

Acute care and primary rehabilitation in ESCIF member countries 2007

Background

One of the opportunities afforded by the creation of ESCIF is the relative ease with which information about member organisations and countries can be gathered, collated and compared.

The exchange of information between member countries is a stated purpose of the Federation. It is assumed that the sharing of knowledge and experience can lead to improvements in the quality of life for people living with spinal cord injuries by creating standards of best practice and by inspiring member organisations to work towards implementing these in their own countries.

Project to investigate acute care and primary rehabilitation

Purpose and aims

This is the first information-gathering project to be initiated by ESCIF. Its purpose was to gather and collate information on the acute care and primary rehabilitation services offered to people with spinal cord injuries in the member countries.

We were already aware that differences exist in the ways in which healthcare and hospital services are funded and organised in the various member countries and we expected these differences to be reflected in the initial treatment of patients with both traumatic and non-traumatic spinal cord injuries. We were, however, interested in identifying more specific differences and in analysing how these impact the perceived quality of care in each country. We wanted to find out more about the issues the organisations were concerned with and what they were working actively to improve. Finally, we wanted to consider the implications of these concerns and efforts for the future policy of ESCIF.

Method: Part one – the questionnaire

The initial investigation took the form of a questionnaire that was sent via email to the contact person in each of the member organisations or countries. As both the questions and responses were in English, the questions were kept as simple and direct as possible in order to make them easy both to understand and answer. Wherever possible the questions asked for factual information, rather than opinions, and/or allowed multiple-choice answers. This not only made the questionnaire easier and less time-consuming to answer, but also facilitated the recording and comparison of responses. In order to give respondents the opportunity to provide more detailed information on core issues, "comment boxes" were included.

Method: Part two – discussion workshop

The second part of the study involved a follow-up discussion at the ESCIF Congress held in April 2007. Prior to the congress a six-page "Preliminary Report" summarising the questionnaire responses was sent to all delegates. In addition, the workshop session was opened by a short presentation outlining the results of the study thus far and suggesting issues and questions for further consideration and discussion.

Delegates were then assigned to discussion groups: all delegates from one country were assigned to the same group in order to ensure that the conclusions reflected some degree of "national"

consensus as opposed to personal opinion. As the aim of the workshop was to encourage the exchange of information and ideas, membership of the groups was designed to ensure ease of communication; for example, each group included two or three fluent English speakers, and those delegates who have some difficulties with English were grouped with others with whom they shared another language – usually German or French. Secondly, attempts were made to link focus areas; organisations working towards the introduction of peer-counselling services were grouped with countries in which such services had been established, and so on.

The groups were then given a sheet of questions or issues to guide the discussion, assigned a group room and told what time they should meet back in plenum. Each group was told to select a person to take notes during the discussion and a “spokesperson” who could report the conclusions of the discussion to all the delegates when they reassembled. These presentations and the ensuing discussion were recorded.

The questionnaire survey

The questionnaire was sent by email to member countries in December 2006 and the deadline for completion was set to mid-February 2007. The covering letter included the following paragraph

Although we have tried to keep the questionnaire fairly simple, there are certain questions that you may find difficult to answer! In order to respond to some of the statistical questions, you may need to ask for assistance from, for example, the personnel at the hospitals or rehabilitation centres in your country. As the services vary greatly from one country to another (and even within the same country), some answers may need further explanation – you have the opportunity to write further comments to most of the answers.

The response rate was good: questionnaires were sent to 18 countries. Completed questionnaires were received from Austria, Belgium, Croatia, Denmark, Finland, Germany, Ireland, Italy Netherlands, Portugal, Scotland, Slovenia, Spain, Sweden, Switzerland and UK. Two countries did not return the questionnaire.

The questionnaire was divided into three sections; general information, acute care and primary rehabilitation. In order to clarify concepts, section three of the questionnaire was introduced by the following text:

This section of the questionnaire concerns primary rehabilitation: in this context “primary rehabilitation” means the first period of (re)training that the recently injured SCI patient undergoes in order to cope with the challenges of living with a spinal cord injury. Primary rehabilitation will address such issues as activities of daily living, bladder and bowel management, selection and use of mobility aids, transfers and wheelchair skills, as well as physical training to gain and improve balance, mobility, strength and so on.

Certain questions or sections of the questionnaire did, indeed, prove difficult or impossible for some countries to answer and, thus, a few of the “completed” questionnaires were not complete. Where possible, these omissions were rectified by direct contact with the respondents.

