A medico-social survey of Romanians with spinal cord injury

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The problems faced by Romanian patients with spinal cord injuries when discharged home were investigated by a medico-social postal questionnaire. All 170 who were surveyed had been treated in the rehabilitation section of the Neurosurgical Clinic of Bucharest from 1.1.92 to 1.1.93 before being discharged home. Those who were still inpatients at the time of the survey were excluded. The response rate was high (133 patients (78%)). Fifty-four per cent were paraplegic and 44% were tetraplegic; 80% were men. They were facing serious financial difficulties through loss of their jobs and the absence of formal and efficient sources of social help. Urinary catheters, condom drainage and drugs were not easily available or were too expensive for many of the patients, and medical facilities were scarce in the remote villages. Sixty-six per cent (71% of whom were tetraplegic) spent most of their time in bed and very few had the resources to adapt their houses. It makes little sense to improve conditions in hospital if conditions at home are not also improved. This paper highlights some of the problems faced by such patients.

Keywords: spinal cord injury; Romania; medico-social survey; community care; social reintegration

Introduction

As a follow-up to a social assessment in hospital and home visits and to discover more about the problems faced by patients at home, a medico-social survey was conducted by a questionnaire of 170 Romanians with spinal injuries who were living at home. They had all been treated in the rehabilitation section of the Dr Gh Marinescu Hospital (now called Emergency Hospital Dr Bagdasar) in Bucharest between 1st January 1992 and 1st January 1993. There were 120 (of a total of 262 admitted in 1992) with new injuries and 50 (of a total of 150 readmissions during the same period) who were readmitted. The 242 patients who were not interviewed were not admitted to the rehabilitation section.

Methods

A questionnaire was posted to 170 patients in February 1993. They were asked to reply within 3 weeks by post giving precise data on:

- social status
- occupation and income
- medical and social problems
- level of activity and independence
- architectural difficulties in the home, eg stairs
- other relevant factors

Results

Seventy-eight per cent (133) responded. Five had died and no information was provided on them, therefore

128 were available for study. Half of the patients had been discharged more than 6 months previously. Fifty-four per cent had paraplegia, 44% tetraplegia, and 2% had recovered neurologically.

Social status

There were 105 male and 23 female respondents. Half (64) were under 40 years of age (Figure 1). Many of the older patients had been injured in falls from horse-drawn carts. Eighty (62%) were married before they were injured (Figure 2). After injury three marriages were said to be in difficulty, and three couples who were cohabiting separated. Sixty-six per cent of all patients had at least one child (30.5% had two children). More than half the children were over 21 and in theory capable of contributing financially to the support of the family (Figures 3 and 4). Seventy-seven per cent of the patients had siblings, who were mostly adults (Figures 5 and 6). Fifty-nine per cent of the respondents lived with a spouse and only 3% lived alone (Table 1). Extended families were common with

Figure 1 Age distribution

Figure 2 Marital status

Figure 3 Number of children per patient

Figure 4 Age distribution of patients' children

Figure 5 Number of siblings

Figure 6 Age distribution of patients' siblings

Table 1 Type of family

Number of patients living with . . .	%	
Spouse	76	60
Children	54	42
Own parents	56	44
Nobody	4	3
No data	3	2

children, parents and other relatives sharing a house. In 62.5% of cases there were at least three people in the household (Table 2).

Occupation and Income

In 47.5% of households only one person was earning a living. Twenty-three per cent of households had two breadwinners (Table 3). Fifty-six per cent had been manual workers before the accident, but only 1% were after the accident. The proportion of pensioners increased from 12% before the accident to 51% after, but at the time of assessment, many, especially those who had been working for the cooperative system, were not eligible for a pension. A new law was passed in early 1993 to correct this anomaly, but at the time of the survey 38% claimed that they had not yet received their pension. Forty-eight per cent were regarded as being poor before the injury. This increased to 82% after injury (Figure 7). Thirty per cent of the injuries had been caused by accidents at work.

