The Tetrafigap Survey on the long-term outcome of tetraplegic spinal cord injured persons, Part II: Demographic characteristics and initial cause of injury

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Objectives: After presenting in part I the protocol and the methodology of the Tetrafigap Survey, this article is aimed at investigating demographic characteristics, initial cause of trauma and spinal injury in the French tetraplegic spinal cord injured (TSCI) population.

Study design: The Tetrafigap Survey is a multicentre epidemiological survey on the outcome of TSCI people following their first admission to a rehabilitation department or centre.

Setting: The survey was conducted with the participation of 35 French-speaking collaborating centres.

Method: A self-administered questionnaire was carried out among consenting TSCI patients followed by the centres. 1668 questionnaires fulfilled all the required criteria for data analysis.

Results: The socio-demographic variables (gender, current age and age at the time of accident, duration of disability), circumstances of accident as well as initial spinal cord lesions are reviewed in the body of the text.

Conclusion: The results from this survey form the first detailed description of the French TSCI population. Whereas demographic data show many similarities with those of previous studies in other countries, some specific differences are highlighted, in particular relating to the type of accident.

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Introduction

The TETRAFIGAP survey is a multicentre epidemiological survey concerning the outcome of tetraplegic spinal cord injured (TSCI) people carried out under the aegis of the French-speaking International Association of Paraplegia Leading Groups (AFIGAP). It involved most of the French specialised rehabilitation Centres and Departments as well as some European French-speaking Centres in Belgium and Switzerland. It is aimed at evaluating the medical situation as well as life conditions of TSCI people. The interest concerning this severely injured population is twofold. On the one hand, patients whose neurological level of injury is high have the most extensive problems relating to physical medicine, rehabilitation, and social reintegration. On the other hand, studies have shown that among spinal cord injured (SCI) patients, the proportion of tetraplegics is increasing.¹

According to major follow-up studies, TSCI patients account for 29%² to 75%³ of SCI patients as a whole; the vast majority of authors indicate a proportion of

around 50% $\pm$ 12%.^{4–8} According to the National Cord Injury DataBase, the rate of TSCI patients is close to 55%.⁹ A French survey of 149 patients by Daverat *et al* mentions a rate of 52% TSCI patients at hospitalisation, but this figure is only 47% among the survivors who could be included in the survey (between 7 and 10 years following the accident).¹⁰ The most recent French survey gives a rate of 38% TSCI, but in this case the survey was conducted outside institutions, a fact which is liable to lower the ratio of TSCI patients.¹¹ A low rate of TSCI patients (31%) is mentioned by Whiteneck *et al* but this survey involves accidents which occurred before 1970.¹² Follow-up of the SCI population by DeVivo *et al* shows a progressive, moderate though steady increase in the proportion of TSCI patients. The last available figure, for the 1984–1986 time period, indicates 57.5% TSCI patients.¹³ Few studies concerning SCI patients are specifically oriented toward TSCI patients. In addition, inclusion criteria (in particular age range) show noticeable variations. Some surveys would appear to deal with populations recruited using very different options.³ Therefore, it may sometimes be difficult to establish firm grounds for making comparisons.

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Several studies have been published in the USA by DeVivo *et al.* They rely on data collected since 1973 by the National Database on Spinal Cord Injured patients. These authors have investigated the effects of rehabilitation on 13 763 SCI patients, of whom 54.2% were TSCI.⁴ They evaluated the prognostic factors,¹³ the changes in demographic data as well as SCI treatment¹ and also the causes and costs of spinal cord injuries in the USA.¹⁴ McColl *et al* analyzed the long-term survival, the life conditions and the medical complications of 606 SCI patients, of whom 44.2% were TSCI patients.⁷