Section one: General information

As anticipated, this was the section that caused the biggest problems. Even in countries where a national and/or regional register of spinal cord injuries exists (Croatia, Ireland, Germany, Scotland,

Slovenia, Spain, Sweden have a national register; Ireland, Germany and Spain have both national and regional registers) most respondents submitted "estimates" of the figures requested. Ireland, Germany and Scotland were the only countries that were able to provide exact figures for a specific year – 2006, 2006 and 2004 respectively – and Scotland was able to provide a breakdown according to the causes of injury. Austria was the only country that did not feel equipped to answer any of the questions in this section, although several other respondents omitted to answer some of the questions – particularly those requesting percentages of paraplegics/quadriplegics and complete/incomplete lesions among the new cases of spinal cord injury each year. See **Table 1: Prevalence, incidence and breakdown of SCI cases reported** on page 4.

The figures given in response to the questions in section one are, even in countries where registers exist, problematic in terms of making direct comparisons between countries. Definitions and reporting practices may differ from country to country. Are, for example, fatalities included in the figures, or only those who survive a spinal cord injury? In the present study, differences in reporting methods were demonstrated by the responses to question 3c, which asked about the incidence of congenital spinal cord injury. Sweden and Switzerland both pointed out that since babies with spina bifida are not treated at SCI units, they do not feature in the annual incidence figures. When asked for breakdowns of the totals into "complete" or "incomplete" lesions, the respondent from Denmark (the chief physician of the Clinic for Spinal Cord Injuries, Copenhagen University Hospital) commented wisely "it depends on the definition!". The responses relating to the incidence of spina bifida and to the breakdown into complete/incomplete lesions were so few that these are omitted from Table 1.

So, as expected, the conclusion must be that the figures provided should be treated with extreme caution!¹

¹ A follow-up to the present study has now been instigated by Jane Horsewell (ESCIF) and Dr Jan Reinhardt (Swiss Paraplegic Research). This includes attempts to gather and collate any official statistics and information available in member countries as a basis for comparison with the information yielded by the questionnaire. The results will be submitted for publication.

Table 1: Prevalence, incidence and breakdown of SCI cases reported

Country	Register		Total no. SCI	Incidence Cases per year	Traumatic/ Non-traum		Breakdown as %age of annual		male	fem
	Nat	Reg			tr	n-tr	quad	para		
Austria	no	no	?	?	?	?	?	?	?	?
Belgium	?	?	7000	150	?	?	?	?	?	?
Croatia	yes	no	3000 ²	100	50	50	50	50	70	30
Denmark	no	no	2500	145	55	90	45	55	60	40
Finland	no	no	3000	140	100	40	50	50	75	25
Germany	yes ³	yes	48000	1800	1200	600	35	65	70	30
Ireland	yes ⁴	yes	1200	50	45	5	?	?	60	40
Italy	no	no	70000	1450	967	483	50	50	75	25
Netherlands	no	no	16000	350	?	?	?	?	?	?
Portugal	?	?	?	363	300	63	?	?	?	?
Scotland	yes	no	3000	201 ⁵	169	21	56	44	63	37
Slovenia	yes	no	1008	50	50	?	30	70	70	30
Spain	yes	yes	35000	1200	840	360	51	49	80	20
Sweden	yes	no	5000	150	100	50	60	40	80	20
Switzerland	no	no	4000	310	186	124	45	55	70	30
Eng & Wales	no	no	40000	1000	750	250	34	66	71	29

² The official figure for 2006 is 3,736 but this includes cases of hemiplegia and cerebral palsy

³ Official figures for 2006

⁴ Official figures for 2006

⁵ The prevalence figure is an estimate, other figures are official figures for 2004

Section two: Acute care

In this section respondents were asked about hospital admission following a spinal cord injury. The possible answers afforded by this multiple choice question were

- A specialised hospital for spinal cord injuries
- A specialised SCI unit/ward in a general hospital
- A neurosurgical ward in a general hospital
- A trauma ward in a general hospital
- A non-specialised ward
- Other (please specify)

According to the responses, six countries in the sample have a specialised hospital or hospitals for the acute care of SCI patients; Croatia, Scotland, Ireland and Switzerland all report one hospital, Spain has two, Slovenia has three while UK has a total of eleven.

Units or wards specialising in the acute care of SCI patients located in general hospitals seem to be a more common and widespread “destination” for the newly-injured patient: Denmark has two specialised wards, Slovenia and Switzerland have three, Belgium has four, Croatia has five, Sweden has six, Italy has ten, Spain has eleven and Germany has a total of twenty-four which together are responsible for the acute care of 80% of SCI patients. Portugal indicates that all acute care is provided by specialised wards, but does not say how many wards actually exist in the country.