Medical problems

As expected urinary tract infection (UTI), gastrointestinal disorders and spasticity were common. Ten had indwelling urinary catheters. Forty-eight patients used intermittent catheters and 60 used condom drainage. Urinary catheters, condoms and drugs were

Table 2 Size of family

Number in household	%	
None	5	4
One	16	13
Two	26	20
Three	24	19
Four	26	20
More than four	30	23
No data	1	1

Table 3 Sources of income

Number of breadwinners	%	
None	19	15
One	61	47.5
Two	29	23
Three	9	7
> Three	2	1.5
No data	8	6

Figure 7 Level of monthly personal income. All values are in US dollars. Very good = > \$130; good = \$51–\$130; average = \$25–\$50; poor = < \$25

Table 4 Medical problems

Medical problem	Number of cases
Diarrhoea	10
Constipation	58
Spasticity	60
UTI	90
Pressure sore	25

Table 5 Mode of micturition

Means of voiding urine	Number of cases	%
Indwelling catheter	10	8
Intermittent catheter	19	15
Condom drainage	31	24
Intermittent catheter and condom	29	23
No device	39	30

not easily available and too costly for many families (Figure 8).

More of the paraplegic patients (13%) than those with tetraplegia (7%) were sexually active.

Patients found it difficult to obtain medical care near their homes. Thirteen were examined by a doctor, 11 by a nurse, and 20 attended a health unit. Five reported that a doctor within their village had refused to visit them at home. Despite these problems, 50% claimed to be coping psychologically; many had come to terms with being dependent, but most were obsessed with neurological recovery and walking. They were in a state of 'despair' and prepared to 'go abroad' for treatment: they felt that they had been 'cursed' or 'punished by God'.

Figure 8 Accessibility to medicaments

Table 6 Type of carer

Carer	Number of patients	%
Spouse	68	53
Children	14	11
Parents	32	25
Other relatives	11	9
Friends	3	2

Table 7 Types of walking aids

Walking aids	Number of patients
Parallel bars	24
Walking frames	12
Crutches	22
Without aid	5
Not walking	65

Social problems

Care was provided by the family in 98% of cases, essentially the spouse in 53% of cases. The strain on the family was considerable and 73% of patients had requested a carer paid for by the State under the provision of a new law (Law No. 53), but unfortunately its implementation was slow.

Level of activity

Only 34% were practising pressure relief. A few had abandoned walking exercises once they returned home, but those with incomplete tetraplegia seemed to show more interest. Indeed 46.9% of patients (57.1% with paraplegia and 34.5% with tetraplegia) were practising walking exercises in hospital. These figures were respectively 42%, 48%, 54% once the patients were back home. Patients with incomplete tetraplegia were more motivated. The use of parallel bars was quite popular.

Level of independence

Seventy-four per cent of those with paraplegia could feed themselves; the others had medical conditions preventing them from doing so. Of those who were tetraplegic, 32% could feed themselves but an additional 54% required feeding aids. Sixty-two per cent of those with paraplegia and 69% with tetraplegia could not cook. However, in Romania men (who constituted 80% of patients) are not expected to cook. Table 8 shows data concerning other activities of daily living. In addition 66% (62% of persons with paraplegia and 71% of those with tetraplegia) spent most of their time in bed, whereas 17% alternated between bed and armchair or wheelchair. About 11% (14% of those with paraplegia and 7% of those with tetraplegia) used their wheelchair regularly.

Table 8 Activities of daily living

Activity	% of spinal injured respondents			
	Yes, with no help	Yes, with help	No	No data
Turn in bed	42	51	5	2
Transfer bed to wheelchair	27	51	10	12
Washing	20	62	13	5
Dressing and undressing	21	58	16	5
Writing	60	9	25	6
Reading	75	11	9	5

Table 9 Reasons for not adapting house

Problem	Number of respondents concerned
Financial difficulties	73
Nobody to do it	34
Unavailability of building material	55
No data	25

Architectural barriers

Fifty-three per cent lived in villages, but those living in a town were in apartments without lifts or in unadapted housing. The rooms were small and there was no indoor toilet. Steep steps sometimes made it difficult for adapted ramps to be built. Over half (52%) were living in unadapted houses. When asked why they did not adapt their houses, patients reported cost and/or unavailability of material as limiting factors. Seventy respondents (54.5%) never left their house, 11% went out every day, 15.5% once a week and 15.5% monthly (no data were available for 3.2%). Architectural, social and psychological barriers were held responsible, as was the mode of transport: 76% of patients had no transport facilities of their own. Eleven patients travelled by a horse-drawn cart, 53 could use a car, 18 a bus, and 12 the train.