The US studies carried out by DeVivo *et al*^{1,4,13} (and a further study in Japan by Shingu *et al*³) are among the largest studies which have included tetraplegics, with 7460 and 7317 TSCI patients, respectively. No European survey could reach such sizes. The main reference surveys, which were carried out in the United Kingdom as well as in Denmark or in Sweden, provided data concerning the overall SCI patients with much lower sample sizes. Whiteneck *et al* and Frankel *et al*^{2,12} carried out their work on mortality and long-term outcome of SCI patients, of whom 31% were TSCI,¹² from files of the two main British specialised rehabilitation centres (834 and 3179 subjects, respectively), providing in this case results used as a bench mark for life expectancy and mortality. Biering-Sorensen *et al*¹⁵ and Hartkopp *et al*⁸ analyzed the SCI population in Denmark and the long-term outcome of 268 and 888 SCI patients, respectively, the latter study including a rate of 47.7% TSCI patients. Levi *et al* conducted the Stockholm SCI Study in Sweden.⁶ This epidemiological study on the outcome of 353 SCI subjects included 41% TSCI patients.

In France, Minaire *et al* investigated the survival and causes of death of 843 SCI patients (including 142 TSCI patients) at 10 year follow-up.¹⁶ Daverat *et al* studied 188 consecutive SCI patients hospitalised between 1982 and 1985, of whom 149 survivors (99 TSCI patients) were subjected to a subsequent survey.¹⁷ In particular, this survey emphasised initial prognostic factors relating to functional independence and quality of life.¹⁷ Recently, Barbin and co-workers interviewed 291 SCI patients (of whom 37.6% were TSCI) living at home. The main issues they addressed were their life conditions and medical follow-up.¹¹

The current paper is aimed at describing the major demographic characteristics of the French TSCI population as well as causes of the initial accident and spinal injury. The above literature review reveals that very few studies are conducted on tetraplegics alone. It was only possible to establish comparisons with the main international studies involving SCI when they could provide specific data on this sub-population.

Method

In an initial publication (part I), the precise methodology employed in this research and the results of the census phase of the Tetrafigap Survey have been described.¹⁸ They can be summarised as follows:

The criteria used for inclusion in the study were:

- (1) A complete or incomplete, including post-surgical, traumatic cervical cord lesion
- (2) Age 16 or over at the time of the accident
- (3) Accident which occurred more than 2 years ago
- (4) All subjects were adults at the time of the survey.

The enquiry consisted of a self-administered questionnaire covering the following topics: the situation at the time of the accident, the medical evolution between the accident and the end of stay in a rehabilitation unit, the evolution after discharge and the current situation (medical, social, professional and personal).

The survey was carried out in 1995/96 thanks to the cooperation of 35 specialised Rehabilitation Centres (33 in France, one in Belgium, one in Switzerland). In a first step, these collaborating centres identified 6082 TSCI patients. After excluding 769 double entries and the 603 known deaths, 4710 people were then sent a letter asking for their informed consent to participate in the survey. Two thousand two hundred and fifty one people gave their consent and received a questionnaire. One thousand eight hundred and thirty questionnaires were sent back (ie a response rate of 77%) of which 1668 questionnaires fulfilled all the necessary criteria for data analysis. These questionnaires are those on which the following analyses are based; they constitute the final population group of the Tetrafigap survey.

The survey population (1668 subjects who answered) and the 4710 persons registered (TSCI assumed alive) were compared with respect to gender and age. While there was no difference in sex ratio between the persons contacted and those who answered, the persons who gave their consent were younger (on average 43.5 years) than those who refused to participate in the survey (48.7 years) and those lost for follow-up (51.4 years). These results match those of Krause who also found a lower mean age for subjects participating in his study than those who did not.¹⁹ The mean age of the 1668 persons who answered the survey (43.6 years) is, however, similar to that of the 2251 subjects who had agreed in principle (43.5 years).

Results

Demographic data

Current age At the time of the survey, the population's mean age is 43.6 ± 13.5 years* (median :

*There are some slight discrepancies between results in Tables and in the body of the text. They are due to different frequency counts because of non responses, which differ according to the variables. Though the sample size is 1668, the total is for instance 1656 in Table 2 or 1521 in Table 3.

41.6 years) with a minimum of 20 and a maximum of 88 years. The age distribution of the Tetrafigap survey is displayed in Figure 1.

