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ORIGINAL ARTICLE

Predictive factors of long-term mortality of persons with tetraplegic spinal cord injury: an 11-year French prospective study

MF Espagnacq[1,2,3], T Albert[4], FC Boyer[5], N Brouard[1,3], M Delcey[6], J-F Désert[4], M Lamy[2], M-A Lemouel[4], F Meslé[1,3] and J-F Ravaud[3,7,8,9,10]

[1]INED (National Institute of Demographic Research), Paris, France; [2]University Paris 1, IDUP, Paris, France; [3]Federative Research Institute on Disability, IFRH-IFR25, Villejuif, France; [4]Centre de Médecine Physique et de Réadaptation, Coubert, France; [5]Physical Medicine and Rehabilitation Department,Champagne-Ardenne University, Reims, France; [6]Association des Paralysés de France (APF), Paris, France; [7]INSERM (National Institute for Health and Medical Research), U.988, CERMES3, Villejuif, France; [8]CNRS, UMR.8211, Villejuif, France; [9]EHESS, Villejuif, France and [10]University Paris Descartes, Villejuif, France

Study design: Longitudinal study with mortality follow-up.
Objective: Identify predictive factors for long-term mortality following tetraplegic spinal cord injury (TSCI).
Setting: The Tetrafigap survey is a multi-centre epidemiological survey on the long-term outcome of persons with TSCI, initiated in France in 1995 with the participation of 35 rehabilitation centres.
Methods: The mortality follow-up involves 1241 persons with TSCI who were admitted to one of the study rehabilitation units at the initial phase and who completed the initial self-administered questionnaire. There were 226 observed deaths (18.2%) during an 11-year period. Logistic regression methods, with estimates of odds ratios (ORs), incorporating clinical, functional and social participation data were used to determine the factors related to mortality. This was followed by multivariate analysis to determine the best predictive factors for long-term mortality.
Results: Risk of death increases significantly with age but not with the time elapsed since the accident. The risk of death is higher in men. Interestingly, clinical variables are not the best predictors of long-term mortality. Instead, the significant effect of poor social participation (being single, infrequent contact with friends) and functional limitations (full assistance required with dressing or eating) persists after adjustment for other variables.
Conclusion: Once the medical situation becomes more stable, factors related to the long-term mortality of persons with TSCI are not exactly identical to those observed in the short acute-phase and during the first year after the accident. Social participation has a significant effect on mortality.
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Keywords: spinal cord injury; tetraplegia; mortality; predictive factor; functional limitation; social participation

Introduction

Since the end of World War II, the mortality of persons with spinal cord injury (SCI) has steadily declined. Several authors have noted a significant increase in survival, particularly in persons with paraplegia.[1,2] Nonetheless, life expectancy remains largely inferior compared with the general population.[3,4] Most of the studies related to this subject focus on early acute phase (or during the first years following the injury), whereas long-term mortality, once the medical situation has been stabilized, is less frequently mentioned.[1–5]

Other studies[1,2,6–8] focus on predictive factors for mortality. Much of this research is based on Model Spinal Cord Injury Systems[1,3] data or on a cohort follow-up study from a rehabilitation centre.[7] The study populations are usually composed of both persons with paraplegia or tetraplegia.

Most of the available information, aside from socio-demographic profiles, comes from clinical data. A number of factors are often considered as correlated with mortality risk. Except for Krause *et al.*,[7] a link has been noted between mortality risk and the level of the lesion. Several works note a link between completeness of the lesion and risk of death.[6–8] However, Lhéritier *et al.*[9] in a study focusing on persons with tetraplegic SCI (TSCI) did not find any such relationship. Age at the time of accident is also often identified as a predictive factor: the later the accident in

Correspondence: Dr J-F Ravaud, CERMES3, INSERM, Campus CNRS 7, rue Guy Môquet, VILLEJUIF Cedex, F-94801, France.
E-mail: ravaud@vjf.cnrs.fr
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the person's life, the higher the mortality.[8–11] The period of the accident or the time since injury are not always related to the mortality risk.[1,2,6] Studies that analyzed the presence of a tracheotomy[6,9] show increased mortality.