There are indications that there is an overlap in certain countries between the “categories” included in questions 5 and 6. In Denmark, for instance, the acute care “wards” are, in fact, sections of the neurosurgical wards of two of the country’s leading university hospitals; since the acute treatment of traumatic spinal cord injuries is officially restricted to these two sections, they were categorised as “SCI units/wards”. In some of the initial responses from other member countries there were some inconsistencies which, perhaps, could be explained by problems involved in deciding between the categories. Further difficulties of categorisation may, of course, arise from the fact that patients with non-traumatic spinal cord lesions may already be undergoing hospital treatment – on orthopaedic or oncology wards for example.

Austria and Finland were the only two countries in which the acute care of SCI patients takes place in either neurosurgical wards or in trauma wards; the Netherlands was the only country to report that all acute care is provided by trauma wards. Spain and Switzerland were the only countries in the sample to “tick” all the boxes – ranging from specialised hospitals to non-specialised wards. Slovenia was the only respondent to use the “other” option; in addition to specialised hospitals and trauma wards, Slovenia mentioned the centre run by the Association of Paraplegics of Slovenia. See **Table 2: Destinations of new SCI patients** on page 6.

Table 2: Acute care – destinations of new SCI patients with percentages where given

Country	Specialised hospital	SCI unit or ward	Neurosurg ward	Trauma ward	Non – spec ward
Austria			√	√	
Belgium		60		20	20
Croatia	√		√	√	
Denmark		√	√		
Finland			50	50	
Germany		80	5	15	
Ireland	100				
Italy		50	25	25	
Netherlands				√	
Portugal		√			
Scotland	√		√	√	
Slovenia	√	√		√	
Spain	40	15	10	10	25
Sweden		√		√	
Switzerland	50	25	25	√	√
Eng & Wales	√	√	√	√	

Funding:

In those countries where specialised hospitals are found, the source of funding varies from country to country. Only Croatia, Ireland, Slovenia and Scotland answered that the hospitals were funded exclusively by the state. Croatia commented that the monthly budget provided by the Institute for Health Insurance was inadequate to meet the hospital's needs. In addition to state-funding, UK mentioned the existence of some private hospitals that provide *rehabilitation* for SCI patients.

Spain and Switzerland both mentioned regional funding, but while Spain referred to private insurance contributions as the other source, Switzerland mentioned private foundations or trusts.

Severe respiratory problems:

In response to the question concerning the existence of special wards or units for SCI patients with severe respiratory problems (i.e. those with high lesions) Austria, Denmark, Germany, Ireland, Italy, Netherlands, Scotland, Spain, Sweden, Switzerland and UK all reported that such facilities exist in their countries.

Psychological counselling:

The provision of psychological counselling services appears to vary greatly from country to country, although there is a general trend that such services are more commonly offered to the patients themselves than to their close family members. The only countries that answered that counselling was always available both to patients and their relatives were Croatia, Netherlands, Scotland, Spain and Switzerland, whereas in Austria, Denmark and England and Wales counselling is always available to the patients themselves. Ireland, Italy, Portugal and Sweden answered that counselling is sometimes available to patients but whereas in Italy counselling is sometimes offered to relatives, Sweden reported that it was seldom offered, and Ireland and Portugal answered that counselling was not available to patients' families.

Contact between organisations and patients/families during the acute phase:

The extent to which the organisations are in contact with the patients and their families during the early, acute stage of treatment also varies enormously in the different countries. Denmark appears to be the most reticent in terms of making early contact – although a folder is currently under preparation, at present no information about the organisation is displayed on the SCI wards and visits are only made in response to a request from the patients themselves. Both Croatia and Netherlands seem to share this more reserved approach, although Croatia will visit both patients and their families if asked to do so by the personnel at the hospital and the Netherlands offers a telephone hotline to newly-injured patients as well as a database of people willing to give support and advice to their relatives. Austria, Belgium, Finland, Ireland, Portugal and Slovenia all have information about the organisation on display on the wards, and both Ireland and Slovenia have produced a special publication for newly-injured SCI patients. Italy and Sweden rely on visits rather than on printed material, whereas Ireland uses a combined approach that includes a hotline for patients and a database of people willing to offer support to families. At the hospital in Gent, the Belgian organisation arranges "cafés" to bring newly-injured patients and their families into contact with those more "experienced" in living with SCI. The most proactive organisations are those in Germany, Scotland, Spain and England and Wales; these organisations report that they employ all the means listed in the questions to make contact – both with the patients and their families. In England and Wales, for example, the organisation has established a Peer Support team at each of the SCI centres comprising a Peer Support officer and team of trained volunteers; relatives are currently being added to these teams.

Organisations' efforts to influence acute care:

The final question in the section on acute care concerned the efforts made by the organisations within the past 5 years to influence various factors related to the care and treatment of newly-injured SCI patients. The most "popular" effort (only the Netherlands, Portugal and Sweden did not mark this) has been the attempt to create closer contact between the organisation and the patients. Similarly, most organisations (although not necessarily the same organisations) have worked to improve contact between the organisation and the personnel involved in acute care.