Sex ratio For this population, the overall male/female ratio is 4/1 (79.9% males). This ratio is high for all age groups, but steadily decreases after 30 years. The rate for women is higher for the older subjects, in particular those over 50, than for the younger ones (before 40 years) ($P < 0.01$). These data are outlined in Table 1. Similarly, TSCI women are significantly ($P < 0.001$) older than men ($46.0 \text{ years} \pm 14.3$ versus 43.0 ± 13.3).

Age at the time of accident The mean age at the time of accident is 30.7 ± 13.2 years. The median (25.9 years) reflects the influence of accidents earlier in life on age distribution (Figure 2). Sixty per cent of accidents involved subjects under 30 and three-quarters of them occur before 40 years of age. The extremes of age at the time of accident are 16 and 78 years. Current age and age at the time of accident are linked ($r = 0.83$, $P < 0.001$): on average, the oldest subjects at the time of the survey had their accident later (in fact there are few accidents distant in time). The rate for men is higher when the accident occurs at a young age ($P < 0.01$). When the accident occurs before 25 years, the male/female ratio is 4:8; it is half this (2:4) after 55 years. About 30% of late accidents (after 50 years) involve women versus a sixth for the earliest. Consequently, the mean age of accident is significantly higher for women (33.5 ± 14.4) than for men (30.0 ± 12.8) ($P < 0.001$).

Time elapsed since the accident The mean duration of disability (time elapsed since the accident) is 12.9 years (median 11.2 years) with extremes ranging from 3 to 50.4 years (accident which occurred in 1945). Therefore, 45% of accidents date back less than 10 years, 23% date back 10 to 14 years, the same proportion (23%) 15 to 24 years and 9% date back 25 years or more (Figure 3). These results depend mostly on the inclusion criteria used for each survey population (in particular, the presence or absence of a minimum delay between the accident and the survey), but they put our survey population in perspective with respect to other survey populations. Thus, these figures are not really comparable, even with studies on long-term outcome.^{7,12} The mean duration of disability for men does not differ significantly from that for women (13.0 versus 12.4 years).

Table 1 Sex ratio by age groups

Gender	Age (years)					Total
	20-29	30-39	40-49	50-59	60 and over	
Males						
n	220	420	320	205	163	1328
%	81.8	84.3	79.6	75.1	74.1	79.9
Females						
n	49	78	82	68	57	334
%	18.2	15.7	20.4	24.9	25.9	20.1
Sex ratio (M/F)	4.5	5.4	3.9	3.0	2.9	4.0

percentages

Figure 1 The Tetrafigap sample age group distribution at the time of survey ($n = 1668$)

Initial circumstances

The survey made it possible to accurately analyze the causes of accidents (Table 2). The most prevalent cause of accident involved is traffic accident (57.9%) followed by sports and leisure (15.8%). Diving accidents have been separated because of their high rate (6.5%).

Links between the type of accident and other factors have been examined:

- Age ($P < 0.001$) : the youngest subjects (under 30 years) have a high rate of traffic accidents (TA) (60.3%) and, more specially, sport/diving accidents

percentages

Figure 2 Distribution by age group at the time of accident

percentages

Figure 3 Distribution as a function of time elapsed since the accident ($n = 1668$)

