concerns centred around the way certain disciplines dominated the meeting, and the poor management of the meeting, which had no means of monitoring whether staff had undertaken work with patients as agreed. Although the meeting was seen as important and the only tool to achieve communication among the disciplines, it was suggested that staff often took their own direction once out of the meeting, and only paid lip service to the notion of a coordinated approach. One of the criticisms was the lack of leadership in the Unit which could have pulled together the different disciplines and attempted to achieve a higher level of coordination.

Leadership appeared to be a confused area with staff suggesting that leadership was held by various staff in the Unit. What was clear from these responses was that, although the consultants had clinical responsibility and the Rehabilitation Officer a leadership role in relation to the programmes, neither of these roles was seen as effective by the majority of staff. What was needed was a person who was able to oversee the treatment each patient received and ensure that the outcome of a programme was in the patient's best interest. Technically the consultants had the power to determine admission, treatment and discharge, but in reality they were not in the best position to consider all the ramifications of the patients' circumstances and had only minimal contact with them. Others were in a better position to play a more central coordinating role as they were based in the Unit rather than visitors from other hospitals, and had day-to-day contact with the staff working in the Unit. The Rehabilitation Officer was obviously well placed to play this role effectively but, as the responses indicated, there was doubt amongst staff about the effectiveness of this role, with heads of departments seen as having responsibility for the direction of work with patients. This research did not attempt to stray into the area of organisation and structure of the rehabilitation service, but the observation and responses of staff suggest that roles and responsibilities in the Unit needed examination. The work with patients was not effectively coordinated and staff were not provided with channels of communication to eliminate some of their disagreements.

Lastly in this section was the evidence provided that strong disagreements existed at both a personal level and between different disciplines on the Unit. These were probably partly a result of the lack of leadership mentioned above. The main conflicts were between the remedial therapists and nurses, with the antagonism running deep among the nurses. The nurses felt themselves to be 'outsiders' in the Unit whose opinions were brushed aside and whose potential to assist the patient was underestimated.

With these divisions so apparent in the Unit no-one seemed to be concerned for the effect of patients who were pulled in different directions in their loyalties to different staff, and occasionally rebuked by the nurses particularly, because of lack of communication with their therapist colleagues when there was misunderstanding over a patient's programme. The doctors did not escape entirely from criticism although this tended to be muted in comparison with the above disciplines. The criticism of doctors focussed on their apparent unwillingness to listen to staff and the tendency to take the patient's view and persist with treatment well beyond what their colleagues saw as realistic. In this respect doctors were supporting patients who had little or no voice in the treatment programme.

In conclusion the analysis in this Chapter has suggested that there is a major discrepancy between the needs of patients in rehabilitation and the manner in which staff are able to identify and respond to those needs. The Unit as a social system is not structured appropriately to deliver a service that is sensitive to the needs of the disabled person. The patient entering the Unit is someone who has been admitted in order to learn new ways of living with a disability. Yet the Unit is structured to deliver a service that is based on a traditional medical model that is not appropriate to someone who is no longer sick, but has major problems of role adaptation and self-management. This model keeps the patient in a passive role with staff setting the goals and expecting compliance to their programmes. After due time during which the patient has been expected to achieve a number of skills measured in terms primarily of the number of days spent in physiotherapy and ADL training, he is then expected to leave the Unit and be an active participant in life outside the hospital. The model of rehabilitation that emerges from the way staff describe their work is not one that seems to be fitted to assist the patient achieve maximum functioning and satisfaction in his life outside the hospital.

7 A VISIT TO A SPINAL INJURIES CENTRE: A FURTHER PERSPECTIVE ON THE REHABILITATION PROCESS

In order to provide further information on the rehabilitation process a brief period of fieldwork was undertaken at a spinal injuries centre. This was a short visit to collect illustrative material from patients and staff who shared many similar problems to the respondents interviewed in the research unit. As this was a brief period of fieldwork the material should not be read in any way as a full scale assessment of the rehabilitation process in that centre. Nevertheless some aspects of the data from this brief visit were consistent with the findings in the Unit.

During the four days spent at the centre arrangements were made by the Principal Social Worker for me to interview four patients and six members of staff. Three of the patients were nearing the completion of their rehabilitation programme and one was resident in the Young Disabled Person's Unit following a readmission to the hospital for social reasons. The staff interviewed were those that agreed to be interviewed and represented some of the disciplines working in the rehabilitation departments in the hospital.

The Rehabilitation Programme

The centre was one department of a large district general hospital. The hospital undertook a wide range of rehabilitation work in addition to the programmes for spinally injured patients. Rehabilitation in the various departments of the hospital was more complex than at the research unit. Patients attended therapy departments from both the general wards of the hospital, the spinal injury centre and the local community. The structure of the rehabilitation programmes bore many similarities to that of the research unit.

Following admission of the spinally injured patients at this acute stage the medical management of the physical trauma was the main focus with those actively involved providing total care of the patient. When the injury to the spine had healed the person is left with a physical disability and unable to perform some functions because of paralysis and sensory loss. Consequently the focus now changes to one of rehabilitation with the patient learning to perform all those activities necessary for survival as an independent person. The rehabilitation programme is based on teaching techniques of mobility and activities of daily living. (ADL). Rehabilitation for the spinally injured patients can mean months in hospital with discharge recommended when the patient is assessed as performing all the mobility and ADL tasks of which they are capable.

Patients, after leaving the ward each morning, moved between the different remedial therapy departments throughout the day, alternating physical therapy with occupational and speech therapy sessions as appropriate. In addition a range of supporting staff including social workers, assisted patients with personal, family and accommodation problems, including providing the link between hospital and those authorities within the patients' home area.

Because rehabilitation activities served the needs of a very large in-patient and out-patient population in addition to the spinal injuries centre with vastly greater numbers of patients assisted each day, the same cohesive feeling that was evident in the research unit had not developed. Many more patients and staff were interacting with each other throughout the day and the pressure on individual patients observed seemed less intense than in the research unit. Observation and discussion with staff also indicated that there was no rehabilitation team with its own separate identity and rehabilitation was said to be something that was the role of the remedial therapists. Other supporting staff, who saw patients in the spinal injuries centre as required, did not make up a distinct team of rehabilitation specialists. The lack of a separate identity was claimed by staff to offer little opportunity for team work, multidisciplinary case conferences and joint approaches to work with patients.

Interviews with Patients

Interviews took place with four patients, all of whom had agreed to be interviewed following a request for volunteers from a social worker in liaison with the ward sister. The interviewer's schedule developed in the research unit, was used as the basis for the interviews. Questions from this schedule were used as seemed appropriate with the patients and no attempt was made to make this later series of interviews directly comparable with those undertaken in the research unit.

The Patients

Name	Age	Family Composition	Household Composition	Last Occupation	Disability
Mr. P.	24	Single	Lives alone	Jockey	Spinal injury
Mr. Q.	22	Separated	Lives with Family	Army Radio Operator	" "
Mr. R.	24	Single	Lives alone	Diver	" "
Mr. S.	28	Separated	Lives with Family	Manager	" "

The Interviews

The patients' responses to questions are reported without additional comment except for a final discussion.

> Int:
> Could you tell me about your rehabilitation programme, and what it's setting out to achieve for you?
>
> Mr. P.
> I think the aim is to get me as proficient as possible. To be independent again, that's the main goal. To be able to get about, whether it's in a wheelchair or on crutches. To be able to look after myself.
>
> Mr. Q.
> It's trying to fit me back into society. It's teaching me to start all over again. Things

> like getting out of bed, getting off a chair, feeding myself. I couldn't do much at first. It's a big thing. It takes a long time.
>
> Mr. R.
> In my opinion they're getting me ready to leave the hospital. To get the bits working again. It's mainly physiotherapy at first but the OT's teaching me how to do things differently. It's a new way of doing things. They teach you how to look after yourself again.

Mr. S. had already completed his rehabilitation and was spending two weeks in the Young Disabled Person's Unit while his parents had a holiday. Mr. S. reflected on his experience of rehabilitation while at the hospital before going home to live with his parents.

> Int:
> Tell me about your rehabilitation programme.
>
> Mr. S.
> I think the physiotherapist saw me as a skeleton with muscles. It was that sort of approach. They looked at me from the neck downwards, rather than neck up as well. I didn't try to influence what happened. They were the experts. I followed them like a sheep not questioning things. I should have realised and asked more questions. I think they thought if they gave me all the help they could with physical things I would merrily get on and do the other things for myself.
>
> Int:
> Could you describe the main activities?
>
> Mr. P.
> It's mainly physical things. It's made a lot of sense. The physio's been great, a real mainstay. The basic programme was laid out for me. I talked to the physios and we worked things out together. I do the usual therapies but I also do swimming, typing and woodwork. I don't have to do it if I don't want to.
>
> Mr. Q.
> I've got stuck in straightaway. I had a good physio. I had confidence in her. At the beginning they know what's best for you. So long as I turned up it was OK. If I didn't, they came looking for me. I picked things up easily. I pushed them so I could do more. I'm quite pushy. They like that. It helps them too.

Mr. R.
It's physiotherapy in the morning and OT in the afternoon. The physio tries to get you moving and the OT teaches you walking, dressing, typing. It's more or less made sense. They explained things. I didn't want to change things. There wasn't any need to. You could ask to change your physio or OT if you didn't get on with them.

Int:
Have there been any difficulties since you started the programme?

Mr. P.
Yes, medically it's been depressing. They tend to be pessimistic. I was a jockey before this injury. I've had lots of injuries, and I got to know doctors can be wrong. They said I wouldn't be able to swim again, but I can. I even swam in the disabled games! It's the same with walking. They said I'd never walk again, but I can get about on crutches. I suppose they don't want to raise your hopes so I can understand their attitude. It's a problem for some patients who take what they saw as gospel.

Mr. Q.
I don't think you get enough information from the beginning. I was told I wouldn't walk again, but they didn't give me any details - you know - your spinal cord's broken, the brain can't pass messages, that sort of thing. There's nobody specifically to talk to you about what's happened. You don't get enough help. The nurses don't seem to have the time and nor does the social worker. Anyway, that's not her job. In the end you get it from people in wheelchairs. I just needed somebody to explain, to help me understand. You're lying there on your back for weeks with your own thoughts, it's difficult.

Mr. R.
I don't think they give a lot of thought to what will happen when you leave hospital during the rehabilitation. They give you a degree of independence, when you can start to do things for yourself, but the longer you're in hospital the more difficult it becomes to make the changes. You need to start doing things for yourself while you're still here. You don't have to think for yourself here. Then suddenly it stops dead and all the ordinary things you don't do here you have to start. I don't think the programme helps you adapt to life outside the hospital.

Int:
Could you describe your progress?

Mr. P.
I've made absolute progress. At first it was hell. I couldn't do anything. It gradually got easier. Mainly through the physiotherapist. I can dress myself now or transfer from my wheelchair to the loo, bath and into my car. I'm more mentally attuned to what's happening and I realise I can live an almost normal life. I know I'm making progress. I'm moving into the hostel next week. That's the next step to going home.

Mr. Q.
Everyday I can feel myself getting better. There's been a big improvement in seven months. I got depressed at first. I could only do so much. I tried to push it to the back of my mind and not think about what I'd be like, but you've got to get stuck in.

Mr. R.
Only a bit at first. When I got up I started to do much more. Then I was able to get around in a wheelchair. You don't notice it over the months, but people comment on what you can do. I don't think it's until you leave hospital that you'll find out and then you're left to your own devices.

Int:
What's your relationship with staff been like?

Mr. P.
One nurse was particularly helpful. She's married to an ex-patient with a spinal injury. Another was the physiotherapist whose disabled herself. They both had the practical knowledge you need, but generally I haven't found them very approachable, particularly the doctors. I'm not being racialist, but some of the doctors are not English and they're difficult to talk to. I think it's a cultural thing. The Indian one was fatalistic and depressed me. I'm a Christian and believe strongly. My doctor was cynical about this and said, 'the Lord only healed saints and as I wasn't a saint he wouldn't heal me'. I think they try to lower your expectations all the time, that if anything happens it's a bonus.

Mr. Q.
I could talk to my physiotherapist. She became my best friend. I spent five hours a day with her. I couldn't talk to the social worker. She was too pushy. She said my wife's 'very attractive, she might run off with someone else'. I felt depressed enough not to have to hear that. She should have been helping me, not saying that. When it comes to the personal side they leave you

to get on with it yourself. They can help you bodily but on the personal side they can't. I think it's embarrassing for them. Some show their embarrassment. You need somebody trained. Somebody you feel you can talk to.

Mr. R.
I've been able to talk to all of them except the consultant. He was a waste of time. He didn't know how to talk to the patients. He was the consultant in charge and an authority on the ward, but you didn't get a response. He didn't give you the encouragement you needed. You couldn't ask him questions. The therapists were better. They talked about how much better I'd be, what I'd be like.

Int:
Have you experienced any particular difficulties in your relationship with staff?

Mr. P.
I had a problem in the ward. You have to go to bed at 8.30 p.m., before the day staff go off duty. I got frustrated with this. I was well by then and getting about on my own. I even had my car brought here by my parents. The staff didn't have to do anything for me. But Sister said, 'you're a patient here so you go to bed at 8.30 p.m.' I complained to the consultant but he deferred to sister. She's a particularly strong character and dominates the ward. I think the other difficulty's been over sexual matters. It's important in the future, particularly if I get married. Nobody's brought it forward for discussion.

Mr. S.
I would have liked to have discussed the problems I met with my wife. We felt complete and utter strangers after I'd been in hospital some months. There was nothing between us after all that time. She couldn't even undress in front of me when I went home for a week-end. We were given no help with regard to what would happen; how the relationship would develop. My wife left me and went to live in Kent with the children. I told her the best thing she could do was to remarry. It was for the best when we separated. She was mentally and physically shattered looking after me and the children. I went into a shell. I still feel I haven't come out of my shell yet. I've no real social life. Life circles around my parents now. I feel a burden on them.

Mr. S. was asked how he felt the staff could have helped him.

Mr. S.
I think you need time outside the stratified programmes. There's lots of areas that need discussion. You need counselling of a quality kind. I needed it badly - about my injury and my relationship with my wife. You need to spend time away from the therapists. How you learn here is very much left to you to find out by talking to other patients. I think there should be counsellors. They should be an important part of rehabilitation.

Int:
Has your family been involved in your rehabilitation?

Mr. P.
Yes, they've been to the relatives' day. They were told how to help avoid pressure sores and how to deal with bladder and bowel things. They've visited me a lot. They've got a caravan and find a park nearby so they could visit regularly. I went home for a week-end and they tried to do too much for me. It's difficult for them to just sit watching me trying.

Mr. Q.
At first she (wife) thought I was just ill and I'd recover. The situation got worse between us. I felt a bit useless and used to shout at her when she visited. She wouldn't visit then. They didn't get us together. We sorted it out ourselves. I got depressed about it and talked to the sister. It wasn't really advice. She told me what she'd experienced with people before. She said, 'you can take it or leave it'. It was difficult for her being asked to help. As regards the future I don't know. I'm going back to live with the family. I don't think the wife would cope with me. The hospital got my family down here. The sister organised it. They gave them lessons. Showed them how you should be washed and turned. They discuss what you need when you go home. It was helpful in that way.

Mr. R.
I didn't live at home before the accident. I was injured abroad. The family didn't like what happened but I was never in contact with them much before. I went home for a weekend, but things were difficult. The woman I was living with didn't work out either.

Mr. S. had described earlier how his wife had separated from him during the period he was in hospital. On discharge he had returned to live with his parents who were both in late middle age.

Mr. S.
My parents are getting older. A longer term view is needed. What's going to happen to me. I've tried plotting out a path of what will eventually happen. Not just in the next two or three years, but longer. I'd like to start a path towards an independent life. I need some kind of residential place to live. The choice is limited. It's a Cheshire Home or the YDU (Young Disabled Persons Unit). Long term I know they (parents) can't look after me. The consultant says I shouldn't go home to them, but I'm not being offered any choice.

Int:
Now you're nearing discharge how do you see your future?

Mr. P.
I think it will limit my life. I was in the army, then I became a jockey. I couldn't see myself going out without a job to do. I'm fortunate I've been offered a job, by the racing world at Newmarket. In my mind I don't feel disabled, although I swam in the disabled games and have an orange sticker for the car. I'm just determined to be as mobile as possible and get involved.

Mr. Q.
I had a physical job. I couldn't do it now. The army and the DRO (Disablement Resettlement Officer) have arranged a course for me. I'm going to a residential centre for assessment. They'll find out what I can do. I'd like to do computer programming. I can still type. Then I could do a course and go home and get a job. I've got to get a job to keep me occupied in the day. The money is less important than having something to look forward to. Eventually I'd like to get a flat. To hold down a job and to have my own flat, that's what I'd like.

Mr. R.
Personally, I didn't have much idea what rehabilitation could do. There should be a stage between hospital and home, when you can start doing more for yourself. There are things you can't learn while you're in hospital. I was a diver before the accident and originally I did a business studies course at college. I've no chance of a job now. What I'd like is a flat. I want to move out.

Mr. S. was asked how he saw his future at the time of his discharge.

Mr. S.
My first objective was to get home. Above and beyond that I wanted to do something to occupy

> myself. I had back-up from my parents but I had to prove to the consultant that I could cope at home with my parents. The consultant said I would never survive outside hospital. My lesion was too high, but high lesion patients have been successfully rehabilitated. If you get enough help and support, and equipment you can do it.

