

## Original Article

# Rehabilitation of spinal cord injury in France: a nationwide multicentre study of incidence and regional disparities

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**Study design:** Multicentre retrospective 1-year survey during 2000.

**Objectives:** To describe the network of physical medicine and rehabilitation units in France that care for people with traumatic spinal cord injuries (SCI), and secondly, to evaluate the incidence of SCI persons who have postinjury rehabilitation care.

**Setting:** Every rehabilitation unit involved in rehabilitation of SCI patients in metropolitan France.

**Methods:** During the first phase of the survey, a questionnaire was used to list the rehabilitation units that treat SCI people among a total of 380 centres. An additional survey was then carried out on a sample of 30 units that did not answer this questionnaire. In the second phase, the units involved were asked about the number of SCI patients received for a first rehabilitation stay during the year 2000 and their demographic and clinical characteristics. The incidence was calculated on the basis of the population census in metropolitan France aged 15 years, above.

**Results:** Of the 275 respondent units, 148 declared that they treat SCI people on a regular or occasional basis. The survey on the sample of 30 randomly selected nonrespondents enabled us to estimate that 10% of the 105 nonrespondent units were concerned. Among the 148 units contributing to the study, 131 identified all the SCI patients received during the year 2000. After a series of adjustments, an extrapolation for all of metropolitan France leads to an annual incidence of 19.4 SCI persons per million inhabitants, or 934 new cases per year.

**Conclusion:** This is the first nationwide survey aiming to estimate the incidence of SCI patients in France. The finding is based on the incidence of SCI persons treated in rehabilitation units. It therefore concerns the incidence of patients who will remain severely disabled.

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## Introduction

This survey focuses on two issues: the incidence of persons with traumatic spinal cord injury (SCI) and the knowledge of rehabilitation networks in France. There is no accurate estimation of the incidence of

SCI patients in France. The only French survey on the subject was undertaken in 1975 and concerned only the Rhône-Alpes region. Using retrospective methodology, the survey estimate of the annual SCI incidence rate was 12.6 per million inhabitants.<sup>1</sup>

Several studies have been carried out worldwide over the past three decades in Northern America, Europe and Asia. Estimations of SCI incidence vary widely, from 8 to 58 SCI persons per million inhabitants per annum (Table 1). Three types of parameters can account for such wide differences:

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**Table 1** Studies on the incidence of SCI classified by the chronological order of date of publication