Table 2 Type of accidents according to demographic variables and type of injury

	<i>Type of accidents</i>							<i>Total</i>
	<i>TA</i>	<i>Sports/ leisure</i>	<i>Diving</i>	<i>Accidents at home</i>	<i>Rare accidents</i>	<i>Falls</i>	<i>Others</i>	
Frequencies	959	264	108	74	45	55	151	1656
%	57.9	15.8	6.5	4.5	2.7	3.3	9.1	100
Mean age at accident*	30.5	26.2	22.2	40.2	31	39	36	30.6
Mean age at survey*	43.1	40.7	35.2	53.0	43.2	50.4	49.9	43.5
Time since injury*	12.6	14.5	13	9.9	12.1	11.4	13.7	12.9
Level of lesion (%)								
C1–C2	7.4	6	4.9	7.7	8.1	9.1	8	7.2
C3	16.4	20.9	22.1	21.5	24.3	20.5	17.5	18.2
C4	26.3	32.8	40.4	38.5	32.4	27.3	26.3	29.1
C5	28.8	25.7	17.3	18.5	16.2	29.5	28.5	26.7
C6	18.6	14.2	12.5	12.3	13.5	13.6	19	16.9
C7–C8	2.5	0.4	2.8	1.5	5.4	–	0.7	1.9
Total	100	100	100	100	100	100	100	100
Rate of complete motor lesions (%)	54	52.5	63.1	46.3	34.1	50	53.3	53.3
Gender:								
Females (%)	78.2	4.8	2.4	4.5	4.5	1.8	7.9	100
Males (%)	52.9	18.6	7.5	4.5	2.3	3.7	10.5	100

*In years; TA: traffic accidents; Rare accidents: war, assaults, suicide attempt, surgical accidents

(32.2%). Diving accidents account for 15% of accidents before 30 years and decrease quickly afterwards (7.3% after 30, 5% after 40, 3% after 50, etc. . .). Age at the time of accident seems to be the decisive factor (*cf.* below). Persons aged over 60 years at the time of the survey, whose accident occurred at an average older age, differed from other age groups because of a higher rate of accidents at home and falls.

- Age at the occurrence of accident ($P < 0.001$): the differences involve all types of accidents with the exception of TA whose rate shows few variations (from 52% to 62.6%) from one age group to another. Accidents at home steadily increase with age at the time of accident (up to 19.1% after 55 years), sport/leisure accidents account for one accident in five before 30 years and then they decrease progressively. Diving accidents are more prevalent in those of young age at the time of accident: 15.7% of accidents before 20 years, about 5% between 20 and 35 years, 2% or less afterwards. Conversely, falls are very infrequent before 35 years but they account for 6% to 7.5% of accidents in all age groups afterwards. Finally, the other accidents (almost all accidents at work) account for the third largest cause of accidents, but are the second largest cause after 45 years of age.
- Length of time after the accident ($P < 0.01$). Differences are low: TA are somewhat more frequent since 1975 – but they already represented the majority of accidents (53.5%) before –, sport/leisure/diving accidents were proportionally more frequent before 1975 (28.8% *versus* 21%). However, one must take into consideration the fact that

survival regarding the type of accident may be different.

- Gender: here there are major differences. The only category which does not separate men and women is that of accidents at home (4.5% for each sex). Women are proportionally much more often involved in TA than men are (78.2% *versus* 52.9%). Conversely, the incidence of sport/leisure/diving accidents is three times greater in men than in women; so are the ‘other’ accidents which are mainly accidents at work; falls are also twice as frequent in men.
- Level of neurological lesion: There is no significant link between the type of accident and the level of lesion reported by TSCI patients.
- Furthermore, the link between the type of accident and whether the resultant injury is a complete or incomplete motor lesion just fails to reach significance ($P = 0.06$). There is no link with the complete sensory characteristic of the lesion. However, two types of accidents differentiate themselves noticeably from the others: diving accidents (63.1% of complete motor lesions) and, conversely, rare accidents (suicide attempt, war, assault, surgical accidents) where only one third of complete motor lesions are found (34.1%) (but only concerning 45 cases). This is to be compared with the role played by age in the complete or incomplete character of the lesion (*cf.* below).

Cervical cord injury

The level of injury (Figure 4) is that reported in the questionnaire by the TSCI patients. The most

frequently reported levels of injury are C4 and then C5, which both account for more than half the spinal cord injuries of the tetraplegics in this survey.

The level of injury is not significantly linked to gender of TSCI patients, while this is the case with the age of subjects at the time of accident : the higher the level of injury, the higher the mean age at accident (32.9 years for C1–C2 *versus* 26.7 for C7–C8; $P=0.04$) (Table 3).