Discussion

The rehabilitation programme for spinally injured patients rightly focussed on the need to teach the patient activities that he would require to survive as an independent person. The focus was on mobility and activities of daily living (ADL). The patients interviewed saw this focus as natural and felt this was their main need; to be able to overcome as many physical limitations as possible and do things for oneself in order to be independent again. Here the work of the physiotherapist was particularly well regarded and the three patients involved in rehabilitation all spoke warmly of the energy and commitment of their physiotherapist. Mr. S. who had already completed his rehabilitation at the hospital and now lived with his parents was able to reflect on his experience in light of his subsequent needs on leaving hospital. He was more critical of the help provided and felt that the rehabilitation programme had placed too much emphasis on the physical functions aspects and assumed that competence in these areas would be sufficient for him to cope with the varied demands of life outside the hospital. Mr. S.'s comments that the programme ignored personal areas that were distinct from physical functioning is important and indicates the imbalance in the delivery of rehabilitation services within the centre.

Progress in rehabilitation was not seen as presenting any difficulties to the three patients completing their rehabilitation. They all felt they had made reasonable progress in physical terms, and again appreciated the support of remedial therapists who had helped them reach personal goals of independence. These three patients were all young and physically fit and had made demands that had been mutually rewarding to patient and therapist. Some limited evidence of ability to negotiate changes within the rehabilitation programmes was present, with the young demanding patients concerns likely to be considered by therapists.

Difficulties tended to focus around medical staff, and problems of obtaining information. Medical staff were identified as a problem by one patient who felt that doctors took a pessimistic line, and had low expectations about the possible achievements of patients. This patient who had already received considerable medical treatment for racing injuries also harboured doubts about the wisdom of all medical decisions and statements, which was only confirmed by his own progress in spite of medical opinion. However this patient admitted that doctors may have taken an unnecessarily pessimistic stance in order to appear not too hopeful about an outcome over which they had little influence. The other area of difficulty was that of obtaining information about the spinal injury and how this had affected the body. One patient who wanted details about the damage to his spine and how that had caused paralysis was unable to obtain this information from staff and, as is the case with many patients, obtained this information from other patients, who are a major source of information to newly disabled people. Mr. R.'s comments were related more to 'preparation' for leaving hospital, but here he was indicating that preparation must begin early, with the patient starting to take decisions as soon as possible, which would have had implications for the structure and content of the rehabilitation programmes as currently organised.

Relationships with staff was an area where there was a positive response about the physiotherapists, and also two other staff, one of whom was disabled and the other was married to a disabled person. The special insights based on personal experience and the detailed knowledge of every-day difficulties which even the most experienced and sensitive therapist can ignore, was seen as a strong point in favour of people with this sort of experience being part of the rehabilitation team. Doctors were seen as staff to whom patients had difficulty relating, either because they were seen as unapproachable and made little attempt to relate to patients, or because of unnecessary personal comments that had little to do with the needs of patients. This probably indicated poor interpersonal skills in the area of therapeutic relationships. Bossiness by nurses was mentioned by Mr. P., which again had considerable implications if this behaviour was experienced by other patients. Strict rules about bedtime were surely undermining to the confidence of patients who were expected to cope independently in the future yet were playing childlike roles while in the centre. The main difficulty expressed by all patients was the lack of opportunity to discuss problems that had occurred in marital relationships following the spinal injury and all its consequences for personal and physical functioning, or the lack of specific help in marital and sexual counselling. Marital breakdown is a possible consequence following the acquisition of a physical disability. The strains placed on the marriage where one partner is no longer able to play the major roles already established within the relationship before the spinal injury was an area given remarkably little attention in the programmes. Two patients who had been married had seen their marriage break up, without any active attempts to provide the marital counselling that might have avoided this additional blow to the family structure and to the disabled person's self-esteem. Family involvement in the rehabilitation programme was concerned with relatives spending a day at the centre learning about disability during the time their relative was an in-patient. This information and training was directed at making the disabled person's life outside the hospital as trouble-free as possible, and focussed on physical aspects of care such as health care procedures and bodily maintenance.

There was no indication of active family involvement with the rehabilitation programme although some families spent considerable time at the hospital, including relatives moving to be near the patient. How far the notion of family rehabilitation was developed is difficult to assess. Again as in the research unit the large catchment area, in this case a national one, must influence the potential for family involvement in rehabilitation.

Lastly, patients were concerned about the future. All patients saw independent living in their own home with a job as their personal goal. The difficulty for three patients who had no job, nor any certainty of their own accommodation, was what the future would hold for them. The option of residential care was not something that was preferred, although it was recognised by Mr. S. that this would probably be the option for him as his parents aged and could no longer offer the level of care he needed. The breakdown of two patients' marriages obviously influenced their accommodation needs and the loss of a spouse deprived them of personal support when it was most needed.

The Staff Viewpoint

Following interviews with patients, arrangements were made by the Principal Social Worker for me to meet some of the staff working in the spinal injuries unit and the remedial therapy department. These interviews took place at a time when I was developing the staff interview schedule in preparation for the next stage of fieldwork in the research unit. It was an opportunity to test out some of the questions that appeared to address themselves to important issues in rehabilitation.

> Int:
> Could you describe the rehabilitation programme?
>
> Nursing Sister:
> At first it's about life saving, that takes precedence. Then it's coming to terms with disability. The rehabilitation timetable is very tight. A lot is pushed into the daily programme in the therapy departments. That sort of routine squeezes out the chance to spend time with patients when you're not actually carrying out some nursing procedure. In the morning the nurse is preparing the patients for their daily programme, and then in the evening preparing them for bed. The nurses part of the rehabilitation programme means doing all the horrible intimate things to do with the bladder and bowels. Because we're doing those sort

of jobs at the beginning and the end of the day we don't have the sort of relationship with the patient that the physiotherapist has. The nurses tend to be jealous of the remedial therapists who are seen giving the patients independence and have more time to spend with them.

Doctor:
Initially it's a medical problem during the acute stage. The patient has a broken back and often other associated injuries. It's the doctors' job to oversee the treatments. Rehabilitation is about a lot of people doing different things. Although the doctor orders the treatment he needs to keep in touch with staff and take advice from them. He's got to pick up the problems that are occurring and adjust the regime. The trouble is the average doctor doesn't take advice easily.

Senior Social Worker:
You can't call this a rehabilitation unit. There's no rehabilitation team as such. Basically we're a general hospital that also has a spinal injuries centre and a young disabled persons' unit. All the departments of the hospital refer patients to the therapy departments. Most of the work is with physiotherapy, occupational therapy and speech therapy. There's only limited emphasis on social rehabilitation and that's mainly the work the physiotherapists do taking patients into the community and organising social events. Social work has very little time allocated in the daily programmes. We have to squeeze in where we can.

Head Occupational Therapist:
Rehabilitation here tends to be concerned with the physical and functional side. It often seems enough to get a severely disabled person moving again. With the present staffing there's not a lot of time to spend talking to patients about their other problems. We do need to look at wider issues though. There are important areas besides the physical ones. A different approach in practice would help.

Principal Social Worker:
It's a tough regime for the patient with spinal injuries. They are expected to work hard at independence and comply with the programmes. This centre was originally set up to treat servicemen. The work today is still influenced by that approach, although it's changed a lot. There's still the view that the patient has got to work it out for himself.

Int:
Patients often express concern about their personal feelings and issues like relationships and sexuality. How much are you able to help in these areas?

Nursing Sister:
The nurses can't always help. They don't always feel confident. The ward is mainly staffed with enrolled and auxiliary nurses who are recruited to undertake basic tasks. They don't get enough training to respond to the demands of patients. They're often embarrassed by the questions patients ask them. They do intimate things in the nursing role, but find it difficult to answer the patients' questions. Many of the patients are young men. They ask a lot of questions about sex. The nurses would rather the patient didn't ask questions.

Doctor:
I try to be frank with the patients. I like to lay the facts of their condition before them. Otherwise they hear stories and misunderstand things. Then resentment builds up towards the doctor because he's not open with the patient.

As far as the sexual function is concerned I don't think the doctors are in touch with the feelings of the patients. It's part of the doctors' role as far as I can see it, but other doctors see it differently. I think they (doctors) need to be much more aware of the patients' psychological state and bring in the social worker to help more. We don't have psychosexual counsellors here, but the social worker could help on that side of things.

Senior Social Worker:
The patients in this Unit have all suffered tragedies. They're young people who've been severely injured in accidents. The tragedy of what's happened to them means they're preoccupied, thinking about their accident. They perceive themselves in terms of physical ability. They're getting to know their bodies and themselves all over again. I don't think they're ready to take on responsibility for aspects of their rehabilitation. They're certainly not ready for social work help. It's too threatening to start working in this way and expect them to take that sort of thing on board. The sort of patients we do get referred for counselling are those that are 'different', they don't accept the authority of the staff. We tried to organise sessions for patients on sexual problems on Monday evenings. The nurses, therapists and social workers took

part. The idea was to provide basic information to start with, but we ended up chivvying patients to attend. The turnout was low. I think the men were too threatened by these sessions. It's the loss of sexual power, their image and the roles they're expected to play. The women were less threatened, they can still conceive, their role is still intact. I think it was very difficult to expect them to hear bad news when they were still coping with the tragedy of spinal injury.

The study days for relatives are useful. They come along and we give information about disability in a non-threatening environment. They're not told what to do by doctors. They get together with staff in a permissive setting to learn about managing disability.

Speech Therapist:
There's a considerable need for counselling work with the patients on an individual basis, and with the relatives. There are enormous personal problems that are not dealt with in rehabilitation programmes. You need to give them time on a one-to-one basis that enables the patient's feelings to emerge and be incorporated within the treatment programme. That's where counselling could help patients.

Head Occupational Therapist:
The roles of O.T.'s are changing. Our involvement in ADL avoids the old image of basketwork. We probably haven't given enough time into looking at the social and psychological factors in rehabilitation. The counselling role is needed, but who does it? We can all offer help. The therapist training makes them aware of these areas, but we need to get together at case conferences.

Social Worker:
Some of the doctors wanted to bring in ex-patients as counsellors. The social workers were worried about this development. They felt there could be dangers. The patients doing the counselling would have to be well adjusted to their disability. The scheme was opposed and in the end didn't go ahead.

Int:
What sort of factors do you take into account when you're looking at a patient's progress?

Nursing Sister:
There's no particular sort of person who makes most progress. I've given up trying to judge people. Progress seems more related to different wards and the relationships the patients make and

how they're handled by staff. The problem is that nurses like their patients dependent. But when the patient's making progress the workload lessens and you have much less contact. That worries some nurses. They can be real 'mother hens' and want to know exactly where a patient is. They like the 'clutch' around them.

Doctor:
I don't know if there are specific factors that indicate progress. At the end of the day they don't make much difference. People have certain personalities and you can't change that. People are people. Of course the more intelligent person is going to make a better rehabilitation than the labourer from a lower social class who's going to find it more difficult because his job's finished and he's unlikely to be insured. We still try to rehabilitate people to a certain level, but we feel we've failed if they can't do certain things when they leave here. You have to accept that some just don't want to know. Patients have their own reasons for not fitting in with the regime. They may be socially unacceptable or show little interest in their programme. That sort of patient loses out or is ignored by staff, but in the end they can still achieve as much as other patients. Some patients go home rehabilitated no matter what we've done with them.

Head Occupational Therapist:
It's about motivation and that depends on things like the personality. Also what the person was used to doing before they came into rehabilitation, and what they've got to look forward to. You help by offering a range of activities that interests the patient and can stimulate a wider interest in other things that the therapist sees as important. Some of the patients are unpopular and it's difficult to get enthusiastic with them. If they're depressed and not interested in trying things you try to match the patient and staff. If people get on or you've got really enthusiastic staff you can get things going.

You've got to look at the patient and his family. Does he really want change? Does the spouse want him to change? It's only when you work with the patient and his family that you can really know. You have to ask yourself ... what's in it for this patient to want to follow a rehabilitation programme?

Speech Therapist:
The therapist always has a goal to work towards, but that has to be realistic. It's also what the patient wants and can achieve. Patients' involvement is necessary. It's what that person wants for himself that's important in the end. It's

difficult to see progress if you set things up that the patient doesn't want. Progress can be measured using before and after treatment recordings. There are many ways of describing progress. If a patient says I've improved, that's important. You must always be looking for progress. It means different things to different patients. It's the view of progress that's important. The important thing is involving the patient. We should start by asking their views and not talking over them. You know, doctors and staff standing around a bed talking about a patient, that's very bad.

Senior Social Worker:
There's the pressure from the patients. They want to do more. They put pressure on the staff. The doctor can have a different interpretation of progress and is less idealistic and recognises the limitations more than the patient. Patients are discharged earlier now and do more on discharge. Patients with high lesions are often driving cars now. That would have been unthinkable five years ago. There's also the 'difficult' patient. What was he like before the accident? If he was used to making decisions he will want to continue making them in hospital. Maybe it's the difficult patients who make the best rehabilitation?

Int:
The team approach is customary in rehabilitation. How is coordination achieved here?

Nursing Sister:
We have a weekly conference. That's when the nurses make their contribution. We make an effort to be there, but working shifts means you're not always available. There's a lack of leadership. The consultants are the leaders, but there's very little respect for them. They all have different approaches and it leaves the rest of us in the dark.

Coordination is a grey area here. There's not enough understanding of what each other is doing and it doesn't work well. There are areas of overlap and staff just rush in without consulting each other, particularly the occupational therapists. Information just doesn't get passed on. It needs trust between different staff. A social lunch once a month with everybody invited would help. It's a big hospital with a high staff turnover, particularly among the nurses and therapists. More coordination is badly needed.

Doctor:
We have a grand ward round once a week. It's used to discuss medical and physiotherapy topics. Afterwards we meet over coffee and talk about the social side. That's when the social workers come in. The problem is that it's only once a week. Problems crop up during the week and then people don't get consulted. It all depends on the consultants. They vary in how much they delegate responsibility to other doctors. The consultants have the power, but they're not picked for their leadership qualities. They don't do much coordinating. Basically they're people who all think differently. They're not used to the leadership role. They don't feel comfortable talking to junior staff. Most doctors will only talk to other senior staff.

The consultants have got a leadership and co-ordination role but they don't do pastoral work with staff. They need to help pull the staff together more and talk to people. The staff need to be a happy family otherwise the patients pick it up and it has an affect on them.

Speech Therapist:
That's the major difficulty. There's a lack of coordinated approach. You spend a lot of valuable time explaining to colleagues the problems you've identified with a patient and the approach you're taking. A coordinator would be useful in bringing together ideas from the different professions. It's badly needed.

Senior Social Worker:
It's a problem getting rehabilitation to work when there's no team with a separate identity, no case conferences and a massive catchment area. We need goals in terms of therapy agreed at case conferences. It's difficult working with the doctors. The three consultants all have different approaches. The one I work with is particularly difficult. He doesn't like conferences or group meetings.

Head Occupational Therapist:
Coordination's a problem while rehabilitation is mixed up with medicine. Medicine is about pathology. Rehabilitation is something that follows on from the work of doctors and nurses. It's something that happens after medicine has completed its work. It's got confused with illness, with the doctors having rehabilitation in their title, even though they're not expert in the subject. We see them making hasty ill-considered decisions concerning the patients. I know we don't always appreciate the pressures they're under, but they're defensive as a group and don't share the pressures with other staff easily.

> The other area of difficulty is between the nurses and the therapists. Nurses don't appreciate the reason for some of the treatments. I don't think nurses understand some of the social and psychological areas. We need to get together more. It's partly the place you work. The location influences people's behaviour towards each other. That's where case conferences and personal contact would help.

Discussion

The impressions gained from the discussions with a handful of staff point to a number of areas of possible difficulty within rehabilitation practice. The physical-functional side is emphasised in the rehabilitation programmes but raises doubts in the minds of some practitioners that this offers an incomplete approach which may neglect the vital social and psychological dimensions of physical disability. Linked with this approach is the possibility that the culture of rehabilitation is one where 'physical coping' is expected with little recognition that patients have other needs that they find difficulty raising with many staff, and an environment that is not organised and sensitive to interpersonal needs of a non-physical nature.

The second area that raises questions from the statements of staff is the emphasis by social workers on disability being seen as a tragedy. This perception may hinder the professionals in their approach and reduce their willingness to become involved with patients for fear of causing what they perceive as further grief. Patients interviewed seemed to want more contact with staff, more involvement and more discussion, and they questioned the reticence of staff, their embarrassment and lack of willingness to provide information. Professionals attribute feelings to disabled people that may not exist in the minds of the patients.

Related to this problem is the recognition by all staff interviewed that the patients need more counselling help, but again doubts about the appropriateness of intervention was raised by social workers who feared that patients would be threatened by counselling techniques exposing more grief following the onset of disability. Again questions must be asked about whether this is not a projection of the professional's anxiety and doubts about working at this level with disabled people. The attempt to introduce peer counselling by ex-patients also foundered because of social work opposition, even though patients interviewed described how valuable they found their learning from patients who had experienced disability for a longer period and had mastered the techniques of increased independence. If patients could not get help from professionals in this area and were also denied appropriate peer counselling, where should they turn to for help?