Other aspects of interest

Wheelchairs were often used as armchairs but in general the orthotic equipment provided by the unit was being appropriately used (Figure 9). Thirty-three per cent of patients had made their own orthoses.

Figure 9 Equipment being used (can be more than one)

Seventy-two per cent reported that it was difficult to have their wheelchairs repaired and to get spare parts. Forty-three and a half per cent had received additional support from the Red Cross since discharge but most respondents wanted the Red Cross (82%) and the state secretariat for the disabled (66%) to do more to help them.

Discussion

We were encouraged by the patients' high response rate to the questionnaire. Many wrote to say thank you for the interest shown in them: this reflects the isolation of these people and their continuing need for help. The specially designed forms, based on a previous study in Pakistan,¹ allowed us to analyse the information by computer. The survey confirmed the findings of home visits and a social assessment. Home visits were carried out before, soon after or at discharge by the members of the spinal injury team between November 1991 and August 1992.² They visited 26 patients. The team particularly sought information on architectural barriers, and geographical and psychological isolation of patients and their families. Often the family had to cope alone with all the consequences of someone with a spinal cord injury. A social study of 59 inpatients on the rehabilitation ward, undertaken from February 1992 to July 1993, gave precise data on the composition of the families, their main problems and preoccupations, and financial constraints.³ The above three studies clearly show that the social reintegration of patients is influenced by a combination of factors.

Family members can help in the rehabilitation process,⁴ and be supportive, provided that account is taken of their emotional state⁵ and their needs are assessed as early as possible.⁶ The family must be encouraged to think of both short and long term goals.⁷ Marital status is a good predictor of independent living outcomes. Patients need lifetime care without endangering the family structure or the traditional roles of the family members.⁸ We found that a few marriages were already endangered. A report from the USA showed that 81% of patients with spinal injuries were still married 5 years after injury (compared with 89% of the general population).⁹

Quality of rehabilitation: It is important to help the patient regain health and confidence in his or her abilities, promote successful adjustment by separating the disabled person from a dependence on medical systems, redirect the life focus back to the family, and address vocational and social issues.¹⁰ M Khalifa suggests that 'the quality of home health care is affected by multiple factors including knowledge of disability, stressful life events, self-monitoring, activities of daily living . . .'.¹¹

Financial means: Most patients were male, working class breadwinners. Many of those who were intellectuals and professionals were also poor. In this transitional phase in Romania, with the shift to a free market economy, the cost of living is high and most patients found it difficult to meet their expenses without social and financial help. We insisted on the local production of orthotic equipment, to reduce the cost of managing spinal cord injuries and to ensure that the project continued after the departure of the Red Cross Movement. To this end, workshops were set up within the hospital in Bucharest, and Romanian workers were trained. Much more needs to be done to make catheters and condom drainage available and accessible and to educate community teams in the management of those with a severe spinal injury. The new law must be implemented, although we can understand the financial constraints on the government.

Medical facilities: These were not within easy geographical reach and a few general practitioners refused to treat such patients, probably because they were unfamiliar with spinal injuries. Some admitted that they had never catheterised a patient. The family physician must pay particular attention to the genitourinary and respiratory systems, autonomic dysfunction including temperature variation, skin care, contractures and spasticity, the prevention of thromboembolic disease and nutritional disease.¹² Patients and their carers require training to improve standards of personal care, hygiene, and knowledge of disability. To this end, the spinal injury team published a booklet entitled *Handbook For Person With Spinal Cord Injury* and produced two videos on the management of spinal injuries which were sent to all main district hospitals of Romania as well as to all its neurosurgical centres. In addition one of the authors (AS) suggested to the International Federation of Red Cross and Red Crescent Societies that a second phase should be added to the spinal injury project, focusing on care in the community. Implementation of this was finally made possible in June 1993 by funding from the International Committee of the Red Cross (ICRC).