The initial neurological injury was complete in 75.5% of cases according to the TSCI patients themselves. Current paralysis (at the time of the survey) is complete under the level of injury for 53.3% of tetraplegics. The Frankel Index, as it can be calculated, provides the following findings (at the time of survey): A: 47%, B: 9%, C: 9%, D,E grouped: 34%.

A major point is the link between the level of injury and its complete nature: paralysis is less often complete when the level of injury is higher ($P<0.01$). However, this link must take into consideration the recruitment modality (retrospective questionnaire study, survival from the beginning of rehabilitation process). It may be possible that a certain number of complete, high level injuries were lost for follow-up.

Finally, one must note the link between the level of injury and current age (45.9 for C1–C2 *versus* 38.6 for C7–C8; $P<0.01$).

With regard to the motor completeness of the lesion (Table 4), those with a complete paralysis are younger than those with a non-complete paralysis are (42.0 *versus* 44.6 years; $P<0.001$). Regarding the age at the time of accident, this result is similar, TSCI people with a complete paralysis being younger (28.6 *versus* 32.2 years; $P<0.001$). TSCI people with a complete lesion have a slightly older injury (13.4 *versus* 12.4 years; $P<0.05$), whereas one might have thought that the oldest subjects survived because of experiencing lesions that were on average less severe (but they were younger at the time of the accident).

Discussion

Demographic data

The mean age (43.6 years) of the Tetrafigap population at the time of the survey is comparable to that of the Swedish SCI population: 42 ± 14 years (median: 41

Figure 4 Level of cervical cord injury

Table 3 Level of lesion and demographic variables

	Level of lesion						
	C1–C2	C3	C4	C5	C6	C7–C8	Total
Frequencies	110	276	442	406	257	30	1521
%	7.2	18.1	29.1	26.7	16.9	2.0	100
Mean age at accident*	32.9	29.8	29.1	29.2	28.9	26.7	29.5
Mean age at survey*	45.9	43.5	42.2	42.4	40.9	38.6	42.5
Time since injury*	13.0	13.6	13.1	13.2	12.0	11.9	13.0
Rate of complete motor lesions (%)	45.2	49.1	52.7	61.6	55.6	55.2	54.5
Gender: Ratio Males/Females	4.0	4.7	4.1	3.5	3.9	3.3	4.0

*In years

Table 4 Current motor completeness of the lesion and demographic variables

	Complete	Paralysis Incomplete	Total
Frequencies	840	737	1577
%	53.3	46.7	100
Mean age at accident*	28.6	32.2	29.5
Mean age at survey*	42.0	44.6	42.5
Time since injury*	13.4	12.4	13.0
Gender : Ratio			
Males/Females	4.1	3.9	4.0

*In years

years)⁶ and the French sample by Daverat *et al*: 41 years.¹⁷ It falls between series of younger (eg Barbin *et al*: 34 ± 11.3 years¹¹), or older SCI subjects (McColl *et al*: 45.6 ± 11.9 years⁷ Shingu *et al*: 48.6 ± 19.1 years³). However, this age is mostly dependent on inclusion criteria selected for surveys, and which are different in each survey.

The male/female ratio in the present study is 4/1. This finding is identical to those of the other major studies of SCI populations. The male rate is 79.9%, ranging from 77%¹⁵ to 87.5%,¹² and identical to French authors' results: 80.3% for Daverat *et al*.¹⁰ DeVivo *et al* observe a male rate of 84.5%¹ and the US National SCI Database a male rate of 82.2%.² A recent French study reveals a more important rate for male, 87% in TSCI patients *versus* 77.4% in SCI patients in general,¹¹ a notion that is not emphasised elsewhere. Frankel *et al*² show that this male/female ratio no longer varies as a function of time of accident since the mid-1960s, while the oldest survivors in their series are almost only male patients (3.4% of females for accidents occurring before 1952). We do not obtain this result since, in our survey, the male/female ratio remains identical, whatever the follow-up time after the accident.