Progress in the rehabilitation programme was an area where there was little unanimity of view, although some common themes emerged. Firstly, the belief that the patient's pre-morbid personality was significant for the progress made in rehabilitation. Secondly, the important role of the environment of the centre and the staff's therapeutic approach, particularly involving the patient in setting realistic goals. It was also acknowledged that some patients were unpopular and staff found difficulty working closely with them. How much staff were able to understand the notion of progress that took account of these and other factors is unclear. Certainly the commitment to a demanding rehabilitation programme is not something that one would expect to exist in a vacuum and is likely to be a direct consequence of the level of involvement of the staff and their sensitivity to the patient and his needs both apparent and unspoken.

Lastly, coordination was seen as a problem in the centre. The organisational structure, with no separate rehabilitation team with its own consultative machinery, together with the medical direction and their influence in the rehabilitation programmes frustrated all the staff interviewed. Alongside these frustrations was the evidence of disagreements and conflicts between therapists and nurses whose different orientations had not been bridged by discussion and joint practice. Similarly the belief that medicine actually created problems for rehabilitation practitioners was evident.

In conclusion this brief but useful discussion highlighted areas of rehabilitation practice that were highly relevant to the problems perceived by the four patients. They showed that practice does not really aim to meet all the disabled person's needs, and that structural factors in the organisation and delivery of services within the spinal injuries centre and the rehabilitation departments frustrate the efforts of both patients and staff.

8 THE DISABLED PERSON AND THE REHABILITATION PROCESS

The two previous chapters have concentrated on the patients' and staff's perception of the rehabilitation process, and brought to light a number of areas where the needs of patients and the staff's response to those needs were inconsistent. This raised questions about the purpose and effectiveness of the rehabilitation model developed in the Unit. In order to extend the understanding of the disabled person's situation during the rehabilitation process this Chapter focusses on a number of areas that appeared significant both for the disabled person and the rehabilitation system in striving for a closer match between the patients' needs and the rehabilitation techniques employed in the Unit.

To obtain a greater awareness of the needs of the disabled person during the period of rehabilitation this Chapter draws primarily on the work of researchers who have explored the rehabilitation process from the disabled person's perspective, and also disabled people themselves whose personal experiences provide a unique account of rehabilitation, particularly those issues that are often ignored or glossed over in the predominantly professional accounts. Where appropriate the comments of patients in the rehabilitation unit and the spinal injuries centre are used to illustrate the issues raised.

The Socialisation Process

In examining the disabled person's needs in the rehabilitation process, it is first important to understand the mechanism of socialisation. Socialisation is the process by which individuals learn the culture of their society. Probably the most important aspect of this process takes place during infancy, normally within the family. The child learns the language and basic behavioural patterns of society through the example of the parents and their approval or disapproval of the child's behaviour.

Other important agents of socialisation include the educational system and occupational settings (Haralambos 1980). Socialisation is not confined to these agents or processes. It is a lifelong process. Some individuals will have to cope with unexpected situations that have an impact on this socialisation process. Physical disability is one such situation because it can affect every activity from getting married to finding and keeping a job. Established roles and the socialisation process are interrupted by disability. This can mean an entire redefinition of the disabled person's situation, with the reconstruction of roles and relationship patterns.

Rehabilitation can be analysed as one of the processes of socialisation. This model of rehabilitation focusses attention on those processes by which individuals acquire new roles and in consequence of these roles new self-definitions, skills, activities and relationships (Cogswell 1978). Socialisation is achieved through the interaction of disabled people who are learning new roles, and the agents of socialisation such as the staff in a rehabilitation unit. This re-socialisation is a learning process to acquire new attitudes and behavioural patterns that help the disabled person adjust to his new life situation. The socialisation agents who control what happens in the rehabilitation process are seen as having a powerful contribution in that they dispense rewards and use coercion, authority and expertise in shaping the behaviour of the disabled person. In this context the disabled person is often perceived as a passive, malleable and powerless individual who responds obediently to the demands of the professionals. But in rehabilitation the disabled person is engaged in activities intended to enable him to become independent of those around him. Consequently the disabled person has to develop an expertise that can be critical to his own survival, and knowledge of the management of his condition is therefore necessary. The disabled person is modifying his behaviour as a result of the training and advice of professionals, but he is also reacting to the rehabilitation process and modifying the behaviour of those around him. Within the rehabilitation unit and the spinal injuries centre conflict between staff and patients was evident, whether by staff voicing dissatisfaction about patients' unwillingness to follow their directions, or by patients who did not respect the professional judgment of staff.

Clearly the rehabilitation process is an area where the agents of socialisation and those who need to learn new roles meet. What is also clear is that newly disabled people, although often strongly influenced by professionals attempt to reconstruct personal identity and give meaning to their lives that is often at odds with how professionals see the future.

Becoming Disabled

Disability occurs as the result of internal disease or external trauma to the body. The onset of disability brings problems to the individual and to those around him. For the individual a complex series of shocks to the body which can result in the destruction of part of the body, an interruption in the physiological process, physical pain, disorientation and confusion occur. Depending on the site of the injury it can also mean limitations in self-help and mobility functions. A major factor accompanying the physical impact is the disruption of social roles and patterns of interactions (Schoenberg 1970).

A critical incident that leads to disability disrupts the person's taken-for-granted assumptions about the past and the future. For the newly disabled person, particularly where the disability is sufficiently severe to restrict the person in many areas of living, the future can no longer be predicted on the basis of past activities. The newly disabled person whose future is unpredictable, is likely to ask a number of questions that might reasonably include: 'who am I now?', 'what can I do?', 'how will others see me?', 'what will others expect of me?', 'why did this happen to me?'. These are questions that are likely to be asked not only by the disabled person, but also those around him who are most intimately concerned with his needs and the future. The difficulty for many disabled people is that there are large areas of uncertainty about their disability and what the future holds. Medical intervention can effectively limit the extent of the physical impairment and reduce the risk of further disablement, but the larger and more difficult question is how the disability will affect the person long-term and what the consequences will be for that person's future life (Albrecht 1976). Although the future consequences of disability can be uncertain at an early stage of rehabilitation, disabled people have nevertheless demonstrated time and again that with effort and ingenuity problems can be overcome, often in the face of considerable medical scepticism.

Where the disability is severe with substantial functional limitations that interfere with the person's normal living pattern it may mean he will have to construct a new way of life with new attitudes, new activities and new social relationships. The questions quoted above take on much greater meaning and make demands on the disabled person that he works at reconstructing, or at least modifying his existence to date. A major problem following the onset of disability is the feeling of helplessness, when the person loses contact with their everyday routines and becomes the subject of professional intervention in the health care system. The person no longer feels in control of his own destiny and with the future uncertain he has few opportunities to take responsibility for his life situation and make decisions in order to begin planning for the future.

At first, of course, he may be grateful to be alive and obviously improving physically. It might easily have been worse. But, eventually thoughts turn to the future and what that holds for the person. A young teacher quoted in Campling (1981), who was severely injured in a motor accident described how she was thankful to be alive, particularly, as her serious head injury and fractured spine had raised doubts about her survival. However, in her case the period of unquestioning gratitude was short lived as she became increasingly concerned about the quality of her life in the future. At first she reported feeling anger, quickly followed by frustration that much of her body no longer worked. The destruction of her self-confidence was for her the most significant effect of her injuries and led her to feel unacceptable and undesirable as a woman, (she felt ugly and worthless, but eventually her self-image was restored mainly through the support of her husband and her family who helped her regain her self-confidence).

It is after this stage of numbed shock and anxiety that the disabled person often has a long period during rehabilitation to ask questions of himself and others, in order to make sense of what has happened. He is trying to make sense of his world even though it is a world full of imponderables. The patients interviewed in the two units had all passed the stage of initial shock, in fact, for some disability had been a slow-developing process rather than the traumatic impact of a serious accident. Nevertheless, questions about the future featured largely in their conversation, both among patients themselves, to staff and in response to questions by the researcher.

In the Unit questions often concerned the lack of certainty in the future, for example Mr. K's continuing anxiety about his sight and lack of any firm information about how much use of sight he might regain in the future. Similarly, Mr. L's concern was also about the future. How much longer would he have to stay in the Unit, and eventually when he was discharged would he be able to resume work and drive a car? These were questions he raised, but also ones where he was fearful of information he might be told by the staff. Likewise in the spinal unit those questions about what the future might look like following the impact of severe disability was an area that preoccupied the patients interviewed. Mr. R. expressed this anxiety in questions about what life would be like when the professional help stopped and the need to adapt to life outside the hospital became urgent. Mr. Q. was equally uncertain in spite of arrangements that had been made for him to go onto a centre to be assessed for employment. He had made the rapid transition from a very physical job to a lifestyle which was radically different and still appeared full of uncertainties.

It is these personal concerns which are wide ranging and can result in questions such as, 'how much movement will I get back in my limbs?', to 'will I be able to have sex again?'. The problem the disabled person faces is that many of these questions are about aspects of future performance that are difficult to predict. Although independence and maximum functioning are usually personal goals for disabled people, in rehabilitation these goals are determined and interpreted as a result of a number of factors, including the disabled person's own personal resources, his own and others' expectations, and his social environment, including the rehabilitation setting. Disability is recognised, particularly where there is severe impairment or obvious disfigurement, as a monumental reconstruction job that presents the person with radical problems most people never have to face. The reconstruction encompasses a range of consequences including re-examination of the person's value system, his goals for the future, learning new behaviours and solving day-to-day practical problems. The successful adaptation to the newly disabled state is contingent on the person changing his values in order that the physical limitations become a more peripheral facet of his life, rather than one of central importance (Wright 1960). The case of Mr. Q. quoted above was a clear example of someone whose life in the army had been of a physical nature and now after a spinal injury had begun to re-evaluate his future life in terms of a sedentary job, although retaining an interest in technology that would enable him to make the transition from radio operator to a hoped-for career in computers.

Alongside this value change is the need to have clear goals for the future which offer some incentive to maintain morale during the rehabilitation process. Goals which offer a future which meets some of the disabled person's needs will enable him to commit himself to learning new behaviours and taking day-to-day problems of a practical nature. Of course, overcoming these problems of re-socialisation is not something that the person does alone or has total control over. The disabled person is just one of the individuals in the rehabilitation picture. His resocialisation is affected by his own actions, but also by the actions of others who exercise some control and influence over him during the rehabilitation process.

The Disabled Person and Relationships with Significant Others

An important concern for the disabled person during rehabilitation is his relationship with other people. Three aspects are of particular importance, firstly the relationship with the family, secondly relationships with professionals and thirdly other disabled people in the rehabilitation system. Before looking at relationships with particular individuals it is necessary to briefly discuss relationships between disabled people and the able-bodied. It is not physical disability per se that is important, but the social meanings based upon it (Tirbutt 1984). Somehow the disabled person is seen as not a 'proper person', and is lacking in areas of social competence or moral character because of their impairment. The problem for the disabled person is that he not only has to cope with the physical consequences of the impairment that created his disability, but he also has to cope with the social and psychological consequences of his socially defined status as disabled. For a person who is born disabled or who acquires a disability at an early age the growing awareness of being different accumulates over time and is 'managed' by the parents. With a sudden, often traumatic acquisition of a disabled identity that is something that is undesired and to a large extent unknown in its consequences for the person. It is particularly difficult for the disabled person whose appearance does not accord with the dominant values of society such as physical attractiveness, wholeness, symmetry of body, and the attributes felt to be the prerequisites for a pleasant and engaging personality (Davis 1963). This stigma is said to 'spoil' the person's conception of himself and during the early period of his 'career' as a disabled person he is expected to come to terms with the notion that he is now an incomplete person in the eyes of others and that he cannot hide his defect from their view (Goffman 1963).

It is in the interaction with others, primarily non-disabled people that Oliver (1981), himself disabled, has used the theories of symbolic interactionism to explain how the disabled person has the meanings of his disability created by his interaction with significant others. He uses the term 'significant others' to refer to those individuals who can have an influential effect on the meaning an individual may attach to his particular situation.

Relationships with the Family

Wives, children and close relatives are unlikely to have positive views about the nature of disability and the problems such as the management of bodily functions. Issues of personal care, relationships, sexuality, mobility and adequacy of finance are matters that may concern family members, and their responses to these provides the crucial meanings of disability for the disabled person.

The family is a primary reference group and plays a significant part in the feedback the disabled person receives from others and this helps shape his expectancy and performance in the rehabilitation programme. If the family communicate to the disabled person that he is incompetent to perform in areas that he previously took for granted this attitude, if internalised, may reduce his self-confidence and his performance level.

A difficulty facing the disabled person is the knowledge that his disability will require dependence on his family to an extent that may have been unthinkable before his accident. The disruption that this can bring to the 'ordinary' expectations of family life needs to be considered during the rehabilitation programme. Worry of not being able to assume the traditional roles, taking responsibility for certain activities can severely affect how the person sees himself.

Keeping in mind the stresses that are likely to be placed on the family of the disabled person it is important to recognise the family as one of the most important of all the external factors contributing to the ultimate success of the disabled person's rehabilitation. The family can erect substantial barriers before its disabled member and by their words and actions can undermine his belief in his ability to cope. On the other hand the family can also remove barriers. The families who are supportive to their disabled members and who allow and work with the person in order to assist him can inspire the disabled person to considerable personal achievement. The support of the family is unique in having a beneficial effect on the disabled person.

Oliver (1981) though sees dangers for the family when the focus of help and positive meanings associated with disability may be concentrated exclusively on the disabled person whilst the family is neglected and not seen as 'disabled'. Oliver asks the professional to look beyond some narrow concept of adjustment to disability being solely an individual process with the family just available to assist the disabled person, and to examine the family's critical role in the creation of the meaning of disability for the individual.

Secondly, the family 'disabled' by their close association with the disabled member have to make significant adjustments to their lives in order to meet the needs of the disabled member. Many of these adjustments, including financial ones and flexibility over tasks and social roles, will probably be at the expense of the family members' own lives. The question of balance needs to be confronted particularly with the evidence that relationships can be put under considerable strain by the presence of a disabled member in the family (Sainsbury 1970).

A breakdown in the relationship can be critical for the disabled person and his family, because this breakdown can lead to the disabled person having no support available owing to the refusal of the carers to continue their commitment. The likely alternative then is admission to residential care.

Examples from the fieldwork illustrate the crucial role of the family in the lives of disabled people.

Mrs. B's family clearly gave their meaning to her disability. Although physically restricted by a long-standing disability, the attitude of her elder daughter who relieved her of many household tasks she could comfortably have accomplished, reduced her opportunities to play a role that could have given her life more meaning and purpose. In addition her anxiety over her sexuality and clear indications that her husband showed little emotional warmth towards her, made her feel no longer an attractive partner sexually and reduced her self-confidence.

In contrast Mr. E. a young active person who had a leg amputated described how supportive his wife had been since his accident. She had encouraged him during rehabilitation and congratulated him on his progress. He had been worried initially about what the loss of a limb would mean to his wife and whether it would mean the end of their marriage. His wife's support and concern, including becoming involved in learning to dress the stump prior to an artificial limb being fitted, had demonstrated the positive role she had played in the rapid progress made during his stay in the rehabilitation unit.

Relationships with Professional Staff

Following the onset of disability the disabled person finds himself in an environment that is alien to him, surrounded by professionals who are experts in his problem. Even when the person has passed the acute medical stage there is a continuing association between medical management and physical disability. The disabled person is no longer sick, he is disabled, nevertheless he is in a hospital setting which dispenses treatments with the disabled person more or less a passive recipient of units of therapy.

All these trappings of hospital care are likely to indicate to the disabled person that he is sick and in a state of helplessness, no matter how much the nurses and therapists try to persuade him to the contrary. The link forged between the sick role and disability means the person is not in a strong bargaining position to make demands on the professionals for information or a share of the decisions about his life. It is not a situation that makes it easy for the disabled person to discover what has happened to his body, what is likely to happen and what the long-term future looks like.

Again like the family the professional staff have a crucial role to play in helping define the meaning of disability for the person. Although staff are seen as one group who can provide positive meanings to the disabled person and those intimately involved with him, it is clear that some disabled writers who have experienced rehabilitation regard many of the attitudes of professionals to be negative, although often in subtle rather than overt ways.

The teacher quoted earlier in Campling (1981) had a brutal introduction into the attitudes of staff when she was told early on in her rehabilitation that she could not expect her marriage to survive her disability. This cruel and unnecessary statement led her to try and persuade her husband to divorce her as she felt imperfect and inadequate. Fortunately, these sorts of statements by staff are not mentioned very frequently by writers on disability although they occur too often for comfort, as in the case of Mr. Q. who was shocked at a social worker's comments about his wife and the likelihood that she would find another partner now he was severely disabled.

What these sort of remarks indicate is that the evaluation of disabled people by staff can actually increase the problems that the disabled person faces, rather than ease them. Kerr (1970), herself disabled, describes how the responses of professionals are so radically different from those the person experienced before becoming disabled, that the person begins to question what sort of person he is, what roles he might reasonably play in the future and doubts about his future activities. She describes the responses of staff, often non-verbal, to the disabled person. These responses include firstly, the behaviour of staff, often seen by them as reasonable that nevertheless results in submission and devaluation of the disabled person. Second, that life is going to be very difficult indeed. Third, earning a living will not be possible. Fourth, the staff know what's best. Fifth, that asking for help means I'm a dependent person who is inferior, and lastly that being disabled often feels like being a child. These responses, often not verbalised, or perceived by staff as harmful, nevertheless are seen to have a marked effect in the rehabilitation process.

