REVIEW OF THE SOCIAL SITUATION OF PARAPLEGIC AND TETRAPLEGIC PATIENTS REHABILITATED IN THE HEXHAM REGIONAL SPINAL INJURY UNIT IN THE NORTH OF ENGLAND OVER THE PAST FOUR YEARS

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Abstract. The social circumstances of newly admitted patients rehabilitated in the North of England Spinal Injury Unit between 1975 and 1979 have been investigated. The following elements of their social circumstances have been briefly reviewed in this paper: housing and facilities in the house, mobility, health, pressure sore development, family relationships, sexual relationships, employment, compensation, and social integration. The resulting information enabled us to appropriately modify our rehabilitation progress as discussed.

Key words: Traumatic paraplegic and tetraplegic patients; Social circumstances; Rehabilitation; Modification of social services.

Introduction

THE circumstances of paraplegic and tetraplegic patients who have been rehabilitated in Spinal Injury Units, and who have been subsequently discharged home, have been investigated by several workers. Frequently, information relating to specific aspects of daily life has been reported (Jackson, 1972; Wilcox *et al.*, 1972; Forner Jr *et al.*, 1976) or the use of particular equipment at home has been reviewed (*e.g.* Spieker *et al.*, 1971 who reviewed upper extremity bracing). The problems of social integration have been studied with emphasis on particular aspects such as employment, services available (Hallin, 1968; Johnson *et al.*, 1972) and degree of independence achieved (Runge, 1966).

We believe, however, that an assessment of these patients at their home on a considerably wider basis would provide a clearer picture of the overall quality of their lives. We would then be in a position to assess the overall value of our rehabilitation programme. We would consequently be in a position to modify appropriately our programme as required in order to provide a further improved service to our patients.

Our present programme of management has extended essentially from 1975. We have therefore examined the social situation of all new patients treated and rehabilitated in our Spinal Injury Unit between 1975 and 1979. This has allowed a minimum follow-up of 1 year since discharge.

Method

The survey was conducted using a semi-structured interview schedule administered by the same individual (Research Social Worker) throughout (M.B.).

Computerised analysis of the results was carried out. Ninety-two patients were eligible to take part in our survey. Fifteen patients were not available for interview.

Of the available patients, only two declined to take part in the investigation, a satisfactory high compliance rate.

Results and Discussion

The age and sex distribution of the 75 patients taking part are noted in the legend to Figure 1.

FIG. 1

Showing total number of cases (75)—age distribution 13–63 years (61 male and 14 female), plotted against grade of disability.

Degree of Disability

The degree of disability was classified according to the amount of function in the upper and lower limbs as shown in Table I. *Note:* All % figures refer to the total number of 75 patients unless otherwise stated.

In our research schedule, facility was built in to allow us to classify upper limb function separately from lower limb function. In the 75 cases examined, however, patients with significantly impaired upper limb function also displayed severe lower limb function and were therefore classified as Group IV (Table I).

The distribution of the degree of disability is shown in Figure 1. As can be seen, about 50 per cent of these patients constitute Groups III and IV which represents a very considerable degree of disability.

Permanent Return Home After Rehabilitation

When asked whether they felt that they were suitably prepared for discharge by the time they left the Spinal Injury Unit 85 per cent of patients felt that they

TABLE I

Code	Degree of disability	Level of function
I	No/Mild disability	Able to walk normally
II	Moderate disability	Some limitation in walking or uses walking aid
III	Severe disability	Relies on wheelchair most or all of the time
IV	Very severe disability	As III with impaired upper limb function

were. On the other hand, 24 per cent of people felt that the support available at the time of discharge was inadequate. Seventy per cent of patients were allocated a social worker by the local authority at the time of discharge. Twelve per cent were allocated an occupational therapist also. Eighty-eight per cent of patients had spent either week-ends or days at home prior to discharge. Patients were asked whether they considered that the service provided by the Spinal Injury Unit (SIU) was satisfactory or otherwise. Ninety-six per cent were satisfied with the service provided by the Unit.

Housing

The type of accommodation in use by each person was recorded (Table II). The conventional house remained the most frequently used type of accommodation throughout the range of disability, though a significant proportion of the very severely disabled lived in a bungalow. Regarding the location of housing and the provision of adaptations, 13 patients (17 per cent) felt that they had not been sufficiently consulted overall. Fifty-six per cent of patients had been able to return to their own home after discharge. About one third of these patients were owner-occupiers and two thirds were council tenants.