	<i>Observation period</i>	<i>Country</i>	<i>Incidence per million inhabitants</i>	<i>Methodology: population studied and mode of inclusion</i>
Kraus <i>et al</i> (1975) <sup>6</sup>	1970–1971	USA (California)	53.4	R, prehospital
			32.2	R, postinjury acute care
Minaire <i>et al</i> (1978) <sup>1</sup>	1970–1975	France (Rhône-Alpes)	12.7	R, postinjury acute care, 1 unit
Gjone <i>et al</i> (1978) <sup>10</sup>	1974–1975	Norway	16.5	R, postinjury acute care, multicentre
Fine <i>et al</i> (1979) <sup>11</sup>	1973–1979	USA (Alabama)	29.4	R, postinjury acute care, 1 unit
Bracken <i>et al</i> (1981) <sup>7</sup>	1970–1979	USA (all states)	40.1	P, prehospital, postinjury acute care and PMR, coding, multicentre
Griffin <i>et al</i> (1985) <sup>8</sup>	1935–1981	USA (Minnesota)	54.8	R, prehospital, 1 unit
			38	Postinjury acute care only
Chen and Lien (1985) <sup>12</sup>	1978–1981	Taiwan	14.6	R, postinjury acute care
Gehrig and Michaelis (1986) <sup>13</sup>	1960–1967	Switzerland	13.4	R, postinjury acute care, multicentre
Biering-Sorensen <i>et al</i> (1990) <sup>24</sup>	1975–1984	Denmark	9.2	R, PMR, multicentre
Garcia <i>et al</i> (1991) <sup>25</sup>	1984–1985	Spain	8	R, PMR, multicentre
Acton <i>et al</i> (1993) <sup>14</sup>	1980–1989	USA (Arkansas)	28.5	R, postinjury acute care, multicentre
Price <i>et al</i> (1994) <sup>15</sup>	1988–1990	USA (Oklahoma)	40	R, postinjury acute care and PMR, multicentre
Thurman <i>et al</i> (1994) <sup>16</sup>	1989–1991	USA (Utah)	43	R, postinjury acute care and PMR, multicentre
Knutsdottir (1993) <sup>17</sup>	1973–1982	Iceland	24	P, postinjury acute care and PMR
	1983–1989		18	P, postinjury acute care and PMR
Lan <i>et al</i> (1993) <sup>18</sup>	1986–1990	Taiwan (rural areas)	56	R, postinjury acute care, multicentre
Shingu <i>et al</i> (1994) <sup>4</sup>	1990	Japan	39.4	R, postinjury acute care and PMR, multicentre
			50.5	Inclusion of forms of ASIA E
Soopramanien (1994) <sup>5</sup>	1992–1993	Romania	18.5	R, postinjury acute care, 1 unit
			28.5	Inclusion of forms of ASIA E
Karamehmetoglu <i>et al</i> (1995) <sup>19</sup>	1992	Turkey (Istanbul)	21	R, postinjury acute care and PMR, multicentre
Karamehmetoglu <i>et al</i> (1997) <sup>20</sup>	1994	Turkey (rural areas)	16.9	R, postinjury acute care and PMR, multicentre
Maharaj (1996) <sup>26</sup>	1985–1994	Fidji	10	R, PMR
Otom <i>et al</i> (1997) <sup>21</sup>	1988–1993	Jordan	18	R, postinjury acute care, 1 unit
Martins <i>et al</i> (1998) <sup>9</sup>	1989–1992	Portugal	57.8	P, prehospital, postinjury acute care and PMR
			25.4	Survivors after postinjury acute care
Van Asbeck <i>et al</i> (2000) <sup>22</sup>	1994	The Netherlands	10.4	R, postinjury acute care, multicentre, coding
Karakan <i>et al</i> (2000) <sup>23</sup>	1992	Turkey	12.7	R, postinjury acute care and PMR

R: retrospective study; P: prospective study

Population studied: prehospital (inclusion of injured people from the time of the accident), postinjury acute care (inclusion of injured people in the postinjury acute care phase), PMR (inclusion of injured people in the rehabilitation phase)

Study cover: 1 unit, multicentre

Coding: medico-administrative coding at admission

- *Temporal parameters*: for reasons relating to the study period, with differences due to the trends in accidentology and care modalities over time.
- *Geographic parameters*: national differences concerning road traffic and lifestyles (high-risk behaviours), environment (safety of substructures) and emergency care (mobile emergency medical services, intensive care units) can explain the discrepancies between regions and countries.
- *Methodological parameters*: the variability of results seems to be mostly related to survey methods (inclusion criteria and follow-up methods).

The highest incidences are obviously found in studies including patients in the prehospital phase. Furthermore, it can be seen that most studies are retrospective.

The lack of knowledge on epidemiological data concerning SCI in France led to the Tetrafigap study, a multicentre survey using a self-administered questionnaire on the medical, psychological and social long-term outcome of tetraplegic SCI persons.<sup>2,3</sup> This survey involved an unprecedented mobilization of the main French rehabilitation units providing care for tetraplegic SCI persons. Nevertheless, it appeared important to undertake an additional survey on the French incidence of SCI, to update previous estimates on the one hand, and, on the other, to obtain valid figures for the country as a whole.

Regarding care modalities for these patients, variations are found not only at an international level but also within a country itself such as France where regional discrepancies are present. Concerning the trends in care management, several experienced specialists for this pathology do feel that there is a growing number of postinjury acute care and rehabilitation units for these patients, and that France has virtually no more units with a majority of SCI patients. Four or five decades ago, the situation was totally different, with a smaller number of specialized units and a higher concentration of SCI patients in each unit.