Maggie Davis quoted in Tirbutt (1984), a former nurse who was severely disabled in a motor accident, describing her stay in a rehabilitation unit, found herself cut off from the sort of life and activities she had been used to. The staff did not communicate difficulties and she was not allowed to make decisions. She was denied information that she felt could have given her the hope that following discharge she could live more independently and could marry and have children. She commented "if I thought about it I could cry at all that time I lost" (p.10). In this comment she is referring to her acceptance of life in residential care and the assumption that she would not marry now she was severely disabled, and furthermore should not think that having children might be possible. Davis is describing how her meaning of disability was clearly shaped by the approach of staff in the rehabilitation unit, with their negative views of the potential of disabled people to reconstruct a life based on independent living and family life.

The manner in which staff transmit to patients expectations about their disability has a powerful affect on how the disabled person constructs his/her reality.

For many disabled people leaving rehabilitation units, their future expectations are lowered by the socially defined attitudes about disabled people. The potential for disabled people to construct independent and fulfilling lives is something that so-called 'experts' in rehabilitation find incomprehensible. The staff in units, although in direct contact with disabled people, are often pessimistic both in general statements about disabled people and in discussing particular individuals. Patients were sometimes seen as unrealistic and 'not yet adjusted' to their disability.

This was certainly how Mr. P. saw his situation. He expressed anger at the fatalistic attitude of the doctors in the spinal injuries centre who he felt had attempted to undermine his commitment to becoming independent again. Mr. P. was a particularly highly motivated individual who had worked out clear plans for his future in terms of accommodation and employment. During his time at the centre he had been successful in obtaining a job which awaited him on discharge. In addition to his disagreement with the doctors was his resentment at being treated like a child over bedtimes which he saw as unrealistically early in a situation where patients were not sick, and were adult and responsible enough to retire at an appropriate hour.

It is the notion of 'adjustment to disability' that has been criticised recently by disabled writers (Finklestein 1979; Oliver 1981), who both feel that the disabled person does not need to be reminded that parts of his body no longer work as they did before, but in spite of impairments he wants to regain and control as much of his old life as possible. It is in this area of control that disabled people often feel they are being 'shaped' by professionals who have a poorly developed understanding of how much their control undermines the acquisition of appropriate behavioural skills and responsibilities by the disabled person.

Relationship with Disabled Peers

Finally in considering the socialisation process and the role of significant others it is important to consider the other disabled patients in the rehabilitation process and the effects they have on the disabled person.

During the period of rehabilitation patients often find a source of comfort in each other's company. Neil Slatter (in Hurley, 1983), whose injury followed a motor-cycle accident resulting in a long period in a spinal unit described the strong feeling of kinship in the ward. "There was a lot of sharing and comparing, and wondering where we'd all end up". This sharing of experience and discussing each other's progress played an important part in Slatter's rehabilitation experience with mutual support and advice something he looked back on as significant. Dawe (Shearer 1983) also describes how important fellow patients are in the rehabilitation process. She describes the valuable role other disabled people play in demonstrating and instructing the newly disabled person in areas that are often inadequately covered or ignored by professionals. Particularly valuable in her view are those disabled people who return to rehabilitation units for further treatment and consequently have had an opportunity to discover for themselves what living with disability means outside the walls of the rehabilitation unit. Davis (in Turbitt, 1984), also severely disabled, likewise describes how counselling from others who have similar disabilities is essential for newly disabled people. She believes that disabled people learn more from their peers than any professional. Professionals tend to be pessimistic in their advice and predictions about the future.

Turning to experiences within the rehabilitation unit these reinforced Slatter's view that patients spent long periods with each other particularly in the evenings after the daily programmes had finished. Because the surroundings of the Unit were only other hospital wards and departments patients spent long periods on the Unit itself. Few activities were organised for patients and apart from passively viewing television and listening to the radio, patients were to some extent thrown on each other's resources. Patients in conversation naturally tended to discuss their programme and their future hopes and wishes. No specific examples were witnessed of more experienced staff using patients as role models in any demonstrative sense, although patients commented from time to time about a fellow patient who was to be discharged shortly, and may have used this to make a rough measurement of their own progress towards discharge. Certainly there were patients in the Unit such as Mr. G. who had been very effective in demonstrating their desire to re-establish their old roles and lead as independent a life as possible. Mr. G. was certainly someone who demonstrated a positive role model of the disabled person in rehabilitation. The difficulty here was Mr. G's development in rehabilitation which had caused him to fall foul of the nurses and he was an unpopular patient and somewhat isolated.

What these relationships demonstrate is that the concept of significant others can include fellow patients who can also define and interpret the meanings of disability for the disabled person. There was no specific evidence on the Unit of the significance of interaction between patients, but this was not an area explored in the questionnaire. Nevertheless in view of the comments of disabled people who have completed rehabilitation it is clear that patients do see their peers as providing help and support in different ways and playing a part in the re-socialisation of the newly disabled person.

Leaving the Rehabilitation Unit

One of the major difficulties faced by many disabled people is trying to picture what sort of life they will lead when the period of rehabilitation is complete. From an early point in rehabilitation the patient is trying to make sense of what has happened to his body, and what the implications are for the future. We have also seen how those around him have an important role in helping him give meaning to his life. The difficulties facing the disabled person at the point of discharge are many; what level of mobility can I expect to achieve in the long run? Will I be able to return to my old job? How will my family feel about giving me personal attention and what will it do to our relationship? These and many other questions will be on the mind of the patient as he is told he is nearing the point of discharge. In addition, depending on his disability, he may have other questions, particularly if his impairment is obvious and is likely to intrude in his interaction with others. Then questions may be about how he will deal with the stares of others now he is disfigured. In trying to answer all these and myriad other questions, the patient is dependent to a great extent on those people around him. Some of these questions will have been answered by the rehabilitation staff, although some staff are reluctant to attempt to predict future potential in many areas, while others make strong and positive statements, often with little heed as to how these predictions are received by patients.

What is clear from the writings of disabled people is that because they normally have no prior experience of disability they often have few expectations of their own eventual level of adjustment and independence. These views of course, are not necessarily views that are developed in isolation, but more often the construction of the future based on the expectations of others. Where staff have low expectations of disabled people's potential to achieve mastery and independence in areas of personal care, relationships and employment, disabled people themselves often leave rehabilitation trapped into similar levels of expectation (Scott 1983; Tirbutt 1984).

In spite of patients waiting to leave hospital and resume their previous life, or as near previous as possible, the future often holds enormous fear. A woman who spent a period in hospital following diagnosis of multiple sclerosis quoted in Campling (1981), described how she entered the mainstream of life again but that the difference now that she was 'disabled' and in the world of 'normal' and 'abnormal' she was finally on the 'abnormal' side of the divide. For her then it was a strange and frightening experience to leave hospital 'different' from when she went in. Although she had found many aspects of her stay in hospital unpleasant nevertheless she had a place in it; everybody else was disabled but outside of the hospital she was on her own. Neil Slatter, quoted in Hurley (1983), describing life in a spinal unit discusses how easy it is to become institutionalised. The Unit is purpose designed to accommodate the needs of the disabled. After months in hospital there's the implicit assumption that the world outside the hospital gates is just as accommodating. The realisation that it isn't can be brutal and Hurley (1983) suggests that the patient should find out sooner about all the architectural restrictions as well as other people's 'reactions'. In the spinal unit wheelchairs are the norm; in the world outside they can be associated with insanity!

Caywood (1974) who was hospitalised following spinal injury describes how he feared leaving hospital and returning home. He felt secure in the rehabilitation centre, and was surrounded by people who were in the same situation, or even worse, and that made him feel comfortable. He also valued the help that was available to meet his personal needs. During his time in the Unit he saw patients leave and make a successful transition to the community, while others found this adjustment difficult and retreated from a hostile world and found reason to be re-admitted.

Evidence from a study of patients leaving rehabilitation units and re-entering the community demonstrates that the newly disabled person often faces a situation that he is unprepared for and this unpreparedness results in considerable stress in areas of personal relationships, and social activities. A follow-up study (Berk & Feibal 1978) of 85 disabled persons discharged from a rehabilitation centre six months previously indicated significant increase in depression and anxiety and a similar decrease in community activities and social relationships. Half the disabled people interviewed reported that they had received little help in working out social and emotional problems, whereas a substantial majority felt they had received satisfactory help in ADL areas.

Cogswell (1968) in her study of 36 young paraplegics suggests that rehabilitation is a process of socialisation, but that this process ends when the patient is discharged from a unit. The disabled person often has quite diffuse images of how he will manage re-integration into the community. He is encouraged by the rehabilitation staff to see personal independence as a goal, but has no help in mastering the intermediate steps to attain this goal in the community. The socialisation that begins in hospital ends at point of discharge with no agents of socialisation (staff) available to present the steps required to make a successful transition from hospital to community. Eventually the disabled person becomes his own socialising agent and discovers problems for himself and works out his own solutions.

All the patients interviewed in the Unit and those seen in the regional centre reported concern about the future. This was the one area where there was consistency in response from patients irrespective of their disability or personal circumstances. A number of writers, including disabled people, have written about the difficulties facing patients when they prepare for discharge or look back on the transition from hospital to community. Any person leaving an environment that has supported him and shaped his behaviour (and has also deferred the need to face the reality of life completely detached from its support), is likely to be anxious about what the future holds.

The patients interviewed expressed their concerns about the uncertainty of the future in different ways. For Mr. H. whose disability stemmed from an act of self-injury, managing the stigma of disability was at the root of his concern. Mr. H. had been described as an unpopular patient, which was mainly attributed to the nurses' negative response to his psychological problems. For Mr. H.

his biggest concern was how he would present himself in the future with a severe disfigurement. He reported that therapy sessions had enabled him to achieve movement in the damaged hand, but his preoccupation was how he would manage interactions in the future. For Mr. C. who could no longer ride his motor-cycle after a serious head injury, his vision of the future was one which would be restricted in terms of personal mobility and social relationships, particularly as so much of his life had been bound up with friendships developed in a motor-cycle fraternity. For Mr. G. it was concern about how his employers were defining his future now he was spinally injured. He saw their perceptions of him affecting his opportunity to resume work again following discharge from the rehabilitation unit. The uncertainty of whether he would be able to resume his old job and the attitudes of colleagues caused him considerable anxiety for which the Unit provided no support.

Summary

In summary this Chapter has examined some areas of the disabled person's needs in the rehabilitation process. It has highlighted through the accounts of disabled writers, and the statements of patients in the units, that the period of stay in a rehabilitation unit is highly significant, particularly in terms of how the disabled person sees himself in the Unit and in preparation for re-entering the community.

First, it is recognised that rehabilitation is a socialisation process first and foremost. During his stay in a rehabilitation unit the patient is shaped by his relationships with staff, his family and other patients. Each interaction with these groups helps to define the meaning of his disability and his outlook on the world as a disabled person. The powerful role played by significant others during rehabilitation needs recognising in order that their responses and their behaviour can be seen as playing a positive part in the rehabilitation process, irrespective of the physical therapies and the treatments dispensed.

Secondly, the staff are major agents of the socialisation process. The severely disabled person who spends a long period in rehabilitation is exposed to lengthy and close interaction with a number of professionals. From the writings of disabled people, and interviews with patients in the units researched, these interactions can take at least two forms. Patients can find staff a great personal support and willing teachers who demonstrate to the patient what is possible even with a body that no longer fully functions. Alternatively, patients can experience unsatisfactory relationships with staff that often only confirm, at least while they are patients in a unit with little opportunity to make comparisons, that staff share many of the attitudes towards disability that are held by members of the community with little direct experience of the needs of disabled people.

The patient who is newly disabled is faced with a threatening and uncertain future which raises many questions that others around may not be able to answer. Even staff who have long experience of disability may be reluctant to offer concrete predictions about the person's future development. It is here that the influence of staff's attitudes and behaviour are particularly important, and examples have been given where staff can so easily undermine the disabled person's search for understanding by chance remarks that are damaging. Staff can stress the negative aspects of disability unnecessarily and undermine the successes and coping skills of disabled people. The negative stereotypes of disabled people held by some staff influences how they see the person and have a powerful effect in terms of the socialisation process.

Third, the family often have a difficult place in rehabilitation. They have an important role to play in both supporting the newly disabled person, but also in the manner they communicate positive attitudes of worth to the person which increases his self-confidence and maintains his identity. The importance of the family in determining the outcome of rehabilitation efforts has been commented on by writers and is an area that requires professionals to involve the family to the maximum extent, and support them, particularly as they are considered also to be disabled by their family member's disability.

Fourthly, fellow patients also play a part in this process. We see in the writings of disabled people that fellow patients have two main roles during the rehabilitation process. Firstly they can provide a considerable degree of mutual support and act as sounding boards as patients attempt to work out questions about their situation. Secondly, for those patients exposed to people whose disabilities are longstanding and have already worked out ways of living successfully with an impaired body, then this can offer an important learning experience in helping predict the future based on the achievements of others.

What was worrying for many patients was what would happen to them after discharge from the Unit. Although it would be naive to assume that all uncertainty could be overcome or reduced, nevertheless it would seem worthwhile for professionals to assume greater responsibility for this critical phase in the rehabilitation process, particularly those areas related to the management of interactions where the stigma of disability was significant.

In conclusion, the period while the disabled person is part of the rehabilitation process is probably the most important in shaping his view of himself, his outlook and his relationship with other people. In order to understand this period from the standpoint of the newly disabled person means acknowledging the crucial role of socialisation in the rehabilitation process.

9 A CRITIQUE OF THE REHABILITATION PROCESS

In order to understand the rehabilitation process more fully this Chapter examines a number of issues that emerged from interviews with staff. The comments of staff in response to questions in some cases confirmed the earlier views of patients that the model of rehabilitation practised in the Unit left substantial needs unmet. Before examining these issues in greater depth an overview of the rehabilitation process indicates broad areas of concern.

An Overview of the Rehabilitation Process

We have seen how disabled people entering a rehabilitation unit are usually concerned to become as independent as possible, and make a speedy return to the community. Following admission patients often face considerable uncertainty about their progress and the eventual outcome of their disabling condition. This can lead to feelings of anxiety and isolation with the patient surrounded by the paraphernalia of the ward and its treatment rooms, treated by experts for an indefinite period. It is during this period that the disabled person becomes a patient with few of his usual responsibilities. He is unlikely to make or be asked to make decisions, except those of a minor or inconsequential nature during his hospitalisation. Patients, particularly those whose disability is of recent origin, are often desperately trying to make sense of what has happened to their bodies. They are also trying to manage the consequences of that disability which may radically alter their way of life in the future, and their relationships with relatives, friends and acquaintances.

During the patient's stay in the rehabilitation unit he is subject to a range of mainly physical activities, sometimes extremely painful and exhausting, as remedial therapists work to increase his level of functional activities, in order that he can cope with everday demands, or compensate for the disabling effects of his impairment.

When the therapist, in consultation with colleagues feels a particular level of functioning has been achieved, the patient is discharged to the community, usually his own home, or occasionally another residential facility where further treatment or long-term care will be provided.

Throughout the period of rehabilitation the patient is largely directed by the staff and plays a minimal role, either in discussion about his situation, or in negotiating on help to meet particular needs. The treatments he receives are primarily physical, and the progress he makes will eventually indicate a readiness for discharge that is based on his ability to meet standards set by the remedial therapists. Younger patients who can sustain the heavy physical programme, and who participate keenly in the physical ethos of the treatment programme are often seen as well motivated by staff, and in some cases are able to play a limited role in the direction of their individual programmes. Likewise patients who are cooperative with the demands of the staff are also often seen as making most progress in rehabilitation.

Outside these activities little is available of consequence to the patients. Patients in the Unit reported, and were observed to have, a low level of involvement with staff at a personally meaningful level. Therapeutic relationships were not a specific feature of the work of the staff, even where patients presented emotional or family problems.

Limited help from the social worker in the Unit was available, but some patients did not find this service helpful, or sensitive to their needs. On the whole many staff did not see relationships with patients as important or necessary. On the contrary some remedial therapists and nurses presented themselves as deliberately tough on patients who needed to be pushed towards a satisfactory level of achievement.

Essentially, what was evident in the work of the Unit was an unbalanced approach to rehabilitation that saw the patient in essentially physical terms, whose body was broken or faulty, and required repair. Areas of personal and social needs were given only minimal consideration. This was particularly critical when patients were reaching the point of discharge. The treatments offered were in the ADL areas, but no evidence was seen of work with patients on dealing with personal relationships for those patients likely to have difficulties in areas of stigma management when interacting with non-disabled members of the community.

Lastly, coordination between staff was limited, with no evidence of effective leadership. The delivery of the service was individualistic which reduced the opportunity for teamwork. Rehabilitation practice requires a high level of coordination if the patient is to benefit from the many professionals involved. At this level significant gaps were evident and in some instances rivalries between different professional groups had an effect on the quality of service provided to the patient.

The Primacy of Physical Treatment

From the description of the rehabilitation process it is suggested that the role of physical therapy is predominant. This is because the traditional rehabilitation approach equates successful rehabilitation with the acquisition of specific functional activities, including mobility training and activities of daily living (ADL). These activities are taught by physiotherapists and occupational therapists. Additional personal care skills will be taught by nurses who also have the job of reinforcing the techniques used by their remedial therapy colleagues.