However, contradictory results were obtained for gender, with some studies finding a higher mortality risk for men,[1,6,8] whereas others[2,9–11] do not find any link. The same holds true for the circumstances of the accident, with some studies showing a link between mortality risk and the type of accident,[1,9,10] and others finding no such relationship.[6,8] Two studies took race into account.[1,6] De Vivo *et al*.[6] found no correlation with the risk of death. Strauss *et al*.,[1] who compared the risk factors for early death (under 2 years) versus delayed death (after 2 years), found a correlation with race in cases of early death, but not afterwards.

Krause *et al*.[7] administered the Life Situation Questionnaire in 1985–330 persons with SCI then studied the risk of death over an 11-year period. Items in the Life Situation Questionnaire were used as predictive criteria for mortality. Social participation, psychosocial and contextual data were analyzed. This study showed that many of the variables were correlated with mortality (apart from the frequency of visits, employment, medical visits, lack of accessibility and social life). These results are crucial, as they showed that medical factors were far from being the only predictors of mortality.

In another study, Krause *et al*.[11] studied health status, community integration and economic risk factors for mortality after SCI. Many variables were correlated with the risk of death. These concern clinical factors (such as level of the lesion, completeness of the lesion, respiratory assistance and so on), functional factors (physical independence and mobility) or environmental factors (marital situation, professional activity and social integration).

In light of these results, as well as data from the Tetrafigap survey,[12] this study has a threefold objective. First, to identify any specific predictive factors for mortality when the study population is composed only of persons with tetraplegia. Second, to determine if the risk factors for long-term mortality are the same as those for short- and medium-term mortality. Last, to analyze hitherto-neglected factors, such as the level of functional limitation and the importance of social participation, to determine if such data are relevant.

Materials and methods

Study population

The Tetrafigap Survey is a multi-centre epidemiological survey conducted in France in 1995 on the long-term outcome of TSCI persons. The protocol and methodology are described in detail in a previous paper.[12] The following inclusion criteria were retained for the initial phase of the Tetrafigap Survey: tetraplegia from traumatic spinal cord lesion, complete or incomplete, including post-surgical, with or without associated brain trauma; aged 16 or over at the time of the accident that must have occurred more than 2 years ago (all subjects were adults at the time of the survey); and admitted to one of the rehabilitation units taking part in the project.

Study protocol for the initial phase

The 1995 Tetrafigap Survey was the largest multi-centre survey ever conducted in Europe, with the participation of 35 rehabilitation centres. Each of the centres listed individually, contacted all persons with tetraplegia who had come under their care, asking for their written consent to participate in the survey.[12–14]

A total of 1830 questionnaires were returned (that is, a response rate of 77%), of which 1668 questionnaires fulfilled all the necessary criteria for data analysis. At the end of the questionnaire, participants were asked if they would agree to participate in a further enquiry and their contact details were requested. The goal was to carry out a follow-up survey at a later date. At 11 years later, the follow-up survey was launched and mortality between the two surveys was tracked.

Determination of vital status

The procedures were approved by the CCTIRS (the French Advisory Committee for data processing in terms of research in the field of health) and authorized by the CNIL (the French National Data Protection Commission). Given the data-gathering needed to determine vital status, the research covered 1380 persons with 227 deaths noted. Mortality was studied between 1 January 1996 (median date of the first survey) and 3 May 2007 (date when the National Identification Register of Private Individuals, RNIPP, was consulted). The RNIPP is the national register tracking the vital status of all French-born individuals and is managed by the National Institute of Statistics and Economic Studies. As the vital status of persons living outside France could not be determined satisfactorily, these persons ($n=139$) were withdrawn from the study.

The final study population therefore comprises 1241 persons, of whom 226 died during the period of follow-up. The following analyses are based on this population.

Study variables

In the initial phase, a self-administered questionnaire with 119 simple or multiple choice and 18 open questions was sent by post. The questionnaire contained a section on the socio-demographic situation at the time of the injury and the type of accident, another section about the clinical situation during stay in rehabilitation unit, a section about the post-discharge evolution, and a final section about the medical and functional situation, the socio-demographic profile and the level of social participation at the time of the survey.