Among those countries without a national or regional register of people with spinal cord injuries, Finland, Netherlands, Portugal and UK list this as one of the organisation's goals; Croatia, Germany, Spain and Sweden have apparently succeeded in achieving the establishment of a register in this period.

The centralisation of acute care is a focus area in Croatia, Denmark, Finland, and Sweden whereas an increase in the number of specialised units is a goal in Germany, Italy, Portugal, Spain and UK. The answers provided by Italy, Spain and the UK do, however, stress the need for centralisation and specialisation in the care of acute SCI patients; the need for more units is obviously related to the geographical size and population size of these countries. Finally, several countries, including Croatia, Italy, Scotland, Slovenia and Switzerland reported that the organisation has worked actively within the past five years to introduce facilities that were otherwise not provided by the hospitals treating patients with SCI during the acute phase.

Section three: Primary rehabilitation

The questions in this section focused upon where primary rehabilitation takes place, the therapies, services and facilities offered, and the role of the organisations during this phase.

Location:

Once again, respondents were offered multiple choice responses to the question of where rehabilitation takes place:

- Specialised hospital for spinal cord injuries (that also treats acute SCI patients)
- Specialised SCI unit/ward in a general hospital (that also treats acute SCI patients)
- Specialised rehabilitation centre/unit for spinal cord injuries
- Rehabilitation centre/unit that also offers services for other diagnoses
- Other (please specify)

The typical locations for the rehabilitation of patients with SCI, together with percentages of patients admitted to the hospitals or centres in the different categories, can be seen in **Table 3: Primary rehabilitation of SCI patients with percentages and number of beds available** on page 9. Please note that respondents were asked only for the number of beds available in specialised hospitals for spinal cord injuries and in specialised rehabilitation centres or units.

Table 3: Primary rehabilitation of SCI patients with percentages and number of beds available where given

Country	Specialised SCI hospital (1)	SCI unit or ward in gen hosp	SCI rehab centre (2)	Generalist rehab unit	Beds avail in 1 or 2
Austria			85%	15%	180
Belgium		60%		40%	126
Croatia			90%	10%	35*
Denmark			90%	10%	67
Finland			60%	40%	43
Germany	√	√	√	√	?
Ireland	100%				50
Italy		50%	25%	25%	500
Netherlands			√	√	?
Portugal	√		√	√	?
Scotland	√			√	48
Slovenia			99%	1%	70
Spain	√	√	√	√	650
Sweden		√	√	√	?
Switzerland	60%	35%	5%		235
Eng & Wales	75%	√	√	√	400

*This is the number approved by the Croatian Institute for Health Insurance. In fact, 50 beds are available.

SCI patients in **Austria** are either offered primary rehabilitation at specialised SCI centres (85% of total), where 180 beds are available, or at centres offering rehabilitation to other patient groups. Rehabilitation times vary widely: 5 to 12 months for quadriplegics; 3 to 8 months for paraplegics. The average period is an average of 9 months and 6 months respectively.

Belgium is able to offer 126 beds in specialised units – either in general hospitals or at dedicated rehabilitation centres – for the rehabilitation of patients with SCI. The usual rehabilitation time for quadriplegics is 10 months (including surgical procedures such as transplantation of muscles) but is only 3 months for paraplegics.

Croatia reports that 90% of SCI patients undergo rehabilitation at a specialised centre – but adds that the facilities/services offered are inadequate. A few (incomplete, walking SCI) choose generalist rehabilitation centres near to where they live. The period of rehabilitation depends, as expected, on the level and extent of the injury: for quadriplegics the usual time is 6 months (but as much as 10 months for high lesions) and for paraplegics the average is 3 to 4 months.

In **Denmark**, an estimated 90% undergo inpatient rehabilitation at one of the two specialised rehabilitation centres where approximately 67 beds are available. Experience indicates that there are some non-traumatic SCI patients who are not referred to primary rehabilitation at one of the specialist centres. Usual rehabilitation time for a quadriplegic is 9-10 months and 5-6 months for a paraplegic.

Finland has 43 beds available for SCI patients at a specialised unit, comprising approximately 60% of the total, while the others receive rehabilitation at generalist centres. Reported usual times for rehabilitation in Finland are generally shorter than in most other countries: 4 months for a quadriplegic and 3 months for a paraplegic.

Germany offers rehabilitation at all named categories as inpatients but it is not possible to ascertain the number of beds dedicated to patients with a spinal cord injury. Again, rehabilitation times vary – between 6 and 9 months for quadriplegics and 4 to 6 months for paraplegics.

In **Ireland**, all SCI patients undergo rehabilitation, either as inpatients or as outpatients, at the National Rehabilitation Hospital. Typically, rehabilitation time for a quadriplegic is 9 months while paraplegics will spend approximately 6 months at the rehabilitation hospital.