It could be argued that the focus on physical functioning is a direct consequence of the medical model with its central concern with physical diagnosis and treatment. Certainly in the Unit the majority of time patients spent in treatment was in the mobility and ADL areas and that much of the work of the Unit was seen to hinge on the success of these treatments. Even when patients moved into the workshop areas the focus was again on physical function transmitted through activities such as simple industrial assembly work or crafts. When these activities had been undertaken for a period of time that indicated to the therapists that the patient had made progress he was deemed fit for discharge.

The problem within the role of physical treatment is that this approach to rehabilitation fails to take account of the knowledge that exists about disabled people's needs, and in consequence is consistent with only one part of the definition of what is required to achieve a satisfactory level of functioning in rehabilitation. This approach risks treating the patient as an amalgamation of faulty and intact parts rather than a person with a disability that involves psychosocial and physical aspects. Each requires help dependent on the patient's particular disability and his broad functioning across a wide range of personal needs.

In taking this focus the Unit was defining the patient's needs too narrowly and failing to recognise that the ability to walk and deal with personal care activities do not automatically ensure success in coping with the world as a disabled person. It was apparent from the patients' response to questions about their relationships with staff that many had concerns about their current situation and the future that were not dealt with satisfactorily within their programme in the Unit. The onset of a disability often has enormous social implications for the disabled person. He perceives himself as different and this is confirmed by the way others react to him. When he has to cope with the world again he needs to have developed skills in order to manage strained relationships with other people, and the devaluation and rejection he is likely to experience.

These latter areas could be considered to fall within the psychosocial areas of disability and require specific work by the staff of the Unit. Within the Unit though these areas played an insignificant part in the treatment programme. Recognition that patients had problems beyond those of physical functions was mentioned by some staff, although there was no evidence that anything was actually undertaken by these same staff to strengthen this element in the rehabilitation process. The involvement of those professions whose work had a clear psychosocial focus, namely the psychologist and social worker, played limited and adjunctive roles in the work of the Unit. In fact both members of staff were not full-time members of the Unit. The psychologist stated that he saw approximately forty per cent of the patients admitted to the Unit and was often referred patients who other staff deemed not to be making progress in the remedial therapy sessions. The social worker, although having personal views about the psychosocial aspects of rehabilitation, tended to be concerned in her limited time on the Unit with the necessary practical issues of service coordination and welfare rights for patients admitted from a wide catchment area.

From this evidence it is suggested that the practices in the Unit are based on an over-simplified and narrow definition of rehabilitation. These practices are heavily influenced by the medical model and fail to recognise that disability can encompass all aspects of a person's situation, not just the functional aspects of physical recovery.

Patient Motivation in the Rehabilitation Process

Most staff describe motivation as the key to success in the rehabilitation process. It is the critical factor that effective work with the patient hinges on. Motivation is perceived to be a characteristic within the disabled person that he brings along with him to the rehabilitation programme (Trieschmann 1980). Consequently emphasis is often placed in rehabilitation units on those who have motivation, with the recognition that some do not have this vital commodity and are unlikely to be 'successful material' for rehabilitation. It is stated by Keith (1969) that rehabilitation services search for patients most apt to profit from their activities. By the time the patient has arrived at the hospital he has been screened by the 'gatekeepers', which includes his own desire to become a patient. This referral process involves the picture of who is an appropriate patient and whether he is acceptable to the staff. In spite of such selection processes many patients enter rehabilitation units but do not profit from the treatment programmes. In the study described by Keith over half the patients surveyed in one hospital were rated as not readily cooperative in physical therapy activities. In another study which examined patient cooperation in a rehabilitation centre, (Ludwig and Adams 1968) carried out a study over a five year period with 406 patients and found that nearly sixty per cent did not complete recommended treatments, although the authors nevertheless state this did not suggest that the patients' rehabilitation was unsuccessful. What the authors concluded from their study was that patients may define rehabilitation in terms of a return to normal social roles, while rehabilitation personnel define success in rehabilitation on the basis of physical functioning which uses professional standards rather than the patients' social criteria.

From these two studies there often appears to be a discrepancy between what the staff in a rehabilitation unit judge to be a well motivated patient, and what the patients themselves may see as success. From observation in the Unit and discussion with staff, patients who were said to be well motivated and making progress, appeared to be those patients who were keen to cooperate with the targets staff had set for them. Nevertheless staff reported a wide range of people who were less well motivated including older, demanding and uncooperative patients. In addition those with behavioural problems risked outright rejection as really being the province of psychiatrists, who should not have been admitted to the Unit in the first place. In the Unit, as in the two studies mentioned above, some patients were motivated and participating in treatments, but others were not and their presence on the Unit was questioned.

According to Roth and Eddy (1967), to talk of rehabilitation success may actually be an artifact. They see staff concentrating their efforts on those patients they value highly or think have the best chance of improvement. In the end, though, this may not accurately predict independent living after discharge. Albrecht and Higgins (1977) in their study of the criteria of rehabilitation success discovered that some patients who displayed the greatest independence (a goal of rehabilitation), were judged to have been uncooperative by staff and to have failed to complete the staff's conception of the rehabilitation programme. These findings would also accord with the statements of disabled people (quoted in Shearer 1983; Tirbutt 1984) who have been most critical of rehabilitation practice but have gone on to achieve a significant degree of personal independence. It was of course not possible to predict whether this would apply to patients interviewed in the Unit as no follow-up studies were made.

In trying to understand the concept of motivation more clearly it is necessary to recognise that it is a summary term which is loosely used to describe the patient's willingness to incorporate instructions into his lifestyle. It is seen as a characteristic of the person and consequently the person is solely responsible for either being or not being motivated. Trieschmann (1980) and Goldiamond (1976) using a psychological framework suggest that the definition of motivation as an internal drive of the person takes too limited a view of the situation. Both authors examine the environment as a critical element in the person's motivation. Using this approach the unmotivated patient is someone who finds no rewards for which to work in the rehabilitation programme. The value of this perspective is in enabling a shift to be made to include factors external to the person and his interaction within the rehabilitation environment rather than focussing exclusively on his internal drives.

Within the Unit staff saw motivation and progress in the rehabilitation programme as resting formally on the shoulders of the patient; where a wider perspective was acknowledged this usually referred to the patient's family situation and the positive features that supported the patient. In examining motivation it is difficult to see how the patient can achieve success in the staff's terms when he is the subject of two opposing pressures. Firstly he is a patient and consequently has had the sick role allocated to him. This means he is sufficiently passive to accept the dependent status the staff require. On the other hand he has to be sufficiently active to function independently in order to successfully achieve a level of independence post rehabilitation that accords with adult social roles. To be successful in rehabilitation may require the patient to resist the sick role and take on roles as a preliminary to independence that bring him into conflict with rehabilitation personnel who may see him as uncooperative and hence not motivated in terms of the physical training programme in a traditional rehabilitation unit.

Communications Between Staff and Patients

From the evidence of interviews some patients reported that they found their communication with staff unsatisfactory. These difficulties in communications fall into a number of discrete areas including - being addressed in a non-adult manner, lack of information on questions raised about their condition and the attitudes of some members of staff towards disabled patients. The patient in a rehabilitation unit is someone who has a hightened awareness to the reactions of others to his situation. It is here that communication can play such a positive part in aiding the patient's progress. Faulty communication on the other hand can retard or undermine progress, often unknowingly.

Some patients in the Unit reported that staff gave them instructions that made them feel like children. The patients resented this assumption and felt that communication of this nature was demeaning. We have already seen that being admitted to a rehabilitation unit means the disabled person adopts a sick role, even though he is not sick in the usual meaning of the term. Nevertheless a patient is someone whose role within a hospital setting is submissive and has devaluing aspects. As Kerr (1969), herself disabled, states being disabled can be the same as being a child, in the eyes of the staff, which often results in responses that range from mild reprimands for being uncooperative to referral on to other specialists if the uncooperative behaviour indicates a more intractable problem. Anderson (1975) drawing on the theories of transactional analysis sees the professional all too often speaking down as a "parent" to the patient as "child". Because this communication is almost unconsciously used by the professional it is difficult for the patient to respond as an adult and he finds himself trapped in a child-like response to the professional. Anderson sees the professional operating within a medical frame of reference having this expectation of patients that inhibits the reciprocity needed in a relationship of greater equality. Kerr (1969), sees staff having clear options in either strengthening the child-like dependency they create and hence the risk of continuing to treat the patient like a child, or alternatively creating a climate that encourages maturity and freedom of choice. By encouraging the patient to take responsibility Kerr feels this can help overcome the problem of the patients playing the sick role and the additional risks of child-like dependency.

A second area of communication that caused much concern was the difficulty patients had in getting answers to their questions, or at least being kept informed about the progress of their condition. We witnessed a number of examples of patients who felt they had considerable difficulty in getting specific information from staff, but also staff who were clearly reluctant to provide information for patients. Hodgins (1965) who described his experience in rehabilitation following a stroke, indicated that in the end patients stop asking questions about things that trouble them because they lose hope or confidence in staff. In the Unit several patients had reached this point and no longer attempted to obtain the answers they required. But as Hodgins makes clear reaching this stage does not mean the patients stop raising the issues within or with other non-staff members as witnessed in the Unit.

In a study which examined the levels of information patients receive from nurses, Summers (1984) first points out that when patients are admitted to hospital they are likely to feel insecure and have little mastery of their situation. Anxiety is produced as a result of these factors, but can be reduced by effective communication between staff and patients. Summers describes how nurses will avoid talking to a patient about their fears or anxieties because they do not wish to find themselves in a position where they have to answer awkward or difficult questions. This can result in nurses actively discouraging patients from asking questions or seeking information. One method nurses use to avoid this difficulty is to use the authority of the doctor as a basis for managing communication. In this way the nurse can resolve her dilemma by delegating the responsibility to the doctor to answer the patients' questions. The difficulty here is that this concern of the nurses may not be effectively communicated to the doctor, and the patient may never receive the information he is seeking. Examples of this technique were seen in the Unit with both nurses and remedial therapists seeing the doctor as the person to discuss difficult issues or answer awkward questions.

The patient who asks questions, particularly if these make particular demands on staff as we have seen above, can become the 'unpopular patient', who is seen as less rewarding to treat and can affect the level of care received. Stockwell (1972) in her study of patients whom nurses classified as 'difficult' suggests that those patients who were demanding, including wanting information about their condition, were likely to be seen by nurses as unpopular patients. Patients interviewed in her study also implied that their own worries and needs were too trivial for the nurses to be concerned about. Although the patients were resigned to this situation, they nevertheless regretted that more time was not made available for their concerns to be discussed. Although these studies all focus specifically on nursing procedures there are some parallels with the communication between staff and patients in the Unit. There we saw that patients had difficulties getting information from many staff, not just nurses, and similarly some patients raised doubts about the importance of their concerns by not wanting to take up staff time.

Summers (1984) discussing solutions to these problems feels that nurses should be made more aware of the type of information patients need to reduce anxiety, and in order to achieve a more satisfactory level of information-giving should be taught the value of therapeutic communication in their training. It could be argued that the situation in a rehabilitation unit demands even greater understanding of the role of communication between staff and patients. Patients here have the same sorts of anxieties Summers describes, but they have additional concerns. The onset of disability is a major event in a person's life at very least it can be an extremely unpleasant experience. For those people who it disables severely, either functionally or visibly, it can be life-threatening. Consequently, it is likely that the degree of anxiety that Summers describes is much greater. This could indicate that patients in rehabilitation units need considerable support through the medium of therapeutic communications, and that much of the anxiety and unhappiness witnessed in the Unit could be reduced by more candour on the part of staff.

Lastly, the role of communication in rehabilitation can be seen in the wider context of patients' perceptions of staff attitudes that are transmitted through both verbal and non-verbal responses. At a time when the patient often has a heightened awareness of the reactions of others the negative response of a member of staff can cause considerable hurt. Kerr (1969) describes staff attitudes in rehabilitation based on her experience where patients are made to feel inferior in the way their questions are answered, or otherwise treated in an evasive or condescending manner. Part of the difficulties patients face is that prejudicial attitudes towards disabled people are seen to be held not only by the general population, but also by some rehabilitation staff (Safilios-Rothschild

1968). In the Unit some statements by staff, particularly nurses, recorded during the observation phase of the research, exhibited negative attitudes towards some patients because of the patients' reluctance to comply with the programme demands, or because patients were seen to have been causative in their disability, for example as a result of heavy drinking. Similarly, patients who were felt to have behavioural or psychiatric problems were sometimes described in negative ways, and considered unsuitable for rehabilitation. From the comments of patients it was apparent that they were well aware of the negative views staff held about them. What those interactions suggest is that working in a rehabilitation unit does not necessarily result in staff having more positive attitudes towards disabled people. In fact Trieschmann (1980) indicates that staff often underestimate the strengths and coping abilities of patients in rehabilitation and have poor opinions about their ability to cope independently in the future. Likewise disabled people themselves have reported on the attitudes of staff which discount the needs of patients (Tirbutt 1984; Scott 1983; Shearer 1985).

Kerr (1969), examining staff-patient expectations, raises a number of questions about the nature of staff-patient interaction and asks under what conditions such interaction can become more positive and growth inducing, rather than reducing the patients' self-esteem. For Kerr the major task for rehabilitation staff is to provide opportunities for the patient that appropriate expectation and behaviour can foster. Finally this is an area where it is difficult to collect objective evidence as much of the behaviour of staff and the responses of patients is clearly part of the rehabilitation situation and the structure of the roles people play. The responses to the interviews in the Unit indicated areas of concern that were only briefly described in this study.

Psychosocial Problems and the Need for Counselling

The onset of disability, or a deterioration in a chronic condition, threatens the well-being of a person.

The resulting psychological pressures can lead to emotional difficulties with patients exhibiting signs of extreme anxiety, self-doubt and depression. These are quite realistic reactions to sudden or dramatic changes in the person's body with all the uncertainty that these changes mean. What this view recognises is that disability has not only a physical dimension, but also significant psychosocial aspects that need to be considered of equal importance. Consequently the process of rehabilitating patients is a psychosocial as well as being a physical process.

Whitehouse (1962) in his description of the rehabilitation of cardiovascular patients emphasis this duality of approach. He describes how patients are rightly concerned with survival following a heart attack with fear of death a central concern. Once this is no longer an immediate danger and physical survival is ensured the patient's concern is likely to turn to questions about his existence in the future and whether normal living will be regained. More fundamental, and often unexpressed to the professionals involved, are questions about the threat to self and one's self-image. The patient is likely to be asking: am I the same person? Did this really happen to me? Am I less worthy and a different kind of person now? Will I lose the regard of my wife, my family and friends?

Similar questions were the concern of patients in the Unit and emerged from interviews, and were also described as important issues by some staff. What a number of patients were expressing seemed to confirm Whitehouse's thesis that although a return to a specific level of physical abilities was important, patients were also concerned about personal and social aspects of living with a disability.

One area that was prominent in the responses of patients was that of personal relationships and sexuality. This was an area where there was a considerable gap between the patient's needs and the staff's responses. It is firmly established that the onset of severe disability can result in a loss of sexual identity (Robinault 1978). Both disabled men and women can experience changes in their self-esteem as a result of the onset of disability and these changes can lead to feelings of sexual inadequacy.

Leahy (1982) examining the needs of disabled adults recognises the importance of a consideration of the patient's needs, but finds that planned sexual rehabilitation programmes are rare. She goes on to quote a disabled person who describes the view of relationships and sexuality on the part of professionals in the following way - "we saved your life for you, you want more". Although Leahy was addressing her comments to social workers, her criticisms could nevertheless be extended to other professionals in the rehabilitation services, who she sees as relating to the patient's survival needs, but then not shifting their focus as the patient's needs change.

Some patients in the Unit were concerned about their relationship with a spouse and the strain placed on a partner as a result of the level of care needed by the disabled person. It is confirmed that marriages are put under strain where one partner is disabled and that discord could easily develop between couples (Blaxter 1976). Many individual difficulties are experienced by families, but the stress on roles within a marriage is a particularly important area requiring exploration and support. Hohmann (1972) has described how woman who care for their husbands physically can have difficulties viewing their husbands as sexual partners. Likewise husbands of disabled women may feel the same. The risks here are that these tensions within roles can put considerable strain on the partners and lead to marital breakdown.

This difficulty was certainly present in the lives of some patients in the Unit who had chronic disabling conditions and needed considerable support from family members; it indicates the need for staff to take account of these potential strains on the marriage in their work with the patient and spouse.

In spite of the needs expressed by patients it was clear that staff were, on the whole, not prepared to become involved in discussion of such matters and in some cases denied that patients had needs that required assistance. How much was this the staff's unwillingness and inability to work with these patients? Kempton and Caparulo (1983) discussing sexual counselling techniques have described the 'Pandoras Box' complex where sexual matters are never mentioned, as discussion may unleash uncontrollable emotions that are best kept closed. Irrespective of whether staff hold such personal views this was a legitimate sphere of concern for many patients and an area where professionals should be receptive to the needs of patients and incorporate discussion of these matters into the rehabilitation programme.

From the evidence of interviews with patients and staff, the Unit failed to meet the psychsocial needs of the patients, particularly in the areas of personal relationships and sexuality. There are many possible reasons why this occurred. Brodsky and Platt (1978) in their study of a rehabilitation unit where similar gaps in the treatment programme existed suggested that staff often fail to see psychosocial problems when the patient's physical problems are so great and the treatment model emphasises this approach. Staff consequently believe that the patient has sufficient physical reasons for being psychologically disturbed that they neglect to examine possible psychosocial problems. They also feel that another major reason for this restricted view of the patient's needs is the manner in which rehabilitation units perceive the patient's treatment, which is segmented and ignores what the patient has to face in his personal life after discharge. Those responsible for treatment programmes tend to see rehabilitation as a short term process and limit their concerns to the patient's physical progress while in the Unit and ignore his fate once he is discharged.