Variables were classified into three groups corresponding to the levels identified by the International Classification of Functioning, Disability and Health of the World Health Organization:[15]

- Data on disorders and impairment provide a picture of the severity of injury (level of lesion, complete nature of paralysis). Additional data indicated a medical complication (presence of a tracheotomy, pressure sores, perspiration attacks, febrile episodes, awkward urinary or bowel leakages and so on) either during rehabilitation or at the

time of the survey. Data from medical follow-ups also provide indications of the person's state of health (taking medications, medical follow-up, number and nature of rehospitalizations and so on) at the time of the survey.
- Data on functional limitations cover the situation of the person at the time of the first survey. They provide clues to the level of physical autonomy, the ability to dress, wash, toilet and feed oneself, bladder and bowel management, the ability to write, walk or drive.
- Data on social participation and individual factors include socio-demographic characteristics (gender, age, living quarters, marital and professional status, educational attainment at the time of the accident or survey); psychosocial factors (perceived level of well-being, perception of disability and so on); indicators of socialization (friend visits, number of outings and so on); and level of activity (type of leisure activity, professional activities and so on).

Statistical methods

Data analysis was performed using the SAS (Statistical Analysis System) software v9.1 (SAS France, Brie Comte Robert Cedex, France). Initially, univariate analyses were carried out to determine which factors were related to mortality. Results were then adjusted for gender, age at the time of survey and the time elapsed since the accident. To avoid excessive shared variance, the correlation between variables has been examined with Cramer's V Significant variables were included in partial models corresponding to the three levels (clinical, functional and social) to determine which of them were most associated with the risk of death for each of these levels. As there were strong associations between some variables (whose meanings were similar), only the strongest of them was retained to avoid redundancy. Finally, a full logistic model integrating all three dimensions was designed, in order to determine the predictive factors for mortality once all aspects were taken into account. The extent of the lesion was included in the final model as a control, even though this variable was not significant.

Results

At the time of the Tetrafigap Survey (in 1995), the population's mean age was 43.6 years (±13.5 years). For this population, the mean age at the time of accident was 30.7 (±13.2 years). The overall male/female ratio was 4/1 (80% males). Paralysis was complete under the level of injury for 53.3% of persons with tetraplegia and 54.3% of them reported levels of injury between C1–C4. Mean time elapsed since the accident was 12.9 years with a range of 3–50 years.[13]

The duration of follow-up was 11 years after this initial survey (2006–1995). For the sample of 1241 persons with TSCI included in this study, the 226 deaths indicate a mortality rate of 18.2% over 11 years. The mean age at death was 56 years (with a range of 24–90 years). Death occurred 20 years on average after the accident (with a range of 3–47 years).

When studying effect on mortality of gender, age and time since the accident, it can be noted that, not surprisingly, age is a main predictive factor of mortality. Also, women have a lower (odds ratio (OR) = 0.5 (0.3–0.8)) risk of dying over 11 years compared with men and this corresponds roughly to the gender differential between men and women in France.[17,18] Although risk increases with the person's age, the time since injury does not have a significant role in the risk of death in all the presented analyses.

Clinical variables

When separately adjusted for gender, age and time since the accident, most of the clinical variables are significantly associated with the risk of death. The following did not have a significant association: degree of completeness of the lesion, level of the lesion, brain trauma, follow-up by a rehabilitation specialist, follow-up by a specialist and pain (data not presented).

We then included in the same model in a multivariate analysis (Table 1), factors indicating the extent of the injury (level and completeness of the lesion (NS)), complications (pressure sores (OR: 2.3 (1.5–3.5)), tracheotomy (NS), embarrassing urinary leakages (NS), frequent perspiration attacks (OR: 1.9 (1.1–3.3))) and clinical follow-up (home nurse (NS), rehospitalization (OR: 1.7 (1.06–2.7)), home hospitalization service (OR: 3.5 (1.3–9)), home physical therapy (OR : 2.1 (1.4–3))). We note that follow-up data are predictive factors for death, as are some data on medical complications (pressure sores and perspiration attacks), whereas the level of the lesion is not a pertinent predictive factor for mortality. The persons most affected by the disease needed a closer medical follow-up, and the variables related to this follow-up had an effect *per se* more important than variables related to medical complications.

Functional limitations

When adjusted for gender, age and time since the accident, all functional factors are associated with a risk of death in a univariate model. When they are included in a multivariate model, the requirement for full assistance in dressing (OR: 3.4 (1.4–8.2)), eating (OR: 2.4 (1.3–4.7)), writing (OR: 1.7 (1.01–2.7)), inability to drive (OR: 1.8 (1.04–3.5)) (Table 2), all continue to be associated with a higher risk of death. However, bowel management and locomotion lose their significance as predictive factors for death. The risk of death is at least doubled by total dependence for the essential activities of daily living.