When adaptations were required to a property (28 per cent) the average time taken to complete the work was 3 months (*i.e.* from time of home visit by the Occupational Therapists to time of completion). In 12 cases, an extension was recommended, though this was actually only provided in eight cases. Access via

TABLE II

Housing	Disability				Total
	I	II	III	IV	
House	9 (12%)	18 (24%)	17 (23%)	5 (7%)	49 (65%)
Bungalow	1	6 (8%)	7 (9%)	3 (4%)	17 (23%)
Flat—Downstairs	1	1	3 (4%)	1	6 (8%)
Flat—Upstairs	0	1	0	0	1
Hospital	1	0	1	0	2
Total	12	26	28	9	75

ramps, when necessary, was generally satisfactory. In nine cases (12 per cent) essential doors were of inadequate width.

Facilities Within The Home

Most homes were equipped with central heating (73 per cent) and a telephone (77 per cent). Everyone possessed a television. In the kitchen, adaptations were broadly satisfactory. In the bathroom also aids such as grab-rails, monkey-pole handles, non-slip mats, etc, were used regularly in a high percentage of cases and were considered satisfactory overall.

Lifts had been provided for ten patients (13 per cent). All those with lifts were satisfied with them and used them regularly. (See Table III—it is acknowledged that these figures are small for statistical purposes.)

Seventy per cent of these patients had been supplied with wheelchairs, 44 per cent had to wait longer than 1 month to be supplied with one. Four patients had to wait 6 months and two patients waited more than a year. A Possum unit had been supplied to 8 per cent of the patients; all patients valued this highly.

TABLE III

Type of lift	No.
Electric—Vertical	2
Manual—Vertical	5
Electric—Stairlift	3
Total	10 (13%)

Mobility

This is an important factor in successful rehabilitation because of its influence on employment prospects, social life and general independence. Seventh-six per cent of patients had access to a car and 44 per cent of people owned their own car. The great majority of people (72 per cent) received no help in buying a car. Four per cent of people used the motability scheme, which however did not start until 1978). Twenty-four (69 per cent) of the 35 cars individually owned were adapted. There had been little difficulty in obtaining third party insurance cover, though 22 per cent of those applying for comprehensive cover had experienced difficulty in obtaining it.

Bearing in mind the degree of mobility conferred by cars, the wheelchair-accessibility of public buildings becomes increasingly important. Considerable difficulty was reported in this respect. Table IV lists the problems of access reported. The lower the facility appears in the list, the greater the difficulty in access.

Health

Since discharge, 50 per cent of patients have required at least one admission to hospital. (Reconstructive procedures, urinary complications, pressure sores, etc.)

TABLE IV

Facility accessibility
Public park/gardens
Club
Shops
Launderette
Cinema
Public library
Post office
Bank
Bingo hall
Swimming pool
Sports facilities
Public house

N.B. Least accessible at bottom of table

Pressure Sores

Nine per cent of people had a pressure sore at the time of the interview. However, if one considered the incidence of sores from the time of injury, 25 people (33 per cent) had developed one or more sores during that time (*i.e.* $4\frac{1}{2}$ years).

Family Relationships

The marital status before injury in terms of the whole group of people is described in Table V. The data shows that 52 per cent of this group of people were married at the time of injury. Since the time of the accident, the following changes in marital status have occurred. In 86 per cent of cases no change had been reported. Two patients had had children since injury; both were paraplegic (disability Grade 2), one a housewife of 33 years of age and the other a 25-year-old man.

TABLE V

Marital status	Before injury	Since injury
Single	30	28
Married	39	35
Divorced	1	4
Separated	3	5
Widowed	2	3
Total	75	75

Sexual Relationships

Fifty-four patients (72 per cent) had a sexual relationship before injury. Forty-eight of them (89 per cent) stated that this had changed or ceased since injury. Space precludes a more detailed review of this subject. Of those for whom

sexual counselling was applicable, 12 had received such help (18 per cent) but 46 (71 per cent) had not. Twenty-seven per cent of patients stated that they would welcome a more readily available sexual counselling service.

Employment

Patients of working age were visited by the Disablement Resettlement Officer (D.R.O.) in hospital (35 patients—47 per cent of the total). Sixteen people were retrained for work (Table VI). Thus 46 per cent of those eligible received some form of retraining. Seventy-seven per cent of the whole group had to abandon or alter their career plans. At the time of interview, 13 patients (17 per cent) were employed—11 males and two females. Ten of these employed people (77 per cent) drove themselves to work. The number of people at work diminished as disability increased (Table VI).

TABLE VI

Disability code	No. of people at work
I	7
II	5
III	1
IV	0
Total	13

Compensation

Fourteen people had received compensation at the time of interview (18.7 per cent). The average time that compensation had been achieved was 31 months. A further six patients expected to receive compensation, making a total of 20 people with a reasonable expectation of compensation in the whole series (*i.e.* 27 per cent).