The first aim of this survey is to characterize the network of physical medicine and rehabilitation units currently dealing with SCI patients in France, and to have a better knowledge of rehabilitation processes and networks both upstream and downstream from the care provided by these departments. The second aim is to assess the annual incidence of SCI persons who received rehabilitation care during the year 2000 in metropolitan France (ie continental France and Corsica without overseas departments or territories).

## Materials and methods

### *First phase: identification and characterization of units treating SCI*

During the first phase of the survey, we compiled the most exhaustive possible initial database on rehabilitation units, from both public- and private-sectors receiving SCI persons for a first stay.

Identifying the units that could be entered into this database involved the cross-referencing of several lists of rehabilitation departments or centres (directory of rehabilitation units of the National Association of Physical Medicine and Rehabilitation physicians; the AFIGAP 'Association Francophone Internationale des Groupes d'Animation de la Paraplégie' address list; and the Tetrafigap survey base). Units that were known to not treat such patients were not asked to participate. Following completion of this initial base, a questionnaire with the following questions was sent to each unit:

- (a) How many rehabilitation hospital beds do you have in your ward?
- (b) Do you receive spinal cord-injured persons (patients with paraplegia or tetraplegia) for their first stay, that is, for the initial phase of rehabilitation?
- (c) Do you have a set of beds reserved for this pathology and, if so, how many?
- (d) Can you state which institutions in your region care for traumatic spinal cord lesions in the first stage of rehabilitation? (Whenever possible, specify the name of the physician, the hospital ward or unit and the address or a town name.)

The last question was intended to enhance the quality of coverage of the initial base. This 'snowball' technique, using local and regional knowledge of preidentified actors, aimed to obtain the most comprehensive inventory of the targeted departments. The final sample of units that contributed to the second phase of the survey consisted of all the units that answered question (b) in the affirmative; that is, those that do admit SCI persons for postinjury acute care.

When a unit failed to respond during this first phase, two alternative assumptions were made, with different impacts on the extrapolation of results: either this unit treated SCI patients but did not wish to respond, or it was not involved in the treatment of this pathology. To test for these two assumptions, a survey on the nonrespondents was undertaken in this first phase of identification. It consisted of telephone interviews with a sample of 30 units selected randomly from among the nonrespondents of the first phase of the study, to ascertain whether they treated SCI patients or not.

### *Second phase: identification of new cases and calculation of incidence*

Once the final sample of units declaring they treated SCI persons had been built up, three questionnaires were sent to each unit:

- (a) The first questionnaire allowed for identification of the number of SCI cases admitted to the unit between 01/01/2000 and 12/31/2000. Each patient had to meet accurate inclusion or exclusion criteria (Table 2).

**Table 2** Inclusion criteria for SCI patients in the survey

<i>Inclusion criteria</i>	<i>Exclusion criteria</i>
<i>Impairment</i>	
New traumatic spinal cord lesion	Brain-related paraplegia
Paraplegia or tetraplegia, irrespective of the level or degree of impairment	Neurological impairment due to isolated peripheral nervous lesion
Flaccid or spastic	
Traumatic cauda equina syndrome	
<i>Aetiology</i>	
Traumatic cause, irrespective of the mechanism	Paraplegia or tetraplegia related to a disease (vascular, inflammatory, tumour, etc.) or resulting from surgery for a nontraumatic pathology
<i>Cause of hospitalization</i>	
Postacute care: initial rehabilitation after treatment in postinjury acute care unit.	Follow-up rehabilitation after treatment in postinjury rehabilitation unit
Admission to the rehabilitation unit must have taken place between 01/01/2000 and 12/31/2000, whether or not the patient was discharged or had died at the time of the survey	Patient readmitted to the rehabilitation unit after a medical complication or for a check-up

Age, sex, nationality, existing pathologies and injuries related to the spinal cord lesions are not criteria for exclusion

- (b) The second questionnaire was designed to identify the individual characteristics of each patient included in the survey.
- (c) The third provided the names and addresses of postinjury acute care units referring the patients, in order to identify all the French units dealing with this pathology at the acute phase.