Socio-demographic variables and social participation

Almost all social participation variables, with the exception of educational attainment, are individually associated with the risk of death (Table 3). Once other factors are taken into account, single persons have a higher risk of death compared with married persons (OR: 1.7 (1.02–2.7)). People with no professional activity are also at a higher risk of death than those who work (OR: 2.1 (1.2–3.7)). To live in an institution represents a predictive factor for death (OR: 2.2 (1.1–4.3)). Sense of well-being is also related to mortality, with a

Table 1 Influence of clinical variables at the initial phase on the risk of death over 11 years

Variables in 1995	*Deceased*		*Univariate analysis*[a]		*Multivariate analysis*[b]	
	N	*%*	*Odds ratio*	*95% CI*[c]	*Odds ratio*	*95% CI*[c]
Gender						
Male (Ref)	194	21.3			1	
Female	32	18.0			**0.4**	**0.3–0.7**
Age (years)						
Under 35	36	9.7			**0.6**	**0.4–0.9**
35–50(Ref)	77	18.2			1	
50–65	70	31.8			**2.1**	**1.3–3.2**
Over 65	43	58.1			**6.7**	**3.6–12.4**
Time since injury (years)						
Under 10	100	18.8			0.8	0.6–1.3
10–20 (Ref)	77	20.5			1	
Over 20	49	26.8			1.1	0.6–1.8
Level and completeness of lesion						
C1–C4 complete	92	22.5	1.6	0.8–3.2	1.4	0.7–3
C1–C4 incomplete	18	14.6	1.0	0.4–2.2	1.0	0.4–2.4
C5–C8 complete	70	18.3	1.4	0.7–2.7	1.4	0.6–2.9
C5–C8 incomplete (Ref)	13	16.5	1		1	
Tracheotomy						
Yes	133	39.9	**3.2**	**1.4–7.4**	1.7	0.7–4.5
No (Ref)	4	28.6	1		1	
Pressure sores						
Yes	57	38.8	**3.0**	**2.4–4**	**2.3**	**1.5–3.5**
No (Ref)	156	17.4	1		1	
Perspiration attacks						
None (Ref)	92	16.9	1		1	
Occasional	82	20.7	**1.4**	**1.01–2**	1.0	0.6–1.4
Frequent	36	31.6	**2.8**	**1.7–4.4**	**1.9**	**1.1–3.3**
Embarrassing urinary leakages						
None (Ref)	87	18.3	1		1	
Occasional	68	18.4	0.9	0.6–1.3	0.9	0.6–1.3
Frequent	55	27.5	**1.6**	**1.1–2.4**	1.2	0.8–1.9
Rehospitalization						
Yes	193	23.9	**2.6**	**1.7–4**	**1.7**	**1.1–2.7**
No (Ref)	30	11.1	1		1	
Home nurse						
Yes	120	27.8	**2.4**	**1.7–3.3**	1.5	0.8–2.9
No (Ref)	106	16.1	1		1	
Home hospitalization service						
Yes	10	45.5	**3.9**	**1.6–9.3**	**3.5**	**1.3–9.0**
No (Ref)	216	20.3	1		1	
Home physical therapy						
Yes	149	26.7	**2.3**	**1.7–3.2**	**2.1**	**1.4–3.0**
No (Ref)	77	14.4	1		1	
Follow-up by general practitioner						
Yes	16	10.3	**2.3**	**1.3–4.0**	—	
No (Ref)	210	22.5	1		—	

Logistic regression model, Ref: reference class for each variable. Bold type: odds ratios significantly different from 1.
[a]For each variable, simple adjustment for sex, age and time since injury.
[b]Adjustment for all variables in the table.
[c]CI, confidence interval of 95% of the Odds ratio.