Similarly, Trieschmann (1980) also sees physical activities taking top priority in most units and as a consequence psychosocial activities are seen as superfluous.

As a result of this bias patients do not get an opportunity to undertake the range of psychosocial therapies that Trieschmann believes are as important as the physical activities of the disabled person if he is to leave the Unit prepared to cope with the difficult aspects of his life following disability.

The discussion of psychosocial problems was an important dimension that was missing in the treatment programme in the Unit. This could have been facilitated through the use of a counselling service where patients could explore their problems, clarify the main issues and search for alternative ways of dealing with their problems. This would have avoided the medically oriented approach of staff handing down solutions to the patient, rather than using a counselling relationship which enabled the patient to search out answers that were satisfying to him, with the support of a counsellor.

The lack of counselling in rehabilitation units has been commented on by a number of observers. Roberts (1977) in his critique of the Tunbridge Report (1972) describes how the report in its numerous recommendations makes no mention of counselling, which he sees as a serious omission, and ignores the difficulties patients experience that cannot be met by traditional medical or physical treatments. More recently Shearer (1984) in an article on the new spinal injury unit at Stoke Mandeville Hospital, describes a similar lack of facilities with the risk that patients will leave the unit unprepared to deal with many issues in their lives. Clearly counselling help was needed by many patients to deal with problems they faced that were not assisted by the predominantly medical/physical orientation of treatment programmes. Far from being something that should be "tacked on" to the existing programmes, counselling should be a central part of the rehabilitation process in providing a basis for the development of self-help among patients.

Staff Coordination and Teamwork in the Rehabilitation Unit

In this final area of discussion the issues raised are concerned with coordination, staff attitudes and leadership. In the interviews with staff it was evident that considerable difficulties existed in these areas and significantly influenced the overall effectiveness of the Unit.

The Unit had a large number of professional staff and many different professions involved in the rehabilitation of each patient. In addition other professionals could be called in on a consulting basis should their expertise be required. The complexity of staffing was necessary because the rehabilitation of disabled people is a multidisciplinary activity with each professional group having specific and delineated responsibilities. This results in the customary team approach with the efficiency of the rehabilitation programme said to be correlated with the quality of communication among team members (Trieschmann 1980).

First, coordination presented considerable problems in the Unit and was felt by a wide cross-section of staff to be inadequate to meet the needs of a multidisciplinary programme of rehabilitation. The main vehicle of coordination was the weekly staff meeting where all disciplines met and discussion took place on the direction of treatment with patients, but was also used to raise more general issues related to the Unit and as a channel of communication on current and future activities. The meeting, although effective in bringing people together, was criticised on a number of grounds. The nurses, almost universally, saw the meeting as a forum where their views could not be heard and consequently they had little faith in its effectiveness and openly described ignoring some of the decisions taken. Secondly, they felt dominated by stronger members - referring here to the remedial therapists - and felt their contribution was not respected professionally. Some remedial therapists were equally critical of the meeting as a vehicle for communication and coordination because of the poor way it was organised; no minutes were taken and no means were available to check on what had been agreed, with consequent action open to individual interpretation.

The second difficulty concerned conflicts between staff. These primarily occurred between nurses and remedial therapists. The conflict between these two groups of staff appeared deep-seated, and at times acrimonious, to the researcher. Although it is difficult to discover the basis for the rivalries and conflicts that exist between different staff in a limited period of fieldwork, issues did emerge that indicated where some of the difficulties might lie. We have seen from the interviews with staff that nurses saw the junior grade remedial therapists as inexperienced and immature and consequently easy-going on patients, who in the eyes of nurses often needed "firm management". The therapists for their part described nurses as staff who did not have specific training in rehabilitation and as a result undermined, or at least did not actively support, the work of the remedial therapy departments. Some of these feelings had been internalised by nurses who described themselves as "the lowest of the low".

Other staff also ventured opinions about these conflicts, without prompting, which indicated that this organisational problem was a focus for ideological differences in rehabilitation. One doctor attributed the problem to the socioeconomic differences of nurse and remedial therapists, while a nurse felt that working with patients in a rehabilitation unit did not fit the views of what nursing constituted for many of her colleagues, and this had its effects on cooperation with other disciplines. But these tensions were not the only ones in the Unit. A number of staff from different professions commented on the struggle for power that centred around the remedial therapists' push for professional autonomy unhindered by medical direction. This was obviously difficult when consultants had clinical responsibility for patients and, in some of the confusion over role boundaries that existed in the Unit, were seen by some therapists to interfere in their specialist areas unnecessarily.

It was this latter issue that illustrated the second problem, that of leadership in the Unit. Clinical responsibility as we have seen rested with the consultants to the Unit. But they were infrequent visitors and not seen by many staff as having any significant involvement with the work of the Unit, at least on a day-to-day basis. Medical leadership was for practical purposes exercised by the registrars who were in daily contact with the staff, particularly nurses, as their main tasks appeared to be monitoring and responding to the health needs of the patients. In a Unit where physical therapies constituted the main focus of work, the remedial therapists are inevitably dominant members. The Head of Rehabilitation, a chief physiotherapist, was seen as the leader, particularly by her own professional colleagues, although other staff, including nurses, did not necessarily respect her position or accord with her judgments. As a result of a combination of lack of role definition and defensiveness by groups of staff little attention was paid to how different disciplines could have used leadership roles that were flexible, but still enabled good relations to be fostered between the professions.

The issues raised by these questions point to a vacuum at leadership level that could have provided the initiative for using the weekly staff meeting to begin to discuss some of the conflicts that were clearly evident to the visitor to the Unit. With so many professionals needing to be coordinated it was obvious that the independence of the professions, as evidenced by the remedial therapists' wish to control their own work, meant that decisions were unlikely to be implemented if they were imposed from the "top down". The participation of all concerned in working out a consensus on values and aims for the Unit as a whole was needed. This is borne out by Raynes et al. (1979), whose research on the organisation and structure of care within similar settings suggests that staff involvement in decision-making is the single most important organisational variable contributing to high quality patient care. This she sees best achieved through regular meetings where all staff have the opportunity both to support each other and deal with the inevitable conflicts, but also to discuss important matters of policy and practice. Raynes et al. pointed out that senior managers need to be part of this process and be fully involved members of such meetings. Presumably if such meetings were to be successful they would require sensitive and skilful leadership, but as we saw its absence was one of the problems in the Unit at an organisation level and needed resolving in order that a start could be made to unify the staff groups and develop a more coordinated approach.

At the patient level coordination was equally important and as a consequence of the wider problems of coordination across the Unit tended to be inadequate. Again techniques existed to assist this problem but were not in evidence in the Unit. Martin (1984) describing methods of improving techniques, specifically focussing on nurses in long-stay hospitals discusses the value of 'individual care planning', which although new to nurses has long been a practice in more established professions. Basically this technique which could have a valuable application in rehabilitation units for all staff involves a 'key worker' who is responsible for developing a care plan based on the patient's needs (and importantly his involvement) and leading to an assessment with goals set and methods of evaluating progress. Blunden (1980) has described a similar technique for use in community services for mentally handicapped people which builds in accountability and a progress-chasing role for the key worker who has the responsibility for managing the periodic reviews used in this technique and acts as a progress chaser with other staff involved. This approach could have been particularly useful in meeting the criticisms of the weekly clinical meeting where no specific measures were available or used to chart the progress patients were making, and vague statements and personal opinions used as the basis for major decisions about the patient's treatment.

A rehabilitation unit is a complex structure and described by Brechin and Liddiard (1981), as one where staff struggle to offer, and patients struggle to receive, a coordinated rational service for rehabilitation. It is evident from the foregoing discussion that significant organisational problems existed at a number of levels that affected the collaboration of disciplines. This also had an impact on patients, as was witnessed by the researcher, and confirms Brodsky and Platts' (1978) assertion that conflicts between staff are acted out in relationships with patients to the detriment of their rehabilitation. Overcoming some of the problems could have been possible if the techniques that have been described in other units were introduced. But this alone might have been insufficient to correct some of the long-standing problems that resulted from the professional, and to some extent, physical isolation of the Unit that have been described by Martin (1984) as a particular feature of hospitals that care for long-stay patients. Although it would be open to question how far it is possible to draw parallels with Martin's examples in the case of the Unit, nevertheless some similarities existed, particularly in the outdated ways patients were seen and the lack of in-service training that offered opportunities for staff to both examine their own and colleagues' roles, but also look critically at their attitudes towards disability. As one nurse remarked - 'it's easy to bring traditional attitudes to work, but it doesn't always help the patients'.

Summary

This critique of the rehabilitation process has suggested that the medical model of rehabilitation influences most aspects of the programme designed for patients, and works against the development of a full understanding of the needs of disabled people. The disabled person on entering the Unit becomes a patient who is allocated a passive role, in keeping with the traditional relationship of the professionals' expertise and authority and the patients' acceptance of this authority. As a result of this approach the Unit is organised around physical treatment and ignores many important psychosocial areas. This imbalance in the treatment programme leads to a poorly developed understanding of the needs of the disabled person that goes far beyond functional attainment.

The Unit also tends to have a narrow definition of those disabled people it can help, who need to be motivated and cooperate with the professional to succeed in their rehabilitation. This approach has been questioned both from the standpoint of motivation, which is not necessarily a personal trait so much as a response to a range of factors in the rehabilitation environment. Secondly, cooperation with its picture of the patient's passive agreement with professional judgment is not necessarily correlated with rehabilitation success, and can in fact be detrimental to the disabled person developing an optimally independent lifestyle.

Communication between staff and patient was at times insensitive and insufficient and resulted in difficulties, firstly for patients who were at times on the receiving end of inappropriate commands and secondly in receiving inadequate or evasive answers to their genuine questions of concern. Similarly, staff of different disciplines also experienced difficulties in working effectively as a team and this resulted in communication problems that reduced cooperation. Underlying many of the staff problems was an unresolved issue about leadership and roles in the Unit.

In order to consider some alternatives to the current model of rehabilitation it is useful to examine next the work of writers who have begun to suggest a picture of what might be needed to supercede the current model of rehabilitation.

10 ALTERNATIVES TO THE CURRENT MODEL OF REHABILITATION

The model of rehabilitation adopted by the Unit studied was strongly influenced by the medical approach with its focus on physical therapy and patient passivity. This approach has been shown in the previous chapter to undermine the opportunity for the development of the participation and self-direction needed by the disabled person if he is to function successfully as an adult in the community. As a result of this primarily physical orientation that reinforces dependency, vital areas of the patients' needs are ignored and staff have little opportunity or inclination to develop techniques and skills, particularly in psychosocial areas that would complement and influence the physical therapies currently offered.

With this emphasis in the rehabilitation programme the skills the disabled person leaves the rehabilitation unit with are not necessarily either sufficient or most relevant to the life he will lead in the future. The model of rehabilitation witnessed in the Unit ignores the social implications of disability, and the expectations of disabled people about how they see their future. Living with disability is not just a physical problem, consequently a physical solution is not sufficient in itself. In order to reduce this imbalance in the current approach the rehabilitation process needs to be modified in order to prepare disabled people to reduce or overcome the barriers that limit or prevent their effective functioning and enable them to live rewarding lives in spite of disability, in environments of their choice.

With these latter concerns in mind this Chapter examines some of the elements of the rehabilitation setting and processes that could usefully influence or modify the current practice. This Chapter takes as a starting point the critique of the rehabilitation process described in the previous chapter. It draws on the work of writers who have suggested alternatives or modifications to current practice, that could begin to answer some of the doubts raised by the fieldwork about specific elements of practice described.

The Transition from a Medical to a Rehabilitation Setting

Arguments for change in the rehabilitation process need to start from the recognition that a strong medical contribution is necessary in the individual diagnosis and prognosis of a disabling condition, and the delivery of definitive care at the point of injury or illness. This is the period when the newly disabled person receives assistance from doctors and nurses who are concerned to achieve medical stability. Likewise with a person with chronic sickness the medical contribution may be important to bring about control of symptoms that are causing the person concern. What this examination of the beginning of the rehabilitation process recognises is that the disabled person initially plays a role where maximum dependency and passivity are major features.

When medical stability has been achieved and the end of the acute (life threatening) stage is reached, or a chronic condition is stabilised, the disabled person is no longer in need of close medical supervision and he then makes the transition from a medical to rehabilitation setting. In terms of roles he moves from being someone whose normal responsibilities are suspended to someone who must learn to manage his life with a disability. This is the point of transition between the medical dimension and the social dimension of rehabilitation, the latter being the central concern of rehabilitation units. Where medical rehabilitation ends and social rehabilitation begins is not always so clear cut and we have seen that the two can run side by side in a rehabilitation unit with the problems created when medical rehabilitation continues to inappropriately influence practices that have little relevance to medicine.

It was the lack of a critical understanding of the importance of this transition that was apparent in the Tunbridge Report (1972) and resulted in adverse comments on the report's recommendations. Agerholm (1972) describes rehabilitation as the process of turning a patient back into a person with the central concern of restoring the person to the community and cutting his treatment dependence as quickly as possible. Her criticism of the Tunbridge Report is that the model of rehabilitation suggested in the report actually implies the opposite principle, so that a person already living in the community might be more likely to be admitted to hospital. This would mean the person becomes more dependent, a process absolutely contrary to the basic principles of rehabilitation.

So clearly one of the first concerns in examining change in rehabilitation units is to structure the environment and processes of a unit to avoid imposing or maintaining the role of dependent patient for the disabled person. Secondly, there is also the need to rethink the existing approach where a treatment package is offered that maintains the focus on patient passivity. What is needed is a rehabilitation process that moves between medical intervention at the first stage to a second stage that is concerned with teaching the disabled person to live with his disability in his own environment.

What is being suggested here is not new. Nichols (1975), a distinguished consultant in rehabilitation, said as much when he described how the persistence of the clinical approach was frequently of little value in rehabilitation, even where the focus was on the physical capabilities of the patient. Nichols suggested that rehabilitation practice needed to develop behavioural, social and economic aims rather than the current clinical emphasis and to best achieve this would require rehabilitation to be separated from clinical medicine which he saw as having little to offer these latter areas of activity.

From this recognition of the dangers of the persistence of the medical approach in what are primarily non-medical areas in the rehabilitation process the remainder of this Chapter examines aspects of the environment and processes within rehabilitation services.

The Rehabilitation Environment

Keith (1969) has described the need to develop living units separate from hospitals where disabled people can live independently while participating in treatment programmes. These would be places that avoid the institutional features described originally by Goffman, but also the barren hospital-like settings that are found in rehabilitation units. What Keith suggests is that the rehabilitation environment should be one where patients can make full use of a range of facilities that they need in order to achieve personal goals for future living that draws its influences from an educational rather than treatment model.

Kutner (1969) likewise sees a need to radically restructure the environment and processes in rehabilitation in order to overcome the deprivational qualities of current settings. Kutner describes these environments as anti-therapeutic in that they actually fail to achieve a realistic simulation of what the patient will face on discharge. Kutner wants units to be a social testing ground for patient performance which can be achieved by patients being given much more self-responsibility for day-to-day living, and secondly, patient-staff conferences where decisions are reached by consensus and the staff veto is used with restraint. Although this would undermine the notion of patients moving smoothly through rehabilitation to some end point when they are considered rehabilitated, it would nevertheless be an advance over traditional approaches in that patients would face problems and issues more openly and squarely, and in doing so test out their capacity to cope in real situations prior to discharge.

Staff Attitudes in Rehabilitation

Although environment factors and instituional process are important components in rethinking the rehabilitation process staff also need to look at their own values, attitudes and behaviour. Safilios-Rothschild (1968) has suggested that the attitudes of rehabilitation staff can reflect the negative stereotypes held by members of the public who have little or no experience of physical disability. Although staff are generally concerned people who assist patients in a professional manner, they nevertheless have ways of behaving towards disabled people that can be impersonal and unintentionally demeaning. Furthermore the deference required towards senior staff and the social distance that exists between patients and staff is said to send clear messages to the patient that he is less worthy of respect since he became a patient in the Unit. Trieschmann (1980) sees the self-image of the disabled person as shaken by his experience; staff can fail to recognise that he feels unsure of himself and anxieties about his worth may be exacerbated by insensitive members of staff. Trieschmann describes staff attitudes and outlooks as particularly critical in supporting disabled people who are living in an uncertain world. Staff can so easily stress the negative aspects of a disabled person's situation and underestimate the person's ability to draw on coping skills in facing difficult situations. Collectively these responses can result in staff having low expectations about the disabled person's own wants and hopes, that risk leaving the person feeling less able to face the future.

Many ways can be found that can begin to influence staff behaviour, but some of the important areas in rehabilitation concern staff's own hidden assumptions about disability, sensitivity to disabled persons' needs that go beyond traditional areas of physical coping, and the recognition that the active participation of disabled people is needed in the rehabilitation process. Obviously in-service training can help in all these areas, but a number of workers have gone further and prescribed approaches that would confront staff with a greater understanding of the disabled person's perspective than often achieved on courses that are organised and taught by non-disabled people.