## Results

### *First phase: identification of units caring for SCI*

During the initial phase of the survey, 380 rehabilitation units were identified and questioned. A total of 275 units (72%) responded to the survey. Of these, 148 declared that they treated SCI, even if only occasionally.

In order to estimate the number of units concerned that could have been 'missed out' during this first phase of identification, a survey on 30 units randomly selected from the 105 nonrespondents showed that three units out of 30 (10%) admit SCI patients. By extrapolating to the 105 nonrespondent units, it can be assumed that there are about 10 units treating SCI persons that could not be included in the final sample of 148 units of the second phase. Finally, the number of rehabilitation units concerned by this pathology (even if only very occasionally) is in the region of 160.

The data concerning the 148 units are displayed in Table 3 and sorted by region. They concern the following:

- (1) The stated number of patients treated in the overall regions.
- (2) The total number of beds in these units. It is not the total number of physical medicine and rehabilitation beds in the region since the units that do not admit SCI patients did not participate in the survey.
- (3) The stated number of beds 'reserved' for this pathology in the wards. An average 10% of the beds in units caring for SCI patients are reserved for this pathology. The number of SCI persons treated in the year 2000 accounted for 80% of this capacity nationwide.
- (4) The number of units sorted as a function of the number of admissions. One can note that 25% (38/148) of the units admitted no SCI patients during the year 2000, 36% (55/148) admitted between one and five patients and 26% (38/148) admitted five patients and over. These 38 units treated 85% of the patients included. One must note that 17 units that treated SCI persons did not specify the number of patients admitted. The histogram of the distribution of units according to the number of patients admitted is also displayed in Figure 1.

Analysis of the answers obtained from the sample of 148 units shows that the response rate is not equal between units specializing in this pathology and units that are less involved. The 31 units that contributed to the Tetrafigap survey<sup>2</sup> all answered the question on the total number of patients admitted. Of these, 21 (67%) admitted at least 10 patients throughout the year. The 31 units account for a total of 511 patients. Among the 117 others that participated in this survey but not in the Tetrafigap survey, 101 responded (85%). Of these, only nine had admitted at least 10 patients. These nine units account for a total of 142 patients.

PMR units that can host SCI patients, and the number of patients treated, do not show an even distribution between the different French regions (Figures 2 and 3). The regions offering the largest amount of units are the Ile-de-France, Rhône-Alpes and Nord-Pas de Calais regions; those offering the fewest

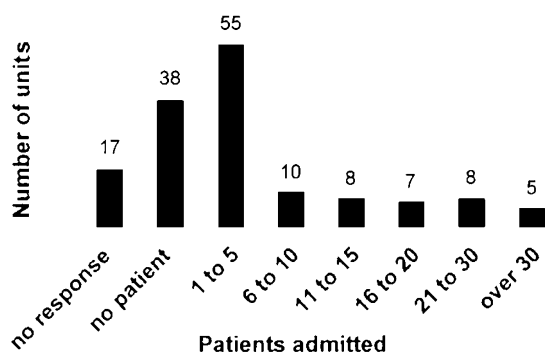
**Table 3** Regional distribution of the number of rehabilitation units, their capacities (number of beds) and the number of patients admitted