Table 2 Influence of functional limitations on the risk of death

Variables in 1995	*Deceased*		*Univariate analysis*[a]		*Multivariate analysis*[b]	
	N	*%*	*Odds ratio*	*95% CI*[c]	*Odds ratio*	*95% CI*[c]
Gender						
Male (Ref)	194	21.3			1	
Female	32	18.0			**0.5**	**0.3–0.8**
Age (years)						
Under 35	36	9.7			**0.5**	**0.3–0.8**
35–50 (Ref)	77	18.2			1	
50–65	70	31.8			**1.9**	**1.2–3**
Over 65	43	58.1			**5.1**	**2.8–9.4**
Time since injury (years)						
Under 10	100	18.8			0.9	0.6–1.3
10–20 (Ref)	77	20.5			1	
Over 20	49	26.8			1.2	0.7–1.9
Bowel management						
Without assistance (Ref)	46	12.7			1	
Partial assistance	29	50.1	1.5	0.9–2.5	0.6	0.3–1.2
Full assistance	144	27.9	**3.2**	**2.2–4.7**	0.7	0.3–1.3
Dressing						
Without assistance (Ref)	21	7.8	1		1	
Partial assistance	29	12.1	1.6	0.9–2.9	1.6	0.7–3.5
Full assistance	175	30.5	**5.5**	**3.3–8.9**	**3.4**	**1.4–8.2**
Eating						
Without assistance (Ref)	61	12.2	1		1	
Partial assistance	93	21.2	**2.0**	**1.3–2.9**	0.9	0.6–1.4
Full assistance	71	49	**8.4**	**5.4–13.1**	**2.4**	**1.3–4.7**
Writing						
Without assistance (Ref)	91	13.5	1		1	
Partial assistance	33	18.9	1.3	0.8–2	0.9	0.6–1.5
Full assistance	98	43.4	**4.8**	**3.4–6.9**	**1.7**	**1.01–2.7**
Driving						
Yes (Ref)	113	27.7	1		1	
No	59	8.9	**3.9**	**2.6–5.8**	**1.8**	**1.04–3.5**
Locomotion						
Able to walk (Ref)	33	22.4	1		1	
With assistance	37	23.1	1.8	0.99–3.1	0.7	0.3–1.3
In wheelchair	144	22.2	**1.7**	**1.04–2.3**	0.6	0.3–1.2

Logistic regression model, Ref: reference class for each variable. Bold type: odds ratios significantly different from 1.
[a]For each variable, simple adjustment for sex, age and time since injury.
[b]Adjustment for all variables in the table.
[c]CI, confidence interval of 95% of the odds ratio.

negative feeling increasing its probability (OR: 2.4 (1.4–4)). In much the same way, the risk of death for persons who have no contacts with friends is greater than for those who have contacts everyday (OR: 1.8 (1.04–2.9)). However, the frequency of outings has no effect and neither does the estimated level of resources or the level of leisure activity.

Synthesis: a full model of predictive factors

When variables of the three studied levels are included in a full model (Table 4), the effect of clinical factors is no longer significant, whereas most of the functional (dressing and eating), personal and social (gender, family situation, sense of well-being, contact with friends and so on) variables continue to be associated with an increased risk of death. Apart from the effect of age (to be old) and gender (to be a male), the best predictive factors of long-term mortality are full assistance for eating (OR: 3.2 (1.7–5.9)) and dressing (OR: 2.3 (1.2–4.7)), contact with friends less than once a month (OR: 2.1 (1.3–3.3), bad sense of well-being (OR: 2.0 (1.2–3.3)) and to be single (OR: 1.7 (1.1–2.7)).

Discussion

The study shows that mortality in this group of persons with tetraplegia remains very high, even long after the accident.

Table 3 Influence of socio-demographic and social participation variables on the risk of death