Social Integration

Forty-one per cent of people had lost contact with friends as the result of being handicapped, against this, however, 72 per cent of people had made new friends through their handicap. Most people (70 per cent) did not feel discriminated against because of their handicap. The most popular leisure activities in order of descending popularity are shown in Table VII.

Conclusions

As the result of this survey (of which this report is a brief summary) we are building into our rehabilitation programme additional elements, some of which are listed below.

1. Study days for relatives and patients in order to prepare them with useful knowledge for the future.

TABLE VII

Leisure activities	No. of patients
Listening to music	66
Watching TV	62
Reading	36
Woodwork/mechanical	32
Animals	31
Home and garden	28
Participating in sport	24
Watching sport	23
Bingo/gambling	15
Crafts	14
Cinema/theatre	14
Playing music/singing	13
Photography	12
Art	10
Writing	9
Religious activity	6

2. Improved liaison with the Specialists in Community Medicine in our region in order to improve the quality of overall care immediately after discharge from the Unit.
3. We are investigating the possibility of developing a liaison with the Department of Architecture at Newcastle University in order that we may set up study days with the architectural students.
4. We have set up a small workshop system as part of the Occupational Therapy Unit. This is run by a Technical Instructor. Articles manufactured are sold in a shop which we have opened within the largest store in Hexham. (We have been greatly encouraged and assisted by the owner of the store and his staff.) It is hoped that this project will maintain the work 'ethic' and will encourage and assist patients to more seriously consider looking for a suitable job and to become more active in craft activities. We believe that the patients' quality of life will be enhanced by these means.
5. We have obtained a (non-mobile) car in order to ensure that all suitable patients are familiar with handling the controls and entry and exit.
6. We are making efforts (as are other groups) to make local authorities aware of the difficulties of wheelchair access to public buildings.

This paper has been of necessity a very brief review of our survey. Apart from revealing ways in which the rehabilitation programme could be improved, it has pointed out positive ways in which a Spinal Injury Unit can help patients once they have left the Unit and are living in the community again.

SUMMARY

The various aspects of the social circumstances of patients rehabilitated in the North of England Regional Spinal Injury Unit between 1975 and 1979 have been investigated. The study was carried out by making use of computerised analysis

of a specially developed questionnaire. A Research Medical Social Worker was appointed to visit each patient at their home in order to record all relevant information into the questionnaire.

A summary of the resulting information is presented. The study has been of particular value in two respects. Firstly, it has revealed the comprehensive social circumstances of these patients. Secondly, it has enabled us to evaluate the quality of service provided by the Hexham Regional Spinal Injury Unit, and it has enabled us to recommend an expansion of some of the aspects of the service provided by a Spinal Injury Unit.

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RÉSUMÉ

On a examiné les différents aspects des conditions sociales des patients qui ont été réhabilités entre 1975 et 1979 dans le service régional des blessures vertébrales dans l'Angleterre du nord. L'examen a été effectué au moyen d'une analyse d'ordinateur tirée d'un questionnaire spécialement rédigé. Une assistante sociale s'occupant de recherches médicales a dû rendre visite chez chaque malade à domicile pour consigner par écrit dans le questionnaire tous renseignements utiles.

Vous trouverez ci-joint un sommaire des informations qui en sont découlées. L'étude a été d'une valeur importante sous deux rapports. En premier lieu elle a révélé les conditions sociales d'ensemble qui vivent ces malades. En second lieu elle nous a permis d'évaluer la qualité des soins que fournit le Service Régional des blessures vertébrales à Hexham et elle nous a mis en état de recommander un développement de quelques-uns des traitements offerts par un service de blessures vertébrales.

ZUSAMMENFASSUNG

Die verschiedenen Aspekte der sozialen Umstände von Patienten im Norden von England, die in der regionalen Abteilung für Wirbelsäulenverletzte in den Jahren von 1975 bis 1979 rehabilitiert wurden, sind untersucht worden. Die Untersuchung wurde mit Hilfe der Komputerveranalyse und eines, für diese Zwecke entwickelten, Fragebogens durchgeführt. Ein medizinischer Sozialfürsorger wurde für diese Untersuchung eingestellt, um jedem Patienten einen Hausbesuch abzustatten und alle wichtigen Informationen in den Fragebogen einzutragen.

Eine Zusammenfassung der Ergebnisse wird präsentiert. Die Untersuchungen waren aus zwei Gründen von Besonderem Wert. Erstens wurden die umfassenden sozialen Umstände dieser Patienten enthüllt. Zweitens ermöglichte es uns, die Qualität der Hilfe, die von der regionalen Abteilung für Wirbelsäulenverletzte gegeben wird, auszuwerten und eine Erweiterung dieser Hilfe in bestimmter Richtung zu empfehlen.

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