Regions	Number of patients admitted; number of beds			Number of units in relation to number of SCI admitted				
	SCI in 2000 <sup>a</sup>	Total beds <sup>b</sup>	Beds reserved <sup>c</sup>	No SCI	5 or less	6 or more	Number of SCI not specified	Total
Alsace	30	329	26	2	0	2	0	4
Aquitaine	77	800	97	1	4	3	0	8
Auvergne	16	206	5	0	2	1	0	3
Basse Normandie	3	254	0	5	1	0	0	6
Bourgogne	18	468	23	2	4	1	0	7
Bretagne	52	573	97	1	4	1	1	7
Centre	28	374	21	1	6	1	1	9
Champagne	15	166	16	0	2	1	0	3
Corse	0	0	0	0	0	0	0	0
Franche Comté	10	340	10	2	4	1	1	7
Haute Normandie	17	377	53	1	0	2	1	4
Il de France	120	1094	265	5	5	4	2	16
Languedoc Roussillon	71	381	141	0	1	3	0	4
Limousin	4	170	0	0	1	0	2	3
Lorraine	25	397	5	1	3	1	2	7
Midi Pyrénées	37	483	73	2	1	2	2	7
Nord Pas de Calais	59	642	52	1	5	4	2	12
Provence Alpes Côte d'Azur	55	1128	58	5	3	2	1	11
Pays de Loire	42	362	40	0	2	2	1	5
Picardie	6	446	0	3	2	0	0	5
Poitou Charente	7	315	0	5	0	1	1	7
Rhône-Alpes	101	947	66	1	6	6	0	13
Total	793	10 252	1048	38	55	38	17	148

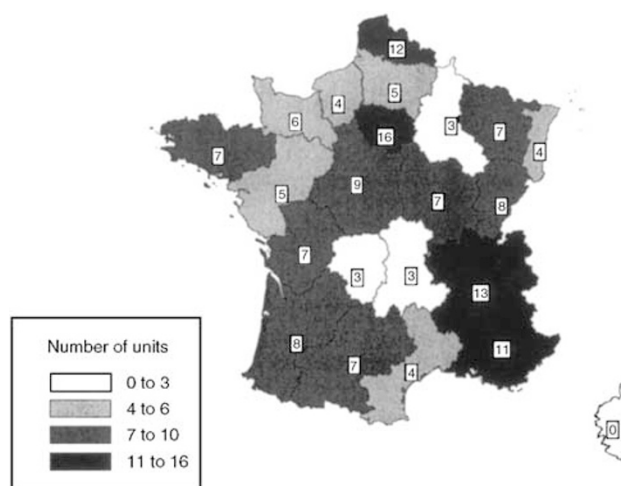
<sup>a</sup>Stated number of SCI patients who received rehabilitation care in the region during the year 2000

<sup>b</sup>Total number of beds in PMR units that treat SCI

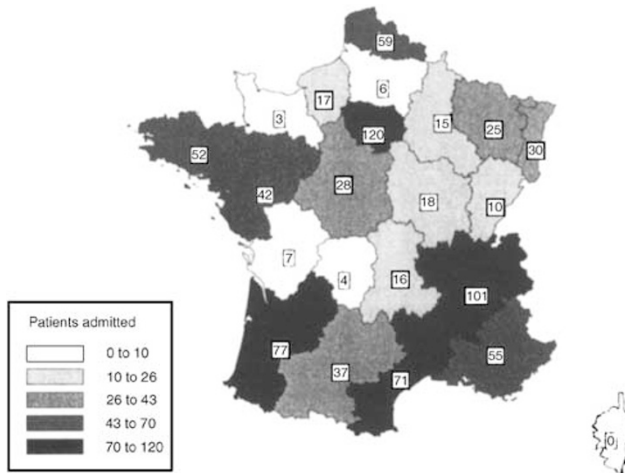
<sup>c</sup>Number of beds reserved for this pathology in the region

**Figure 1** Distribution of rehabilitation units in terms of the number of persons with SCI admitted during the year 2000

number of such services are the Auvergne, Limousin and Champagne-Ardenne regions. The largest numbers of SCI patients treated coincide with the former group of regions with most units, as well as Aquitaine, Languedoc-Roussillon and Provence-Alpes-Côte d'Azur (PACA), followed by Bretagne and Pays de Loire. Finally, the regions in which the mean number of SCI patients per unit is the highest are, in descending

**Figure 2** Regional distribution of the number of rehabilitation units caring for SCI

order of magnitude, Languedoc-Roussillon, Aquitaine and Pays de Loire, followed, in equal place, by Alsace, Ile-de-France, Rhône-Alpes and Bretagne.