Most SCI patients in **Italy** receive rehabilitation in specialised units within general hospitals or at specialised rehabilitation centres – there are approximately 500 beds available at specialised centres. However, an estimated 25% of SCI patients are offered rehabilitation in non-specialised centres. The organisation, FAIP, is aiming to double the number of beds available in SCI rehabilitation units. According to official protocol, the standard rehabilitation period for a quadriplegic should be 6 months and for a paraplegic 4 months. FAIP expresses concern that these standards will be reduced.

In the **Netherlands**, rehabilitation is available either at specialised SCI centres/units or at generalist rehabilitation centres. A quadriplegic usually spends 9 months as an inpatient whereas a paraplegic spends approximately 6 months.

Portugal offers specialised rehabilitation for SCI patients, both as inpatients and outpatients, but no information is available regarding the number of beds available or average rehabilitation times.

Scotland has 48 beds available for SCI patients at specialised hospitals. The usual primary rehabilitation time for a quadriplegic is 6 months and for a paraplegic 4 months.

In **Slovenia**, 99% of SCI patients undergo primary rehabilitation in a specialised rehabilitation centre either as inpatients or outpatients. Rehabilitation times vary from 6 – 12 months for quadriplegics and approximately 6 months for paraplegics.

Primary rehabilitation in **Spain** is apparently spread throughout all named types of institution but 650 beds are available in specialised SCI hospitals or rehabilitation centres/units. Rehabilitation is offered as a combination of inpatient and outpatient care. The usual rehabilitation times are 8 months for a quadriplegic and 6 months for a paraplegic.

SCI patients in **Sweden** receive rehabilitation in SCI wards in general hospitals, specialised SCI rehabilitation centres or at generalist rehabilitation centres as a combination of inpatient and outpatient services. Again, rehabilitation times vary: 4-8 months for quadriplegics and 3-6 months for paraplegics.

In **Switzerland**, 60% receive rehabilitation as inpatients at a specialised hospital, 35% at a specialised unit of a general hospital and 5 % at a specialised centre for SCI patients. Estimated rehabilitation time for a quadriplegic is 7-10 months and 4 months for a paraplegic.

In **England and Wales**, an estimated 75% of SCI patients undergo rehabilitation as inpatients at specialist hospitals which have 400 beds available; the usual rehabilitation time is 6 months for a quadriplegic and 3 months for a paraplegic – although this varies according to the individual and to the centre.

Individual therapy, sports activities and access to individual training facilities:

Considering the average rehabilitation times reported in the previous section, it is interesting to consider how rehabilitation is organised in the member countries.

The table on the following page **Table 4: Individual therapy, sports activities and individual training facilities** summarises the answers to the questions on the average number of hours of individual physiotherapy and occupational therapy received by the patient undergoing primary rehabilitation. In addition to the hours listed, Austria commented that patients receive 10 – 15 hours of group therapy and Denmark added a further 5 hours of group training; this information was not directly asked for, but one could expect that a similar situation is found in other countries.

Table 4 also lists the responses to the question of whether patients are encouraged to participate in sports during primary rehabilitation. Generally speaking, the answer to this was affirmative; the majority answered “always”. There was, however, a wide variation in the range of wheelchair sports available in the different countries. The sports and activities offered do not seem necessarily to demonstrate the “standard” of the facilities of the rehabilitation centres but may reflect the kinds of sporting activities that are generally available or popular in the different countries. As might be expected, sailing and water sports are restricted to those countries where there is easy access to the sea or lakes, whereas skiing and other winter sports to areas where there is snow and mountains! Most countries seem to offer the traditional wheelchair sports; basketball, rugby, table-tennis, boccia (boules), archery, and swimming. As these sports are relatively low-cost sports in terms of the equipment and facilities needed, it is hardly surprising that they are the most popular and widely-available.

The table also shows whether or not patients have access to individual training facilities: in the “Yes” column, √ means “always”, 75/25 means “often” and 50/50 means “sometimes”.