Variables in 1995	*Deceased*		*Univariate analysis*[a]		*Multivariate analysis*[b]	
	N	*%*	*Odds ratio*	*95% CI*[c]	*Odds ratio*	*95% CI*[c]
Gender						
Male (Ref)	194	21.3			1	
Female	32	18.0			**0.5**	**0.3–0.8**
Age (years)						
Under 35	36	9.7			0.6	0.4–1.1
35–50 (Ref)	77	18.2			1	
50–65	70	31.8			**2.6**	**1.6–4.5**
Over 65	43	58.1			**7.0**	**3.7–17.8**
Time since accident (years)						
Under 10	100	18.8			0.9	0.6–1.4
10–20 (Ref)	77	20.5			1	
Over 20	49	26.8			1.2	0.7–2.0
Family situation						
Single	74	18.1	**2.0**	**1.4–3**	**1.7**	**1.02–2.7**
Married (Ref)	112	20.9	1		1	
Widow/Widower	9	36.0	0.9	0.4–2.2	1.4	0.7–2.5
Divorced	30	25.9	**1.8**	**1.1–2.9**	1.5	0.8–2.6
Professional situation						
Working (Ref)	19	7.3	1		1	
Retired	69	40.4	**2.5**	**1.3–4.9**	1.2	0.7–2.0
Other inactive	138	21.0	**3.5**	**2.1–5.9**	**2.1**	**1.2–3.7**
Sense of well-being						
Bad or worse	106	37.2	**3.3**	**2.2–5.0**	**2.4**	**1.4–4.0**
Rather good	69	17.4	1.3	0.8–1.9	1.3	0.7–2.1
Good or better (Ref)	41	11.1	1		1	
Estimated level of resources						
Inadequate	51	22.4	**1.8**	**1.2–2.7**	1.0	0.6–1.6
Just enough	87	24.2	**1.5**	**1.1–2.2**	1.2	0.8–1.8
Reasonable (Ref)	79	17.2	1		1	
Outing						
Never or once a month or less	98	45.0	**4.6**	**3.1–6.7**	0.9	0.6–1.5
Once a week	53	20.4	**1.8**	**1.2–2.7**	1.2	0.7–2.1
Daily or almost daily (Ref)	67	11.6	1		1	
Contact with friends						
Never or once a month or less	69	33.8	**3.1**	**2.1–4.6**	**1.8**	**1.04–2.9**
Once a week	81	22.8	**1.9**	**1.3–2.7**	**1.6**	**1.01–2.5**
Daily or almost daily (Ref)	71	13.9	1		1	
Living quarters						
House (Ref)	202	19.8	1		1	
Institution	23	35.4	**2.5**	**1.5–4.4**	**2.2**	**1.1–4.3**
Leisure activity						
Few (Ref)	175	25.7	1		1	
Moderate	49	13.0	0.5	0.1–1.01	0.7	0.4–1.05
Many	2	6.3	**0.2**	**0.4–0.8**	0.4	0.1–1.9
Educational attainment						
Primary school/none	58	28.7	1.4	0.8–2.3		
Secondary school	93	16.9	1.2	0.8–2.0		
Higher studies (Ref)	31	15.6	1			

Logistic regression model, Ref: reference class for each variable. Bold type: odds ratios significantly different from 1.
[a]For each variable, simple adjustment for sex, age and time since injury.
[b]Adjustment for all variables in the table.
[c]CI, confidence interval of 95% of the odds ratio.

Table 4 Influence of variables of the three levels on risk of death

Variables in 1995	*Odds ratio*	*95% CI*[a]
Adjustment variables		
Gender		
Male (Ref)	1	
Female	**0.5**	**0.3–0.8**
Age (years)		
Under 35	**0.5**	**0.3–0.8**
35–50 (Ref)	1	
50–65	**2.3**	**1.4–3.9**
Over 65	**7.4**	**3.2–17.0**
Time since accident (years)		
Under 10	0.8	0.5–1.3
10–20 (Ref)	1	
Over 20	1.1	0.5–2.4
Clinical level		
Level and completeness of lesion		
C1–C4 complete	0.7	0.3–1.5
C1–C4 incomplete	0.8	0.3–2.1
C5–C8 complete	1.1	0.5–2.4
C5–C8 incomplete (Ref)	1	
Pressure sores		
Yes	1.5	0.99–2.4
No (Ref)	1	
Rehospitalization		
Yes	1.4	0.8–2.3
No (Ref)	1	
Home physical therapy		
Yes	1.4	0.9–2.1
No (Ref)	1	
Functional level		
Dressing		
Without assistance (Ref)	1	
Partial assistance	1.2	0.6–2.3
Full assistance	**2.3**	**1.2–4.7**
Eating		
Without assistance (Ref)	1	
Partial assistance	0.8	0.5–1.4
Full assistance	**3.2**	**1.7–5.9**
Personal and social level		
Professional situation		
Working (Ref)	1	
Retired	1.4	0.6–2.9
Other inactive	1.6	0.9–2.9
Family situation		
Single	**1.7**	**1.1–2.7**
Married (Ref)	1	
Widow/Widower	0.9	0.3–2.7
Divorced/separated	1.6	0.9–2.8
Sense of well-being		
Bad or very bad	**2.0**	**1.2–3.3**
Rather good	1.2	0.7–1.9
Good or better (Ref)	1	
Contact with friends		
Never or once a month or less	**2.1**	**1.3–3.3**
Once a week	**1.6**	**1.1–2.5**
Daily or almost daily (Ref)	1	

Logistic regression model, Ref: reference class for each variable. Multivariate analysis, specific effects of each variable, after adjustment for all the variables in the table. Bold type: odds ratios significantly different from 1.
[a]CI, confidence interval of 95% of the Odds Ratio.