**Figure 3** Regional distribution of the number of patients with SCI who received rehabilitation care

#### *Second phase: identification of new cases and calculation of incidence*

During the second phase of the survey, 132 of the 148 questioned units responded. Their answers concerned the number of SCI patients treated during the year 2000, their individual characteristics and upstream postinjury short-term care units. These answers were either full or partial ones (ie indication of the total number of patients, without clinical data), but they nevertheless enabled to calculate the SCI incidence. In this phase, the response rate was 88.5% for these units.

One can note that the annual incidence is defined by the following ratio: number of yearly new cases over the total number of people exposed in a given population (per million inhabitants).

After eliminating duplications (by comparing individual files: dates of birth, accident and admission), the total number of SCI patients that the 131 respondent units claimed to have treated during the year 2000 was 793.

Analysis of the 148 units that contributed to the survey showed a lack of units specialized in paediatrics. This might be due to the fact that the networks caring for adults are very different from those for children. It is therefore very likely that the number of children under 15 years is underestimated in this survey. Accordingly, the decision was made to discard the SCI patients under the age of 15 years from the calculation of the incidence rate. Thus, the 16 patients in this age group were discarded, leaving a total of 777 SCI patients aged 15 years or above.

The mean number of patients treated in each unit is neighbouring 6 per year. Since 17 units did not respond and as there is an estimated 10 or so caring for SCI who are not included in the survey (cf. survey on the nonrespondents), the number of 777 patients is underestimated. In order to estimate the actual number of patients, it was assumed that these 27 units (17 + 10)

treated an average number of patients that is identical to the others, that is, around 6 per year. According to this hypothesis, and after adjustment, the total estimated number of new cases of SCI patients over the age of 15 years that received rehabilitation care in the year 2000 is 934.

Only units in metropolitan France were asked to take part in this survey. The reference population thus corresponds to the French metropolitan population over the age of 15 years: a total of 48 071 349 people, according to the 1999 census.

To calculate the incidence of SCI patients over the age of 15 years in metropolitan France, the estimated number of new cases (934) has to be related to the reference population (48 071 349).

We end up with an annual incidence of 19.4 SCI patients over the age of 15 years per million inhabitants who were hospitalized for a first rehabilitation stay during the year 2000.

## Discussion

### *Rehabilitation networks*

One of the aims of this survey was to describe the network of Physical Medicine and Rehabilitation (PMR) departments that treat patients with traumatic spinal cord lesions. The comprehensive nature of the sample of units included in the survey is therefore one of the most prominent aspects of the methodology. This sample was initially obtained from lists of units specialized in PMR, rather than from a database of care settings mid-term stay and rehabilitation services. Indeed, SCI patients are assumed to be mostly referred to units specialized in PMR and not to nonspecialized mid-term stay or follow-up care services. This assumption was confirmed by the requested units to mention the other units in the region possibly involved in SCI rehabilitation, with a view to adding to our initial list. The number of rehabilitation units in France involved even very occasionally by this pathology is neighbouring 160. Since the study also drew on the units' knowledge of care networks available in the region, the national coverage at this first phase can be considered satisfactory, and the 148 units can be seen as representative of the care network for adults with SCI in metropolitan France. Two reservations have to be made, though. First, since the sample contains only one paediatric unit, the representativeness of this type of unit in the sample seems insufficient. To avoid an underestimation of the specificity of child care, the reference population was only the over-15 age one. Besides it is likely that some very old SCI patients are treated directly in geriatric mid-term or long-term stay units. These very numerous units were not questioned in the first phase of the survey and the presence of elderly people, although obvious, may also be underestimated.

Analysis of the distribution of rehabilitation units emphasizes the present existence in metropolitan France of about 30 units particularly specialized in SCI, since

these 30 units treated 70% of the patients included in the survey. It is interesting to note that some of these units did not contribute to the Tetrafigap survey. Thus, the present survey allowed for refining the knowledge on the care networks of units that are most concerned by these care modalities. The annual nationwide average number of SCI patients per unit is 6.