Table 4: Individual therapy, sports activities and access to individual training facilities

Country	One-on-one physiotherapy (average hours per week)		One-on-one occupational therapy (average hours per week)		Sports	Individual exercise	
	Quad	Para	Quad	Para		Yes	No
Austria	5	3	5	2	√	√	
Belgium	15	10	15	10	√	√	
Croatia	5	5	5	5	75/25	√	
Denmark	5	3	5	1-2	√	50/50	
Finland	7	5	3	0	√	75/25	
Germany	5	5	2	2	75/25	75/25	
Ireland	10	10	10	10	√	50/50	
Italy	12	8	10	6	75/25	√	
Netherlands	5	4	6	3	√	50/50	
Portugal	?	?	?	?	50/50		√
Scotland	3	3	2	2	75/25	√	
Slovenia	30	20	?	?	√	√	
Spain	14	20	20	14	√	√	
Sweden	5	5	4	4	75/25	75/25	
Switzerland	7	5	5	2	√	√	
UK	?	?	?	?	√	√	

Therapies

One area in which there appears to be very large differences between the rehabilitation offered to SCI patients in the member countries is that of the range of therapies available in addition to physiotherapy and occupational therapy. To some extent this is influenced by the respondents' interpretation of what constitutes therapy. Some countries, for example, listed "leisure activities", computer training and even driving lessons; others included various kinds of training in wheelchair skills and gait training; while others wrote psychological therapy, art therapy, music therapy and creative therapy. Many reported that the rehabilitation centres in their country offered balneotherapy, FES, speech therapy, various forms of massage and specific types of therapy such as volta-therapy.

Teaching and advisory services

Turning to more general "educational" and advisory services, nearly all countries answered that courses are offered to patients and their families concerning the physical, social, psychological and sexual consequences of a spinal cord injury. Only Croatia and Portugal reported that no courses were offered and Slovenia answered that courses were available to the patients only. Similarly, advice regarding mobility aids, personal aids, adapted cars or vans, pensions and other financial entitlements appears to be available in all countries – but advice on accommodation and the adaptation of current housing, (re)education or other vocational issues was not.

Facilities for patients and their families

The facilities available to patients vary widely. Finland was the only country to report that private bedrooms, private bathrooms, television and telephone in the room, a television lounge, a computer room with internet access, a library and a games room were always available to patients during primary rehabilitation. Furthermore, Finland can offer a café/ restaurant and visitors' lounge to family members; overnight facilities for family members are only sometimes available whereas overnight facilities for patients and their partners are always available. Slovenia and Switzerland offer a café/restaurant, visitors' lounge and overnight facilities for family members and patients and partners; neither country, however, always offers private bedrooms and bathrooms to the patients themselves. Ireland responds that private bedrooms, private bathrooms and rooms with television and telephone are not available – and adds that patients are still in wards with up to 10 beds. The other shared facilities, for example, TV lounge, computer room and games room are always on offer to patients. Ireland offers no overnight accommodation to family members or to patients and their partners. Portugal reports a rather gloomy picture of patient facilities; apart from library access, none of the other facilities are offered to patients and, although a café/ restaurant and visitors' lounge are usual, no overnight accommodation exists. The other countries fall somewhere between the two extremes of Finland and Portugal in terms of facilities. Interestingly, though, despite the rather long periods that patients spend undergoing rehabilitation, few countries offer them the privacy of a private bedroom and bathroom.

Peer counselling

Most rehabilitation centres in the ESCIF member countries draw on some form of peer counselling or peer support. In many countries this is entirely dependent upon the voluntary services of the organisations and, in a few countries, on peer counsellors employed by the organisations. In Austria, Finland, Germany, Sweden, Switzerland and Spain peer counsellors are employed by the rehabilitation centres themselves but, even here, the counsellors seem to draw quite heavily on assistance from volunteers from the organisations.

Relationships between the organisations and the rehabilitation centres

Contact between the organisations and the rehabilitation centres seems to be much closer than that between the organisations and the hospitals or units providing acute care. Many organisations report regular contact with the personnel at the centres and some report that members of staff are also active in the organisation. The actual degree of involvement of the organisations in the activities of the rehabilitation units varies widely: a few appear to be very active in arranging courses, evening activities or other events for the patients and their families; rather more participate when such activities and events are arranged by the centres or units.