The clinical, medical and socio-demographic characteristics of persons lost to follow-up after the 1995 survey, for whom we could not determine vital status ($N = 398$), were compared with the rest of the study population. The main difference involves the country of residence. Persons living abroad were harder to track, and were therefore withdrawn from the scope of this study. Women and the elderly were not as well-identified in the RNIPP. For this reason, results were systematically adjusted for gender and age.

When long-term mortality is analyzed, clinical factors are not the most pertinent predictive factors, whereas social participation and functional limitation have specific effects and provide prognostic data. This is the most striking finding of the study.

With the methodology used, Cox proportional hazards models or a 'person-year' approach are inappropriate, because the study-population was not followed since the accident, but since the first survey. The survival since the accident cannot be estimated, and that is why logistic regressions were employed to determine predictive factors (from the first phase) of the mortality.

Another limitation of this survey lies in its declarative nature. Although a rich source of information for different topics, there is a margin of uncertainty for the medical data owing to potential errors in declarations. The level of the lesion declared by the person with SCI does not necessarily match the one observed medically. One of the difficulties encountered when comparing results with those from other studies is because of the fact that this is a long-term study, rather than a short-term follow-up after the accident. Some of the deaths, particularly early ones, are thus not taken into account. Factors associated with later deaths are better studied in this survey, which probably explains the lesser impact of the clinical characteristics. Indeed, the most severely affected persons have a higher probability of death during the acute phase, and they are not included in these analysis. Moreover, the mortality cannot be approached during the complete period after accident, but only between 'two cross-sectional approaches', which limits comparison with pure longitudinal studies.

Moreover, although most studies of mortality cover persons with SCI in general, the sample for this study is homogeneous, as only persons with tetraplegia are included.

As for the link between mortality and the level and extent of the lesion, most authors note a correlation between these variables and death,[6–8] a result found in the univariate analysis for extent (but not level) of lesion. The association disappears in multivariate analysis. With regard to the level of the lesion, other studies draw a contrast between persons with paraplegia or tetraplegia, whereas only cervical lesions are included in this study. This may explain why the variable loses its predictive power. The presence of a tracheotomy is identified as a long-term predictive factor for death by Lhéritier *et al*.[9] and De Vivo *et al*.[6] A similar observation is found only in univariate analysis. For these studies, this variable was collected during the rehabilitation phase, that is, shortly after the accident. However, for this study, data was collected on average 13 years after the accident.

Consequently, these two sources of information do not reflect the same level of severity.

Regarding the age at the time of accident or the time since accident and the risk of death, we found no significant relationship, in contradistinction to several other studies.[6,8–10] However, as in Strauss *et al*.,[1] a higher risk of death was found with increasing calendar age. The observation that mortality is higher when the person was older at the time of the accident may simply indicate an age effect. For this reason, it was necessary to adjust the analysis for age. There might also be a selection effect due to short-term mortality, with the oldest persons dying early, resulting in time since accident no longer being a significant risk factor for death in the period of follow-up in this study.

Like Strauss *et al*.,[1] De Vivo *et al*.[6] and O'Connor,[8] the study shows that gender is associated with mortality, women having a lower risk than men, as in the general population. The study corroborates the results presented by Krause *et al*.[7,11] on contextual and social participation data. Contacts with friends are related to the risk of death, as are psychosocial variables (for example, a positive sense of well-being is correlated with a lower risk of death). Both studies also have some resemblance in the variables that are not correlated with the risk of death: professional activity and financial satisfaction. A recent study by Krause *et al*.[16] has given evidence for the necessity to go further than the traditional health parameters for the prediction of survival.

Although being less accurate than others for medical data, this study complements previous findings by taking the three levels into account simultaneously, whereas highlighting the importance of data on functional limitations and social participation as predictive factors for mortality. These results are particularly important for both medical teams and associations for disabled persons, as they are deeply involved in the long-term outcome for persons with SCI and their living conditions long after the initial rehabilitation period.

Conclusion

This study has opened up new areas for reflection, as it has demonstrated the importance of taking functional limitations and contextual factors into account when studying the factors contributing to the risk of death. Such factors have often been neglected in other studies because of the dearth of information, but they are in fact highly relevant and, compared with medical data, are much easier to collect through self-administered questionnaires.

Conflict of interest

The authors declare no conflict of interest.

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