The regions in which the highest number of SCI are treated (Ile-de-France and Rhône-Alpes) also appear to be the regions where the road traffic is the heaviest and most probably they have the highest regional accident rates. There are differences in the distribution of patients between regions. Some (Languedoc-Roussillon, Aquitaine, Pays de Loire) have a higher concentration; other regions tend rather to spread patients over a larger number of units. Are these differences linked to differences in the organization of rehabilitation networks or to different attitudes in short-stay care units following injury? Are some of them more prone to refer patients to the first PMR unit that gives a favourable response, even if it is not really specialized in the field of SCI? Both explanations are probably intermingled.

From a more informative point of view, the survey allowed us to draw up a region-specific list of short-term stay care units (mainly primarily intensive care, neurosurgery, orthopaedic and traumatology surgery departments) involved in postinjury acute care.

This research constitutes the first attempt to investigate the care network for SCI patients on a nationwide scale.

#### *Incidence of SCI*

Estimating the incidence of SCI requires the utmost accurate inventory of patients meeting the inclusion criteria. It depends mostly on the comprehensiveness of answers from the units that treat these patients. We have extrapolated from the survey on the sample of 30 units selected randomly that approximate to 10 treated SCI. These units are not in the group of 148 participants in the study. Moreover, 17 units of this group did not reply; thus, there is a total of 27 units for which the exact number of patients is unknown. We therefore applied to each one the mean number of patients per unit (6 per annum), calculated from the respondent units. This average number is probably too high because among the respondents we find all the specialized units, whereas there are probably none among the 27 nonrespondents. However, based on the hypothesis that elderly SCI patients may have been referred directly to mid-term or long-term stay geriatric units, beyond of the scope of this study, it is likely that there are in fact more of these elderly patients than the study reveals. Therefore, one can assume that the correcting method applied reaches a balance between these two error margins.

The survey covered units in metropolitan France for the sake of feasibility. Hence, the calculation of incidence must be based on the metropolitan population statistics.

Since the survey concerned the rehabilitation stage, patients who died in the accident or during acute care were not included. In studies that include patients from the prehospital or acute care phase (Table 1), there is a higher incidence, partly because patients who die more quickly are taken into account, but also because those who recover quickly and sometimes fully (ASIA E) are included.<sup>4,5</sup> These patients, who usually do not need to be hospitalized for rehabilitation, do not appear in studies focusing on the rehabilitation stage. It may also occur that patients with a minimal cauda equina syndrome may have been referred to PMR units specialized in orthopaedics or nonspecialized follow-up care units. The choice of focusing the survey on the rehabilitation stage seemed relevant insofar as the estimated incidence of 19.4 cases per year and per million inhabitants over the age of 15 years is not the incidence of all SCI persons but does cover those who will remain severely impaired.

The retrospective methodology was chosen for the sake of feasibility of the study. It is easier to mobilize a large number of units to gather data from several medical files and to answer questionnaires once and for all than to maintain them involved in this type of study over a long period of time.

The only other French survey on this topic is that of Minaire<sup>1</sup> in the 1970s. His work concerned the Rhône-Alpes region, and was carried out between 1970 and 1975 including 351 patients. The patients were included from the postinjury acute care stage in the only regional hospital receiving spinal injuries at that time. The incidence was 12.7 per million inhabitants. In the present survey, 13 PMR units in this same region have participated. All filled in the questionnaire and 101 patients were included for the year 2000. They came from 11 different acute care hospital units. It can be noted that the annual number of SCI was higher in the year 2000 (101 *versus* 70 in 1975), but the methodologies of the two studies are quite different. There are several possible explanations accounting for these differences. First, the regional population has increased, so that the number of exposed people is higher. Second, this region has probably become increasingly attractive in terms of care offered for neighbouring regions that have fewer specialized units. Finally, the incidence of traumatic spinal cord lesions is perhaps higher in 2000 than in the 1970s. In any case, today, in this region, these patients are disseminated in a larger number of units, both in short-term care and rehabilitation units.