Organisations' efforts to influence primary rehabilitation

The final questions concerned the efforts of the organisations to influence and improve the rehabilitation services offered to SCI patients. Each organisation was asked whether it had formulated a vision for future rehabilitation in its country. Some countries, for example **Belgium**, stated that their earlier goals had now been incorporated into the rehabilitation system. At the other end of the spectrum, **Croatia** felt that the organisation's attempts to collaborate with the country's main rehabilitation centre had been perceived as interference rather than assistance or support. The organisation's vision is, therefore, to establish a new spinal cord injuries centre that fulfils its vision. In **Denmark**, the organisation has a good relationship with the management and personnel at the country's two rehabilitation centres for spinal cord injuries but government cutbacks on hospital spending have created problems particularly in terms of patient-staff ratios. The management has been rather successful in coping with these cutbacks and in maintaining the level of service provided, but this has demanded changes and reorganisations that have not always been popular with the staff and patients. The organisation's immediate goal is to persuade the authorities to employ peer counsellors at both centres and its long-term vision is to create two geographically and administratively centralised spinal cord injuries centres, in order to gather and cement expertise in SCI treatment, rehabilitation, life-long care and research. **Finland** has achieved a major goal through the establishment of its super modern rehabilitation facility in Helsinki; even so, the organisation's vision is to centralise the acute care of SCI patients, to ensure lifelong follow-up and to establish a central SCI register. **Italy** has been lobbying for the establishment of spinal cord injury units in the southern part of the country and has been working with medical and clinical personnel nationwide to set common protocols for the running of spinal cord injury units. In addition, it is trying to persuade the government to hold an "awareness day". Research into various aspects of spinal cord injury is a further Italian priority. **Portugal** is collaborating with parliamentary groups to introduce legislation regarding independent living in the community. **Scotland** is currently working to increase the time spent by the organisation's employees and volunteers at the rehabilitation units. In **Slovenia**, the organisation's focus is upon social programmes in order to create networks and on providing information about life in a wheelchair. As in Croatia and Denmark, the organisation in **Spain** is trying to improve both the physical and organisational conditions for rehabilitation, but its long-term vision concerns the promotion of basic and clinical research into issues related to spinal cord injuries. **Sweden** has invested a great deal of time and effort in publishing information material; the organisation's vision is clearly presented in a policy programme. In **England and Wales** the organisation has formulated a charter defining the demands to a SCI centre in order to ensure that such centres are "centres of excellence" in treatment, care, rehabilitation and research, and, consequently, its vision is to develop the care and support at the rehabilitation centres so that they conform to these standards.

Discussion workshop

The countries represented at the ESCIF Congress in April 2007 were not exactly the same as those who responded to the questionnaire (these were the member organisations who attended the assembly founding the Federation in March 2006); Portugal and Sweden were unable to attend in 2007 but France and Albania were additional participants. The representative from Denmark was not actively involved in the workshop discussions and group presentations.

The brief presentation that acted as an introduction to the workshop session posed six questions for discussion:

- Why is it difficult to access the figures on the prevalence and incidence of SCI?
- Is a national register useful? How can it be used?
- What can organisations offer the newly-injured patient?
- Is it better to have peer counsellors employed by the rehabilitation centre or by the organisation?
- What are the advantages of dedicated spinal cord injury centres for acute care and rehabilitation?
- Should ESCIF formulate a policy defining its demands to SCI care and rehabilitation?

The participating organisations/countries were divided into four groups (following the considerations explained earlier):

- Group 1: Switzerland, France, Albania, England and Wales
- Group 2: Scotland, Spain, Germany, Belgium
- Group 3: Netherlands, Slovenia, Austria
- Group 4: Ireland, Italy, Croatia, Finland

The groups had approximately 1½ hours to discuss the issues – but were told that they should allocate their time so that they spent most time on the questions they found most interesting and relevant. When the delegates reassembled, the spokesman appointed by each group presented its conclusions: Bart Hellyer from England was the spokesman for group 1, Dougy Johnstone from Scotland represented group 2, Winnifred Bokma from the Netherlands presented the conclusions from group 3 and Colm Whooley from Ireland summarised the discussion in group 4.

Why is it difficult to access the figures on the prevalence and incidence of SCI?

Group 1 reported that although figures exist in both Switzerland and England and Wales, they are somewhat compartmentalised; in Switzerland each Canton keeps a register whereas in England and Wales each spinal centre has its own records. Confidentiality rules make access to the figures difficult. In France too, the rehabilitation centres keep their own statistical information but the information is not collated nationally. As Albania lacks centres for the rehabilitation of spinal cord injuries, no official figures exist. Group 2 – which included two very large countries and two rather small countries – cited the size of the country as a potential problem. Although both Germany and Spain have registers, not all the information available is really useful to the organisations as much of it is targeted to the needs of, for instance, insurance companies. Group 3 reported that the incidence of SCI in the three countries has only been recorded for a short time (in Holland, for example, for the past four years). This means that no trends can be discerned at this stage and that prevalence remains an estimate. The four countries in Group 4 each reported different problems: in Croatia, problems of definition have caused some confusion in the official statistics;

in Italy, the geography of the country and regional differences have made the centralised collection of information difficult; in Finland, the information exists but is not accessible; in Ireland, the statistics are kept by the National Rehabilitation Hospital.

Is a national register useful? How can it be used?

All four groups felt that it would be extremely useful to have a national and/or regional register – and for the organisations to have access to it. In terms of how it could be used the groups cited financial planning as a main consideration – and from the organisations' point of view, the possibility of using the information for negotiation purposes relating to funding (in some countries the organisations receive some kind of government funding to support activities). But it was also argued that statistical breakdowns could be used in accident prevention campaigns, for research purposes and in the formulation of future governmental and organisational policy. Furthermore, it was pointed out that it would be useful for national registers to be harmonised, in terms of reporting practices, so that figures relating to the prevalence and incidence of spinal cord injuries would be comparable throughout Europe.