Age differences versus sex are likely to be related to a different mean age at the time of accident, and with the type of accident *versus* subjects' gender. This result differs from the findings by Levi *et al*, who do not find significant age differences according to gender,⁶ but it is close to those of Hartkopp *et al* where the male mean age (27.5 years) is lower than that of females (31 years).⁸

Mean age at the time of accident is similar to that by Levi *et al*: 31 ± 14 years⁶ and DeVivo *et al*: 31.2 years old in their most recent series (1984–86), a figure that is increasing moderately but steadily since the 1970s (28 years old for the time period 1973–1977).¹ Whiteneck *et al*, whose results are expressed as a function of age groups, display values which are comparable to ours (69% of patients injured before 35 years).¹² Frankel *et al* reported similar data: 57% before 30 years of age.² However, all these mentioned studies deal with SCI patients in general and not specifically TSCI.

The increased rate of males in early accidents ($P < 0.01$), which is characteristic of our series, is not observed by Levi *et al*⁶ but there are noticeable differences with respect to the causes of accidents in both surveys.

Initial circumstances

There would appear to be some French specificity with regard to the rate of Traffic Accidents. They account for less than one in two accidents in all other studies: from 43% to 45% for Levi *et al*,⁶ DeVivo *et al*,¹ Shingu *et al*³ or also for Whiteneck *et al*¹² but 57.9% in the current study. According to these authors, the second cause of accidents is falls (20% to 40% according to the series). In our series, this cause is less important, while, on the other hand, the proportion of sport/leisure accidents is higher in our survey than any other above-mentioned surveys involving the overall SCI population. These sports accidents, in particular diving accidents, appear therefore to be one of the specificities of the tetraplegic population. This finding is similar to that of Minaire *et al*, who found in TSCI patients a rate of 19% for sports accidents (and, 65.8% of sports accidents had caused tetraplegia).²⁰

Conversely, the rate of accidents caused by violent assaults (war, crime, aggression), is noticeably low in our series, in particular with respect to North-American studies (16% for DeVivo *et al*,¹ 5% for Whiteneck *et al*¹²). However, it must be said that legal regulations, for instance regarding weapons, are very different in these countries.

Our findings about links between gender and type of accident contrast with those of Levi *et al*, who report a similar proportion of traffic accidents in men (45%) and in women (47%).⁶ Biering-Sørensen *et al* even reported results which were the converse of ours: women in their study were proportionally less involved (40%) by TA than men (48.5%).¹⁵ On the other hand, this very same study reported the highest rate of sport accidents in men (6% *versus* 3.2%).

Cervical cord injury

The injury level (Figure 4) is that reported by the TSCI patients themselves. When several levels were mentioned (most frequently: two levels, for instance C4/C5), the highest level only was taken into account. It is therefore very likely that this has led to our recording an average shifted toward higher levels (predominance of C4 injuries, which is unusual in the literature data where C5 tetraplegias are predominant). These results will be verified during subsequent clinical surveys.

While caution must be maintained with respect to the reported data outlining neurological lesion level, as far as the accuracy of observed prevalences is concerned, it can be assumed that this does not question the validity of the observed results.

The rate of complete paralysis is the lowest for the highest lesion levels (Table 3). This result may be attributed to the fact that high-level lesions are more common amongst older subjects whose lesions are more often incomplete.

Surprisingly, a link was observed between the complete nature of injury (initial lesion or after-effect) and the time elapsed since the accident, but the trend was unexpected: the oldest SCI patients have more often an incomplete lesion while their longer survival would have been in favour of the opposite. In fact, part of the explanation may lie in the fact that the oldest patients were on average much younger at the time of their accident (at that time, the oldest survived to a lesser degree), and the complete nature of injury is linked to a younger age at the time of the accident.

Comparing our findings with data from the literature shows that they match those by Maharaj.²¹ Lin *et al* reported an even higher proportion of complete lesions²² while most of the other series^{3,6,7,12,15} show a majority of incomplete injuries. It is worth noting that the most recent studies^{21,22} are the ones that found the largest number of complete injuries.

The very wide scattering of data at the FRANKEL index from one study to another is striking, the TETRAFIGAP population being very close to the reference survey by DeVivo *et al*.¹

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