The survey revealed an incidence rate of 19.4 SCI patients over the age of 15 years per million inhabitants, who received rehabilitation care in metropolitan France. This survey is the first one on this topic nationwide. Therefore, there are no available data that can be compared with our findings. At an international level, the studies on the subject are numerous but the methodologies used differ from country to country. A review of the literature shows that the majority of studies are also based on a retrospective methodology, whereas a prospective one would be more suitable and

accurate. Moreover, most studies face the dilemma of either including patients at an early stage but most often with limited geographic coverage, or having a broad coverage but taking patients into account only at a later stage. The studies that record patients from the time of the accident mention incidence rates ranging from 40 to 57.8 per million inhabitants.<sup>6-9</sup> Martins *et al*<sup>9</sup> studied a region in Portugal from 1989 to 1992. All patients with SCI were included, even those who died at the time of the accident (autopsy was systematically carried out in this case). The incidence was 57.8 per million inhabitants. After a month of postinjury acute care, the number of survivors was 188 out of 398 and the incidence dropped to 27.3. This figure concerned all the sections of the population and all degrees of severity of impairments. Among the survivors, 30% were referred to hospitals for rehabilitation and 38% were followed up as outpatients since they had recovered a sufficient degree of autonomy. The incidence of patients in PMR units in this area of Portugal is thus 9.5 but this figure, far below that of the present survey, probably reflects the lack of beds for PMR. It is very likely that with a better offer of PMR care, the number of patients receiving rehabilitation would be higher.

The majority of studies include patients in the postinjury acute care stage, without taking into account the mortality at the time of the accident.<sup>1,4-6,8,10-23</sup> These studies reveal a wide range of incidences, from 10.4 to 56, which can be explained partly by the different methodologies used (retrospective or prospective, mono- or multicentre surveys). The use of medical coding upon admission to register patients allows for a high level of comprehensiveness but sometimes these codes lack reliability and do not always enable to differentiate new cases from old ones.<sup>4</sup> Finally, in some countries, the context of accidentology is particularly severe, which explains high incidences.<sup>18</sup>

Studies only focusing on patients in PMR units<sup>24-26</sup> are fewer. The incidence found in this survey is higher than in the former ones. The multicentre feature of this survey and the large number of units involved may have contributed to this result, but it may also be depicting a French peculiarity regarding traffic accidents.

This retrospective survey was indispensable to identify the units involved in the management of this pathology, SCI. Based on this identification, other multicentre epidemiological studies would allow us to establish current data accurately, especially from an evolving point of view, and to further our knowledge on other causes of SCI. This type of organization exists in the US and regularly provides very accurate health and social epidemiological data.<sup>27</sup> Initially, a regional study might be necessary and sufficient since, from a medical and functional point of view, there are probably a few differences in the aetiological and evolving characteristics between French regions. The response rate of this survey on 148 units was 87.2%, which suggests that many units might be concerned by such an epidemiological approach.

## Conclusion

This is the first nationwide multicentre study on the incidence of SCI persons who received rehabilitation care in France. The estimated incidence rate is 19.4 SCI persons over the age of 15 years, per million inhabitants, or 934 new cases per year. This survey was not aimed at investigating all new cases of SCI, which explains the methodology used and the field of investigation chosen, that is, PMR units. However, the study does allow for an evaluation of the number of new cases of paraplegia and tetraplegia during the course of the year 2000, which will account for major residual impairments and disabilities.

This study also enhances our knowledge of PMR units caring for these patients, especially regarding their regional distribution and number of patients admitted (on a regular or occasional basis). As a result, it offers prospects for improving epidemiological knowledge in a field that is still relatively uninvestigated, and proves the feasibility of the broader mobilization of PMR teams to participate in multicentre studies such as the present survey, provided that the protocol implemented is simple and accurate.

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