What can organisations offer the newly-injured patient?

As might be expected, all groups emphasised the importance of information. Group 1 stressed that newly-injured patients need a lot of information in order to cope with their new situation - and they need it fast. The information required can include legal advice, insurance issues, information about benefits, entitlements and pensions, housing and accommodation. In the presentation from Group 3, the delegates from the Netherlands said that this was the purpose of their telephone "hotline" which is used by both patients and their families to request information. In fact, all groups mentioned support for the families of the patients as a very important task for the organisations. Generally, it was felt that hospital personnel – often due to time and work pressure but also because they do not define this as part of their responsibility- were reluctant or unable to assist and support family members through the shock and worry that typically follow the diagnosis of a spinal cord lesion. Peer-counselling was another service mentioned by all groups: there was general consensus that newly-injured SCI patients can learn a great deal from meeting with those living with a spinal cord injury and that this includes everything from "tips" that can be used in everyday activities, through the more sensitive issues of sexuality and identity, to the overall problem of "coming to terms" with what has happened and how to move on.

Is it better to have peer counsellors employed by the rehabilitation centre or by the organisation?

There were mixed opinions both within and between the groups regarding this question! In those countries where peer-counsellors are employed by the organisations (for example, Switzerland, England and Wales, Italy and Croatia) delegates stressed that it is important that peer-counsellors are independent of the management and personnel of the rehabilitation centres. Group 3 expressed the same opinion – even though none of the countries in the group offer peer-counselling services. Group 2 emphasised that even where peer-counsellors are employed by the organisation then a close cooperation with the staff of the centre is essential. Group 4 reported that in Finland the peer-counsellors employed by the rehabilitation centre function as links to the organisations and coordinate the efforts of volunteers from the organisation with respect to activities at the centre. This is, in fact, the model that is currently being developed in Denmark, and Ireland also found this model "persuasive".

What are the advantages of dedicated spinal cord injury centres for acute care and rehabilitation?

All groups agreed that the primary advantage to be gained from centralising knowledge and expertise is quality assurance; personnel with an in-depth knowledge of spinal cord injury and its consequences, necessary support from other medical specialisations and opportunities for

research. As Group 1 expressed it – dedicated centres of excellence for both treatment and research. Group 2 pointed out the benefits in terms of cost effectiveness and planning, and Group 3 stressed the advantages for the patients of having social contact with others facing the same problems. Group 4, however, raised the problem of geography; in Finland, Ireland and Croatia there is only one specialised centre for spinal cord injuries and this can lead to problems of isolation (because families are unable to visit regularly) and the decision on the part of the patient to move to a generalist rehabilitation centre nearer to home.

Should ESCIF formulate a policy defining its demands to SCI care and rehabilitation?

The unanimous response to this final question was a resounding “yes”! In the plenary discussion that followed the presentations of the groups’ conclusions, it was agreed that the Executive of ESCIF should initiate the formulation of a common policy that would then be made available to the member organisations for their comments, objections and additions. As a starting point, it was agreed that the policy statement should include basic demands to the acute care, rehabilitation and lifelong follow-up of people with spinal cord injuries; it was acknowledged that it was important to strike a balance between the different systems and conditions in different countries and well-defined demands, as over-generalised criteria would not be applicable. The aim, therefore, is to attempt to establish certain standards of best practice on which the organisations can agree.

It was generally agreed that the workshop discussions and conclusions had provided a skeleton for a future ESCIF policy in so much as they had identified certain core issues and points of focus. These include the centralisation of spinal cord injury treatment, rehabilitation, long-term care and research into centres of excellence; the importance of peer-counselling for recently injured patients with a spinal cord injury; the need for family support services and the desirability of registers in each country that provide access to up-to-date and comparable statistical information.

Conclusion

As is the case with most research projects, it is quite apparent that the present study could be concluded by stating “more research is needed”! There are, without doubt, certain omissions and ambiguities still to be rectified or clarified. It is, however, important to consider what the study has achieved in relation to its stated objectives.

It must be remembered that the study was designed as an information-gathering project among the ESCIF member organisations representing people with spinal cord injuries. As such, one of its goals was to familiarise the organisations with the conditions prevailing in other countries in Europe; in doing so the study has been instrumental in the exchange of information and ideas – one of the express purposes of the Federation. Differences between the systems were identified and discussed but, perhaps more importantly from the Federation’s point of view, shared concerns and interests were also revealed. The study has provided the ESCIF member organisations with a common platform from which to proceed: the decision to formulate a common ESCIF policy on the issues that have emerged from the study is a milestone in the development of the Federation.

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