Medical complications: Because of lack of facilities, many patients experienced medical complications despite emphasis on the education of patients and carers during the rehabilitation programme. It is the duty of a comprehensive spinal cord injury unit to offer help after discharge in the medical follow-up, prevention

and treatment of complications, as well as in ongoing support and education of the patient and his family.¹³ The risk of developing a sore increased with age, but the duration of the paralysis was equally important. After discharge from hospital the presence of a caring relative or friend was essential for survival. Many patients developed sores due to poor facilities at home or from inappropriate advice from those who looked after them.¹⁴

These reasons convinced the hospital authorities that each patient should be admitted with a carer of his choice (very often a family member or close friend). The latter was trained in the management of spinal injuries and was present during both the acute and the rehabilitation stages of his or her programme. We also emphasised the importance of making patients fully aware of their condition.

Architectural and social barriers: These issues were difficult to tackle. Most patients were living in unsatisfactory conditions, and were either hiding in their homes or could not get out. This is unfortunate because leaving home at least once daily (as opposed to less frequently) is associated with a lower risk of readmission.¹⁵ In Japan 44% of tetraplegic patients were confined to living in their homes compared with 71% in Romania.¹⁶ We were aware that it would be difficult to deal with the issues of housing and social prejudice against the disabled.¹⁷ The occupational therapists devised standard adaptations that could be made by the families, and our team tried to involve other non-government organisations in an attempt to use cheap and simple technology. The members of the spinal injury team organised outings to bring the disabled into contact with the outside world. We recommended that the second phase of rehabilitation should concentrate on finding original solutions to architectural and social barriers and bring these problems to the attention of the public, and decision makers in particular, in addition to organising workshops on spinal cord injuries for community medical and paramedical staff. This will require long term effort. International organisations (WHO, UN, EEC) could help the government and non-governmental organisations (NGOs) by providing funds and expertise to overcome medical, social and architectural barriers. The lessons learnt from the Romanian example could be used in other developing areas.

Vocational issues: Hardly any of the patients returned to work. Work is just as important for the physical, social and psychological well being of people with spinal cord injuries as it is for the able bodied. Those with spinal cord injuries should be offered the opportunity to work, but that rarely happens, even in developed countries. Social reintegration in Romania has not previously been compared with that in other developing countries.

Several questions arise from our findings:

- (1) If the primary goal of rehabilitation is to promote the patient's independent thought and restore a

sense of power through self-directed behaviour, and if he or she should achieve a meaningful life and not just physical survival,¹⁸ is the spinal injury project heading towards meeting these objectives?

- (2) If the long term goal of spinal cord injury rehabilitation is to achieve community reintegration with maximal functional independence and a return to preinjury lifestyle,⁹ have we succeeded?
- (3) Is it useful for an international organisation to initiate a spinal injury project if its involvement does not extend beyond treatment in hospital?

To pool resources and coordinate aid to those with spinal cord injuries, we helped to set up a charity in the hospital, the Romanian Foundation for Spinal Trauma, led by a dynamic orthopaedic spinal surgeon, Dr Florin Exergian.

Conclusion

This survey highlighted the many problems faced by patients. National and international resources need to be pooled to find low cost, lasting solutions. This is a difficult task. One of the authors (AS) recommended that phase II of the spinal injury project (which started in July 1993) should concentrate on community based rehabilitation. We need to increase awareness of the problems of this particularly vulnerable group, who face financial and social difficulties, and architectural barriers. It makes little sense to improve the conditions in hospital during the acute or rehabilitation phases and to ignore the home conditions. Fortunately in Romania the extended family help to support these patients. But at what personal cost, and for how long?

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