Trieschmann (1980) calls for the use of role play in disabled roles to begin to give staff an experience of what coping with disability means. Stewart (1981) calls for staff to analyse their own feelings about disability that can have a subtle influence on how they respond to patients, particularly if they have doubts about their own feelings about coping with disability, and this is then transmitted by obvious staff discomfort or unwillingness to let patients express their feelings. Wright (1980) in an article on deploying constructive views on living with disability sees the need to change attitudes through simulation training and direct contact with disabled people in order to increase awareness of constructive aspects of their lives. Summing up her approach Wright states that positive attitudes cannot thrive where the predominant focus is exclusively on the disabling aspects of disability. Second, that disabled people should not be seen as passive; they do and must actively take charge of their lives and they are highly differentiated as individuals. Lastly, disabled people have assets and abilities that are there to be tapped to bring about needed change.

Finally, almost all articles on shifting attitudes towards disabled people describe the need for disabled people to have a much greater say in things that affect them in the rehabilitation process. It is important to state nevertheless that when a person enters a rehabilitation unit for the first time there may be many unknown factors facing him, and he is unlikely to know what he needs to consider. This is where initial advice and guidance is given, with decisions about the content and direction of the programme taken by professionals, but still placing emphasis on involving the patient to the maximum extent even at this early stage. Once the person feels he is ready, or is deemed ready by staff, he should be expected to assume more responsibility for his own care. He should help plan his own programme and make decisions about his body and his future. The total approach in a unit should be geared to the patients taking control of their own lives, and the processes within a unit should facilitate, support and guide this effort. Obviously this would call for much greater flexibility in the approach that staff use and would lead to staff having to make compromises, and also go along with some decisions they may find unacceptable. Nevertheless the current rigidity of treatment models permits very little decision-making or self-planning on the part of the patient.

Joint Patient-Staff Planning

The need to change staff attitudes is critical to new developments in rehabilitation. The willingness of staff to share some of the power and control they currently exercise is an important factor. Safilios-Rothschild (1976) has stated that some of the newer and less powerful rehabilitation professionals are already agreeable to new treatment paradigms that would enable a greater involvement of disabled people in programme planning, and the shared control of some aspects of the rehabilitation process.

One particular approach that has been developed in a rehabilitation unit in the United States has been described by Becker and her colleagues (1974) and overcomes the central problem of the patient being the 'silent member of the rehabilitation team'. Their approach starts from the premise that treatment goals are often ineffective and time wasted if the patient does not fully participate in the planning process. Their response was to develop a joint patient-staff goal setting plan with a contract established on agreed goals with subsequent monitoring of the plan to check goal achievement. What this approach recognises is that when the patient (and his family where relevant) has a central role in determining the direction of treatment goals, the patient is much more likely to see these as relevant functions that can be carried over into the home environment. Similarly this involvement is also much more likely to generate commitment to treatment programmes and avoid patients undermining therapies as is so often noted in traditional programmes. Again as in the last section on attitudes, staff members have to consider the patient's point of view and allow the patient's goals to take prominence over their own ideas for his treatment. What this approach points out is that when there is drastic variance between patients and staff goals it is almost impossible for staff to attain these goals through therapy.

Becker makes the following observation on this goal setting approach. First, this approach helps identify conflicts in patient-staff goals. Second, it individualises the treatment programme. Third, it enhances patient-staff interaction through negotiation and the setting of treatment priorities. Fourth, it includes the patient as a responsible team member. Fifth, it teaches staff how to achieve longer lasting goals through the achievement of short term or compromise goals, and lastly, it reduces the risk of programmes being undermined by patients or staff.

This approach described by Becker has many similarities with the individual care planning described in the previous chapter. It is also similar to the first stage of individual programme planning described by Blunden (1980) which is a technique for setting goals up to one year ahead with periodic reviews and a progress chasing role by a 'key worker'. The combination of joint goal setting and longer term planning techniques with an identified member of staff acting as coordinator for the patient could offer an alternative to the highly individualised approach currently undertaken. It is this latter approach that fails to recognise the need for close interdisciplinary working with the patient playing a significant role in decision-making.

Psychosocial Techniques

One area that is mentioned repeatedly in discussions about rehabilitation services by both disabled people and professionals is the need for help with psychosocial problems, and the apparent lack of help often witnessed in rehabilitation units.

With the imbalance in rehabilitation programmes where physical therapies predominate, other approaches are either ignored or squeezed to the point that they can make little significant contribution to the patients' needs. To consider therapeutic techniques that address themselves to psychosocial problems recognises that the disabled person has needs that are not met purely by physical therapies. The fieldwork highlighted this problem when patients had obvious needs that did not fit in with the help offered in programmes designed for them, while some staff recognised that their work with patients ignored some areas seen as vital by patients. The problems patients were experiencing or likely to face on discharge were very wide-ranging and required a similarly wide range of responses specifically geared to meet the difficulties experienced or anticipated.

What is important to acknowledge in the context of therapeutic techniques is that focussing on the body to the exclusion of the mind can reinforce an attitude to disability which risks ignoring the disabled person's needs. Kennedy (1980) in his critique of modern medicine has described the concentration on the body as a mechanical object that needs repair as a process that is simplistic in the extreme. He sees patients needing much more than a simple repair service, in fact requiring assistance that is both complicated and subtle in its approach. It is in these areas that are outside the physical and functional aspects of disability that therapeutic techniques can be employed such as counselling, group discussion and social skills training. Counselling is often seen as a panacea for all forms of psychosocial problems in rehabilitation but it is just one technique for helping people that could usefully be incorporated into the rehabilitation process alongside other equally valuable approaches.

Gruen (1975) describes individual counselling techniques in cardiovascular rehabilitation. Here the techniques were found to be valuable in providing an opportunity for patients to discuss questions that were causing them anxiety, but also an opportunity for the counsellor to provide feedback to the patient on areas of doubt and uncertainty. In addition the counsellor was able to positively reinforce the patients' attempts to begin planning their lives again after a heart attack. Where these techniques were found particularly useful was in enabling the patient to cope with uncertainty in a supported relationship and to begin to direct their energies away from excessive self-analysis to external demands and future actions. Gruen sees these techniques as offering the patients the opportunity to begin actively pushing their lives around in their thinking and developing a blueprint for a future life.

Milne and Matthews (1979) working primarily as occupational therapists have described the development of counselling techniques in their work with disabled people. They see the value of remedial therapists having these additional skills which recognise that disability involves much more than physical problems. They describe the sorts of problem areas that present in their practice, which includes loss of self-image, loss of roles in the family, sexual problems and adjustment to disability following the loss of a limb. What these writers see as important in their approach is giving the person time and developing a sensitive and facilitating approach in their relationship to the disabled person which offers a warm and empathetic understanding of the person's situation. In Milne and Matthews description of their work the importance of combining the practical skills of a therapist combined with an understanding of counselling techniques are seen to be a valuable blend that can assist the disabled person in problems that arise both from physical and social origins.

But this individual approach is not the only method that can be usefully incorporated with a rehabilitation programme. Group techniques can have an important role to play in dealing with specific problem areas. Romano and Lassiter (1972) have described sexual counselling with physically disabled people, which ideally includes partners, with the emphasis on giving patients information and using group discussion as a vehicle to increase knowledge about the parameters of sexual functioning and opportunities to modify attitudes about sexual potential following disability. Bass (1969) has described similar approaches in the area of vocational problems and has used group counselling and behavioural rehearsal to assist disabled people prepare themselves for employment again. Here the main focus of intervention is on the person's feelings about themselves and others, role play of workplace behaviour, and strategies for making relationships with others in the workplace.

Trieschmann (1980) has described these differing techniques as valuable in providing the opportunity for the person experiencing problems in rehabilitation to begin anticipating ways of approaching that problem so that discussion of coping strategies becomes the first step that can lead to guided practice in problem solving in the real life situation.

In developing psychosocial techniques Trieschmann warns us that these approaches are not the preserve of particular disciplines and that the psychosocial aspects of disability need to be acknowledged by all staff involved in rehabilitation. She sees psychosocial techniques having their place in all aspects of the rehabilitation programme and to all rehabilitation personnel.

Staff Support in Rehabilitation Units

In order to meet the psychosocial needs of patients, staff support should be recognised as an essential component in rehabilitation units. Staff, as we have seen earlier, need to be aware of patients' feelings and acknowledge what is being expressed, rather than ignoring or denying their existence.

In the Unit, during the fieldwork period, there was no evidence of training or support for staff that was directly concerned with psychosocial problems. This is also said to be the situation in other rehabilitation units (Jacobs 1984), and indicates that insufficient attention is given to the situation of staff working with severely disabled people who may spend long periods in hospital. Staff working with such patients are described as subject to more frequent and intense personal distress than are staff treating less severely disabled people (Gunther 1977). The distress staff experience is said to arise from the particular demands that such patients make on those who care for them. These demands are wide and varied and in turn cause staff to make responses that are often negative and unhelpful. Gunther states that staff will inevitably experience distress as a consequence of the depth and duration of their contact with highly dependent long-stay patients.

A consequence of the emotional stress of working with severely disabled people has been described as "burn-out" (Maslach 1978). Burn-out involves losing concern for people, through physical and emotional exhaustion. Staff affected can find themselves having little positive to offer the patient in terms of therapeutic concern. Although the fieldwork in the Unit did not attempt to measure levels of "burn-out" among staff, using Maslach's criteria it was apparent that some staff, for whatever reason, found difficulty in responding positively to patients, even where patients were, in the opinion of the researcher, in need of emotional support during a period of intense distress. The demands that patients in the Unit made on staff meant that those staff needed training and support in order to understand both the patients' feelings, and in turn their own feelings. Maslach strongly recommends such training programmes with a focus in the areas of interpersonal skills, and professional support systems as a method of preventing or reducing staff burn-out.

Jacobs (1984) a Senior Research Officer working at the National Spinal Injuries Centre, Stoke Mandeville has described her work with staff, based on her research in hospitals over many years, indicating the need for the type of programme outlined by Maslach. Jacobs has conducted such a programme over a period of eleven months with the principal aim of providing support to staff working with spinally injured patients. An important point of the programme is to enable staff, through discussion, to understand more fully the meaning of a patient's feelings and behaviour in order that staff could then modify their own responses to the patient's demands. Jacobs describes her group meetings containing both training and support elements with the core theme the psychosocial implications of spinal injury. It is stressed in the discussion of this programme that group meetings are not a substitute for the regular training programmes available to staff, but a complementary activity that is as essential if staff are to respond sensitively and with confidence to the needs of disabled people. This innovatory programme described by Jacobs provides an example of staff support that recognises the full complexity of interaction between staff and patients. It is essential that staff confronted with distressed patients understand why a person is likely to feel this way and can respond appropriately. To expect staff to work effectively in a rehabilitation setting without such support fails to recognise the therapeutic importance of the relationships between staff and patients.

Peer Counselling

One recent development that is seen as particularly important in the context of psychosocial problems is the introduction of peer counselling into rehabilitation units. This development has grown out of the consumer led Independent Living Movement in the United States that has been comprehensively described by DeJong (1979). The basis of this approach is that disabled people themselves have much to offer the rehabilitation process and can provide a unique service to other individuals with disabilities. The Independent Living Movement arose because many disabled people believed that their experience in rehabilitation centres had not equipped them to meet the demands of life outisde hospitals. The peer counsellor advises others with disabilities on how to cope with various problems based on their own experiences. An important feature of peer counselling is the modelling potential of the role where competent people with severe handicaps who have succeeded in handling the daily problems of living are demonstrating what the future could hold for the newly disabled person. Peer counsellors are also seen as a vital resource in that they anticipate questions that might otherwise go unanswered, identify problems that might otherwise go undetected and offer viable alternative solutions to living problems that might otherwise overwhelm a newly disabled person.

Similar developments have begun to take place in Britain mainly in the area of spinal injuries through the work of the Spinal Injuries Association (SIA). Hasler and Anderson (1984) describing developments at the new spinal injuries unit at Stanmore discuss the SIA's involvement in the education of professionals by providing regular information and contacts with social workers in the Unit. Hasler and Anderson describe how the SIA members have shown that they have informed attitudes to rehabilitation and strong opinions to contribute to the process. What the use of SIA members at Stanmore indicates is the beginning of the involvement of disabled people as advisers to staff and counsellors to disabled people in rehabilitation units. The SIA is keen to extend this service and Hasler and Anderson report of other units where disabled people are involved in similar activities.

A comment by Trieschmann (1980) is pertinent in the context of these developments. She poses the question whether these developments will influence attitudes towards disabled people by challenging the stereotype of the disabled person as someone needing pity and constant assistance from non-disabled people. Bearing in mind the comments of Safilios-Rothschild (1969) that some of the negative attitudes towards disability are said to exist among rehabilitation personnel, the increasing involvement of disabled people as advisers and counsellors, who have skills to offer and demonstrate competence in their everyday lives, may also influence the attitudes of staff. What these techniques suggest, whether they are delivered by professionals or non-professional people with disabilities, is that a wide range of approaches that go beyond the traditional ADL and mobility training are needed. The reality of the disabled person's situation requires a much wider base of activities, that are also sensitive to his psychosocial and social needs if he is to learn to live effectively with disability.

Rehabilitation Team Practice

Two of the difficulties identified in the fieldwork were the poor level of communication between some disciplines, and hence the affects on teamwork, and second the problems created by the lack of clear leadership in the Unit which affected the overall efficiency of the different disciplines whose work was not coordinated adequately.

Teamwork is vital to the success of the rehabilitation of the disabled person. It is important because the disabled person usually presents the professionals with a range of needs that no one discipline or person can respond to individually. The disabled person's needs are multiple and consequently teamwork is necessary in order that the different elements of the practice fit together, and importantly avoid the patient receiving contradictory advice or treatments that actually cancel out each other's gains. But in spite of these justifications for the team approach there is strong evidence to suggest both from the fieldwork, and the accounts of those who have studied this area of practice that it is difficult to achieve. The barriers that can exist need to be recognised so that action can be taken to reduce or overcome them and enable teamwork to flourish.

A number of writers (Haselkorn 1958; Szasz 1970; Coe 1976) have described the factors that are likely to be present in a multidisciplinary setting that inhibit the development of teamwork. First, the professionalisation of disciplines within rehabilitation can actually create barriers to cooperation. As disciplines expand their knowledge and perfect their skills, this growing specialization can inhibit collaboration with other disciplines. Ironically the therapeutic advances that are achieved as a result of greater specialisation can be made at the expense of coordination and a more comprehensive service delivery. Second the model of professional education and training for those disciplines working in rehabilitation services helps perpetuate disciplinary specialisation, often with only lip service paid to interdisciplinary efforts. Here the attractiveness of becoming an "expert" with the power of highly developed technical skills can help to prolong the unidisciplinary approach to what are multiple problems. Third, differences in approach to rehabilitation can exist because of the status position of staff within the social structure of a unit. Closely associated with these factors are differences in power that also influence teamwork. Lastly, poor communication can exist where the ethos of a unit does not engender freedom of communication with the result that staff do not share their perspectives and understandings with other people which results in loss of opportunity to learn from each other. This latter area is seen as particularly important by Blaxter (1976) with the inefficiencies, inappropriate actions and distress caused to patients because of poor communication between professionals.

There are some factors though that are increasingly pushing disciplines towards more cooperation. It is increasingly recognised that the problems presented by disabled people are the products of a number of causal factors, some which will be of lifelong duration. In addition these problems do not necessarily yield dramatically and quickly to specific techniques over a long period of time. This inevitably leads specialists towards greater interdependence and cooperation in working towards a common goal. A second factor that is seen to generate the potential for closer teamwork is the increased demands by disabled people to be part of the decision-making process. This is seen to stem from both consumerism, but also dissatisfaction with the quality of services and the increasing recognition that patients cannot be excluded from the treatment programme (Coe 1976). These are seen as factors that contribute towards interdisciplinary cooperation, but it is recognised that it is unrealistic to expect professionals who are produced by training programmes that are unidisciplinary to know intuitively how to work with other professions. Coe sees the key to greater understanding between professionals coming from training together, at least for some periods. Training together is essential if the professionals who offer the various skills are to recognise the need and feel comfortable working together as a team, but also moving eventually towards collaboration where numbers of differing disciplines work together to reach a common goal.

Turning to leadership within the multidisciplinary world of rehabilitation this is likely to be a difficult issue particularly where consultants retain clinical responsibility, and as a result tend to influence the other disciplines whose practice has to be tailored to their viewpoint. Martin (1984) recognised this problem when he highlighted the difficulties that can exist in psychiatric hospitals, which have equal relevance for rehabilitation units. Discussing medical policy he sees the need for doctors to share their power with the multidisciplinary team, as there are limits to what doctors can achieve, particularly in long term care. This problem is exacerbated with the increasing professionalism of other disciplines who are evolving their own planning techniques which conflict with a simple model of medical direction. Martin sees it as increasingly unlikely that the old unquestioned medical dominance can continue unchanged in these circumstances.

In order to develop a more satisfactory approach to decision-making and leadership in rehabilitation calls for an approach to leadership that Martin describes as cooperative enterprise. In this approach it is recognised that each discipline has something to offer the rehabilitation process and that the individual contribution is relevant to the needs of the disabled person, and in this way a balance is maintained in the multidisciplinary approach. What needs to be recognised in using this model is that there are risks to the cooperative enterprise if it is seen, or felt, that one discipline is dominating the structure and the risk of breakdown is present.

This model offers an alternative to the approach witnessed in the Unit where a power struggle existed between medical and remedial practitioners. It could also have helped overcome the problems identified by nurses where they felt their contribution to the multidisciplinary discussion was undervalued.

From the foregoing suggestions it is clear that working in a rehabilitation unit requires staff to achieve effective teamwork in order that they feel confident not only with their own judgments, but also feel they can openly question their colleagues so that a critical approach to decision-making is achieved. Discussion with staff in the Unit researched suggested that the team had not reached that stage of organisational maturity or personal self-confidence, although there was an enthusiasm on the part of some staff to work towards a more dynamic and coherent approach to service delivery. Alongside this personal commitment existed a number of timetabled meetings that could have been used to increase communication among staff and the development of more congenial interpersonal relationships.

In this area of interpersonal relationship it is seen as crucial that teamwork involves service planning and case review functions (Wagner 1977) as this leads to a more consistent rehabilitation ideology with encouragement of democratic and collaborative teamwork elements. A coherent rehabilitation model that recognised the necessary ingredients of multidisciplinary teamwork and leadership skills would permit the practitioners to respond to the total person rather than place greater value on individual achievements that result in limited cooperation and risk of conflict amongst staff.

Reducing the Divisions Between Hospital and Community-Based Rehabilitation Practice

The main focus so far has been on changes to the current model of rehabilitation, and has examined activities that take place within a unit. In order to improve the rehabilitation process it is necessary to examine issues concerned with a unit's relationship with the community services.

Currently there is said to be a considerable gulf between those rehabilitation practices that take place in hospitals, and the activities of staff in the community services when the patient is discharged to his home. Official reports (Tunbridge 1972) and individual accounts (Blaxter 1969), have both described the failure of communication and coordination between these different elements of the rehabilitation services. Practitioners have also criticised the problems created by hospital practices that are cut off from the community services. Orsborn (1982) has described hospital rehabilitation as too narrow in its focus with patients discharged home 'rehabilitated', but who because of lack of understanding of their needs in the community subsequently break down and have to be re-admitted. Similarly, Sharman (1972) also criticises hospitals for passing their 'unfinished business' to the community. What is being implied by this statement is the poor service coordination for patients discharged into the community and swallowed up and forgotten.

The fieldwork in the Unit did not specifically examine the relationship between hospital and community services. There was evidence that the existing system had many shortcomings. Patients reported lack of preparation for returning home and were anxious about whether future arrangements would be adequate. As we saw earlier patients were 'managed' by staff up to the point of discharge, but then expected to cope smoothly with discharge, and return home able to cope independently. Although some patients returned home at weekends and families visited and met staff, there appeared to be only limited understanding of the patients' home situation. A full appreciation of the family dynamics and home circumstances was missing. Staff, similarly had doubts about much of the current practice. They recognised that there was insufficient work on preparing the patient for discharge, and that the level of family involvement in rehabilitation was inadequate. Patients also appeared to be returning to the community without support adequately identified. The practice of rehabilitation in the Unit which cut the patient off from the community created the 'crisis of discharge' described by one staff member of the Unit.

The problems created by the division between a rehabilitation unit and the community services was studied by Forder, Reti and Silver (1969). Their research was initiated as a result of concern about the high level of re-admissions following discharge of patients from a spinal injury centre. They describe how breakdown and readmission are not closely related to the severity of disability, but rather failure in service coordination. Patients returned home, but faced hazards without the involvement of appropriate support services. Forder et al. state that successful rehabilitation depends on a close relationship between services, particularly where assumpations are made about who takes responsibility for coordinating particular service initiatives.

This study produced a number of important recommendations about communication and coordination procedures. The authors stress that procedures need to be developed in ways that take account of the complexity of services, with the emphasis on increasing the dialogue between staff in the respective services. There is also the need to develop foolproof channels of communication in order to ensure against breakdown. Additionally case conferences need to be held where staff from the community services are able to visit a rehabilitation unit and make plans with hospital colleagues for the patient returning to the community. A further important recommendation is the need to identify a member of staff who acts in a liaison role between the patient and services.

It is clear from the recommendations that increasing integration between services has many advantages, and could begin to overcome the risk of units being cut off from the community and the social world of their patients. Likewise there are similar advantages in unit staff having an opportunity to play a greater role in the community. The advantages would not only be in the area of service integration, but in the opportunity for staff to see the disabled person's needs in a wider context. This would enable staff to take factors, like the patient's family, housing and neighbourhood aspects, into account when developing programmes tailored to his needs.

An example of how working in the community can help staff re-think their approach is described by Lamont and Langford (1980) who work as community physiotherapists. They state that staff working with disabled people in their own homes are much more aware of that person in the context of the family and neighbourhood. This wider perspective helps to counteract the current practice where patients' needs are assessed within a clinical setting, with minimal awareness of factors operating in his life outside a unit. A further important change resulting from community involvement, according to Lamont and Langford, is the way in which the relationship between the professional and the disabled person is established and maintained. The professional is no longer in control, but operates in the disabled person's world in a relationship of greater equality. Consequently a better balance of power is achieved, with both parties having an opportunity to contribute to resolving difficulties. The authors believe that the onus is then placed on the professionals to prove their worth, rather than direct treatment with the patient passively accepting their plans.

A greater involvement in the social world of the patient and contact with community staff could go some way to reducing the traditional clinical orientation of rehabilitation programmes. If staff were more aware of these wider aspects of the patient's situation, this knowledge would then have an impact on their approach and make them less inward-looking and bound by traditional assumptions about disability. It would be more difficult for staff to persist with treatment programmes based on narrow hospital assessments if the patient's family and home circumstances were more central considerations. A further spin off would be the opportunity for staff, playing coordinating roles, to improve their understanding of the dynamics of life with a disability in the community which is very different from life in a highly structured rehabilitation environment. This knowledge would begin to influence the rehabilitation process os that it becomes more sensitive to the needs of the disabled person.

Of course it is easy, but shortsighted, to suggest simple blueprints for service structure that take little account of existing constraints. As Blaxter (1969) warns when discussing shifts in the distribution of resources from "cure" to "care" with its emphasis on community rather than hospital care, these new ideologies will have to be grafted on to what is an existing extremely complex structure of services that have evolved over a long period of time.

Further difficulties face rehabilitation units in that they serve the most disabled people, who are relatively few in number and therefore need specialised treatment facilities that tend to be centralised. This results in large catchment areas with the inevitable intricate web of relationships with numerous local agencies spread over a wide geographical area. This means that links between services are likely to be complex and potentially fraught with problems. Blaxter's (1969) recommendation that there should be more regional rehabilitation centres, would of course begin to make catchment areas more manageable and offer increased opportunities for professional cooperation across service boundaries.

It is also necessary to remember that specialist units, where therapies have evolved and improved, have led to higher expectations, particularly in the rehabilitation of the most severely injured (Brechin and Liddiard 1981). These authors rightly argue that nothing should be done to undermine these developments, but rather that structures are developed that link together the two worlds; the world of the specialist rehabilitation unit and the world of the community, with professionals making their expertise available to both, with each informing the other.

Lastly, taking into account the above statements, there is a need to examine further the present structure of services which have evolved in a manner that reflects the interests of the professionals. Their thinking has not been significantly influenced by the new service ideologies and practices described by Blaxter, nor the increasingly articulate views of the disabled themselves who believe their needs are often inadequately met by the current services.

Summary

This Chapter has suggested a number of areas where modifications to the current model of rehabilitation would overcome some of the difficulties witnessed in the fieldwork. It is clear from the fieldwork, and from the work of those critics of the current model that the persistence of a medical treatment orientation into what is essentially a learning situation could be counter-productive. This is particularly so where the disabled person's role is one that offers few opportunities for personal development and self-control.

The hospital environment in which rehabilitation takes place also has features that can inhibit development. The hospital setting has many deprivational features both in terms of architecture, and also routines that can work to limit or undermine the disabled person's need to use a range of personal skills and make decisions for himself. Secondly, within this environment staff attitudes, which are critical in the rehabilitation process, need to be seen as important tools in a unit just as crucial as the apparatus and therapies that are often seen as of sole importance. The need to sensitise staff to a range of issues within the field of human relationships is necessary to increase staff's ability to respond to the patients' psychosocial needs. Here the use of training and support groups focussing on psychosocial problems offers staff the opportunity to extend their understanding of the disabled person's needs.

Techniques that can assist the disabled person in order to meet his needs are available. These techniques involve both patient and staff working together in both identifying goal areas and sharing in the decisions that need to be taken in the direction of a programme to achieve these goals. In addition to these joint approaches to goal setting a range of psychosocial techniques are available that could do much to counteract the imbalance in current programmes with their physical focus. In the context of these approaches, the recent development in peer counselling is obviously a valuable addition to the range of techniques available in rehabilitation that can help bridge the gap between the able-bodied helpers' perspective and the disabled person's viewpoint.

Teamwork has been described as vital to the success of the rehabilitation process, but evidence presented suggests that its achievement is sometimes difficult. The recognition of the barriers to teamwork is the first step in developing measures to overcome them. The value of interdisciplinary training cannot be overestimated as one method of bringing staff of different disciplines together to examine common practice areas. Associated with high quality teamwork is good leadership. It is seen to play a crucial part in generating commitment to service goals that are reached with equal involvement of staff with decision-making agreed by the consensus of staff meetings under sensitive leadership. Leadership roles in multidisciplinary settings present potential problems, although it is recognised that traditional medical pre-eminence is less easy to maintain with the growth of professionalism and the specialised techniques of other disciplines.

Finally, problems resulting from the artificial division between hospital and community-based services need to be overcome. The world of rehabilitation is neither the exclusive concern of hospital or community as each has something unique to offer the disabled person. Integration of these two service spheres would provide the opportunity to take greater account of the disabled person's social situation. It would also assist in overcoming the abrupt break between hospital and home by preparing him for discharge with the prospect of community support services involvement at an earlier stage of his rehabilitation.

11 CONCLUSIONS

This study has examined the rehabilitation process through the accounts of patients and staff in a medical rehabilitation unit, with additional data collected from a spinal injuries centre. The fieldwork was concerned with an exploration of the rehabilitation process using qualitative research methods.

The research drawing on a small sample is open to the criticism of generalising from limited evidence. Nevertheless, this study has revealed and documented a number of significant problems in the rehabilitation process that were evident from the accounts of patients and staff. The main finding of this study is that the rehabilitation process as witnessed in the Unit, and the spinal injuries centre, is based on a range of activities that stress physical recovery, placing emphasis almost exclusively on the remedial therapies as the main treatment focus. As a result of this focus the consequences of the psychological distress associated with physical disability is largely neglected. In addition little attention is given to the patients' social world with poor preparation for discharge or the involvement of family or community services.

It is described in Chapter 1 how this imbalance in the rehabilitation process, with its emphasis on physical coping, is a consequence of the persistence of the traditional approach in rehabilitation that is based on the medical model with its concern with 'bodily repair'. Rehabilitation services have been described as evolving from work with servicemen and the industrially injured where a speedy and efficient return to active service or productive work was a priority. Although the conditions that produced this model of rehabilitation no longer exist, it is suggested that significant elements of this earlier approach have still not been replaced by a model more relevant to the needs of disabled people using the service today.

A further reason for this imbalance in the rehabilitation process is the hospital-centred approach taken in the Unit. A specialised rehabilitation service, like all such facilities, carries the risk that only those factors related to the patients' specific condition will be considered relevant for treatment. As a result of this narrow perception of what constitutes rehabilitation, the patients' disability is not seen in its wider context. Thus, staff with their limited appreciation of the patients' circumstances are unable to take into account factors that could lead to a more balanced approach in treatment programmes.

This hospital-centred approach suggests that the Unit shares some similar problems to those that have been identified in studies of total institutions. As in other institutions for long-stay residents, admission to the Unit effectively cuts the patient off from the community, with staff routines tending to be exclusively unit-based. In this segregated environment treatment becomes 'situation specific', with rehabilitation programmes uninfluenced by broader considerations of coping with disability. Although it is important to avoid oversimplifying the parallels with other institutions, the picture that emerges from this study lends weight to the viewpoint that the structure and practices in the Unit created conditions where staff are likely to become inward looking, and develop treatment routines that bear little relation to the reality of patients' needs following discharge from the Unit.

Turning to alternatives to current provision, Chapter 10 of this thesis has described a number of techniques that have been developed, and where a considerable degree of knowledge and experience has already been acquired in rehabilitation practice. Many of these techniques are concerned with the psychosocial problems of disabled people and if adopted by rehabilitation units would significantly influence practice and make it more relevant to the real needs of patients.

What then are some of the essential elements of practice that could demonstrate what might be done if the service was sensitive to the needs of disabled people?

First, the setting where rehabilitation takes place should offer an environment that takes account of the fact that a disabled person may spend a considerable period in residence. Therefore the traditional hospital ward is not an environment that is well adapted to become a patient's temporary home. The environment should provide facilities that would enable the patient to live as self-sufficiently as possible in order to avoid the passive dependence currently witnessed in units. To borrow a psychiatric term, the environment should be a 'total therapeutic milieu', that is constructed and organised to promote the growth and independence of the individual.

Secondly, staff engaged in rheabilitation programmes who have face-to-face contact with patients need to be made aware of the psychosocial consequences of physical disability. In addition they need to be trained to assess psychological distress in patients and to develop skills that could be used to support patients. A particularly important component of this training is the development of counselling skills which prepares staff to work with patients who have personal problems, but who have difficulty expressing their feelings where staff are not sensitive to their distress.

Thirdly, staff who are undertaking this work need support. There should be an opportunity for new staff to familiarise themselves with the distinctive characteristics of a rehabilitation unit and the psychosocial consequences of physical disability. Regular individual and group consultations for staff, led by professionals who are experienced in the use of psychosocial techniques, are essential. Staff who are more emotionally involved with patients need opportunities to discuss their work and the feelings generated by these techniques.

Fourthly, and directly related to staff support, is the need for good staff communication. It has been described earlier that the quality of leadership is a vital factor in a unit. A democratic minded leader who brings staff together and involves them in decision-making could increase the potential for staff cohesion. Team work is an essential part of rehabilitation practice. Therefore work needs to be undertaken that helps generate a commitment to staff working more harmoniously together. A close relationship is said to exist between staff satisfaction and the quality of patient care. This suggests that positive benefits accrue to both staff and patients from greater staff cohesion and feeling of commitment to their work.

Fifthly, more emphasis should be placed on rehabilitation being seen as a long-term process that goes beyond the rehabilitation unit and continues into the community. Rehabilitation in a unit is only one stage in what can be a life-long activity for the patient. Consequently the involvement of family and community services is essential in order that they play a significant part in the programme prior to the patient's discharge. This would also help staff to see that their work extends beyond the unit and would help break down some of the insular approaches that ignore the patient's social situation in the community. A further potential area of support is through self-help activities and here the role of disabled peers can play an important part in working with the patient based on personal experience of adapting successfully to life with disability.

In order to bring about the conditions that would enable these essential elements of practice to become integral parts of day-to-day practice, it would require fundamental changes in the structure of hospital rehabilitation services. Three specific changes can be identified as important in helping direct the service towards a role that is less isolated, more sensitive to patients' needs and based on firmer theoretical foundations.

For those severely disabled people who cannot be treated effectively in the community, more regional rehabilitation centres need to be established. These centres, with smaller catchment areas and integrated with local services, would have a wider role, including resource and advice services, along with training and research functions.

The professionals who practice in rehabilitation, need to have a much greater understanding of psychosocial consequences of diability, and the need to involve patients in the management of their condition. In the long term, this would mean a greater emphasis in professional training on the social and behavioural sciences, in order that these subjects take their place alongside clinical studies, and subsequently influence the practice of professionals.

For existing staff who need to update their skills, in-service training is required. This training should be planned to provide staff with opportunities to develop practices that enable them to see beyond physical restoration, and understand the needs of patients in their widest context.

If the rehabilitation programmes offered in centres are to be based on techniques that have been thoroughly evaluated, then research needs to be 'built in' to the work of such centres. Much of the current practice in rehabilitation is said to be based on techniques whose value is unknown. Certainly improvement in a patient's condition is assumed to be due to the treatment provided, although little is understood of the outcome value of the various rehabilitation interventions. Outcome studies could begin to provide a clearer understanding of which treatment procedures offered the most beneficial change, providing the opportunity to plan intervention on a more rational basis.

In describing some of the new directions needed to produce a high quality rehabilitation service, it should be recognised that changes start from a much clearer understanding of the needs of those who use the service; the person with a physical disability. The rehabilitation professions have tended to adopt stereotyped and common-sense views of disabled people, their families and their problems. These views, as we have seen through personal accounts, are not necessarily related to how disabled people see their lives and the issues that concern them. In considering a disabled person's needs it is important to understand that his development does not end when he becomes disabled. It may be interrupted, but eventually he will want his life to continue in the direction it was heading before injury or illness struck. Severe disability can of course radically change a person's life, but the clear message from the personal accounts of disabled people, is the wish to live life as normally as possible, with whatever adaptations are needed. Rehabilitation practitioners then, need to listen to the voice of disabled people, and try to comprehend their hopes and fears in order that the model of practice in rehabilitation units supports and promotes disabled people's potential, however limited it may appear to the able-bodied professionals.

In conclusion, this study by examining the reality of the rehabilitation process seen through the perceptions of patients and staff, provides an insight into the effectiveness of treatment programmes in a rehabilitation unit. The research has raised further questions about the content of rehabilitation programmes, and how far they adequately prepare patients for the future, and the social reality of life with a disability.

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