

All reproduction is prohibited
but direct link to the document is accepted:

<http://www.irdes.fr/english/issues-in-health-economics/212-the-consequences-of-a-traumatic-tetraplegia-on-forming-a-union.pdf>

The Consequences of a Traumatic Tetraplegia on Forming a Union

Maude Espagnacq (Irdes),
Jean-François Ravaud (Inserm, IFRH)

Understanding the links that can exist between a severe disability, such as tetraplegia, and marital status is especially difficult as the data on the subject is rare. The *Tétrafigap* surveys, conducted in 1995 and 2006, permit to study the medium and long term evolution of union-formation, by monitoring the same population of spinal cord injured tetraplegics over more than ten years. The aim is, first, to measure the impact of severe disabilities on couple formation and, second, to define the elements that influence the possibility of a union.

These injuries, often due to public highways or sports accidents, mainly concern a young male population, about 80% of men in their twenties at the time of the accident. In *Tétrafigap* cohort, over 60% of respondents were single at the time of the accident and 50% of them forming a union since. Starting a union after such trauma is no marginal phenomenon. The analysis of factors influencing the union formation has shown that socio-environmental elements have a much stronger influence on the probability of forming a union than elements referring to autonomy or to the clinical situation.

The lesion of the spinal cord, also called spinal cord injury, is the most serious complication of spinal trauma. It most often results from road traffic, sports or domestic accidents. This type of injury causes more or less significant irreversible damage depending on the type of injury and its location on the spine. The height of the lesion on the spinal column shows the neurological level and, therefore, which muscles and organs are affected. The word "paraplegia" is used when there is a lesion at dorsal or lumbar level – lower limbs – and "tetraplegia" when it is located at cervical level : upper and lower limbs are affected. A series of sensory bladder and sphinc-

ter disorders arise in addition to motor paralysis. In case of tetraplegic spinal cord injury, the injured person may also suffer from respiratory complications. The damage may be complete or incomplete. The creation of emergency and intensive care services and the development of reeducation and rehabilitation centers have significantly increased the life expectancy of those injured. Besides, though it is not as high as that of the general population, these people can live several decades after their accident (Espagnacq *et al.*, 2011).

The increase in their life-expectancy has opened the debate on the future of this population – besides medical con-

cerns. According to the International Classification of Functioning, Disability and Health (*Classification internationale du fonctionnement du handicap et de la santé*, WHO Cif-2001), illnesses, accidents or defects can generate deficiencies that may impair motor, sensory or mental functions. These functional limitations may lead to limitations in daily living activities. When such difficulties affect core activities necessary to perform a social role, they result in social disadvantage or restrictions in social participation. This classification also takes into account the existence of environmental and personal factors (gender, age...). Couple

forming is the type of social participation studied here from 1995 and 2006 by the *Tétrafigap* surveys (Sources insert). The objective is to identify which factors (clinical, functional, environmental and personal) most influence the risk of social participation restrictions. Indeed, studying singles at the time of the accident makes it possible to highlight the mechanisms that cause couple forming difficulties. In principle, but for that accident, these people would have broadly enjoyed the same probabilities of union-forming as the general population. Union breakdowns are less frequent and are not analyzed in his article.

Due to the nature of the accidents, victims of trauma causing spinal cord injury have specific socio-demographic characteristics (Ravaud *et al.*, 2000): most frequently, young men are involved, overwhelmingly so. Their accident often occurred just before or at the age when people generally form their first couple (median age at the time of the accident is 24). So, one may wonder whether the accident impacts the age when forming a couple without necessarily reducing the number of people who will form a union or whether it reduces the likelihood of a sustainable unions. Existing studies on the topic show that celibacy levels are higher than in the general population (Banens *et al.*, 2007). The first reason for celibacy is said to be the person's clinical situation and heavy dependence;

yet hardly any study incorporates socio-environmental elements to account for their marital status. In the general population, factors such as level of education, employment and gender influence the probability of forming a union (Daguet *et al.*, 2010). Considering all factors will be helpful to grasping which elements are favorable to union formation and which ones act against it.

This population is made up of a majority of young, single men at the time of the accident

Tétrafigap surveys offer an abundance of both clinical and functional data, and on the socio-environmental context as well (Table 1). These were the inclusion criteria: traumatic spinal cord tetraplegia condition, whether complete or incomplete, including post-surgical; in association, or not, with head injury; admission in one of the 35 rehabilitation services (all 33 French centers receiving spinal cord injury victims, a Belgian and a Swiss center); 16 years of age or over at the time of the accident; the accident occurred at least two years before the first investigation.

Of those surveyed in the 1995 and 2006 *Tétrafigap* surveys, 61% of the population were single (never lived with a partner) at the time of the accident (Table 2). Here is

the reason for such a high proportion of singles: these injuries are often caused by road (56%) and sports (27%) accidents [Table 1]. These accidents often result from risk behaviors, which young and single men are overwhelming prone to (nearly 80%, Table 1).

Among single people at the time of the accident, 57% were still single in 2006 and 50% had never experienced a union (Table 2). The average age of people in a couple is 32 years and the time elapsed between the accident and forming a

SOURCES

The *Tétrafigap* cohort is the largest European database for tetraplegics. It is based on a ten year follow-up survey. The first phase took place in late 1995 and early 1996 (Ravaud *et al.*, 1998; 2000) and the second, in 2006, with the participation of 33 French rehabilitation centers for spinal cord injury, a Belgian and a Swiss center. Centers would send the questionnaire to tetraplegics by mail. Of the over 2000 respondents to the survey, 1639 questionnaires were usable.

Study population. The population addressed in the survey consists of adults who have a complete or incomplete spinal cord injury that is stabilized because they have survived at least two years after the accident.

Ten-year period follow-up. In 2006, the second phase of the survey was conducted by interviewing the same people again. In 2006, 1.325 people were again interviewed. 547 people responded to the

second phase, 30 refused and 227 were declared dead; regarding 208 of them, the mail was returned, mentioning "Return to sender, address unknown", and 313 did not respond to the investigation after one reminder.

Questionnaires. The 1995 survey was self-administered and consisted of about 130 questions on respondents' socio-demographic profiles at the time of the accident and at the time of the survey, on their living conditions and functional and clinical situations (Method insert). The 2006 questionnaire, also self-administered, addresses these persons' clinical, functional and socio-environmental developments. It includes new questions not asked in 1995, including sexuality and procreation and on the role of informal carers.

¹ An address research was conducted when the mail had bounced and was returned bearing the mention "RTSAU", and the person was not declared dead.

T1 Characteristics of the population that was interviewed again in 2006 (%). (N=547)

Clinical situation	
Location of the lesion on the cervical vertebrae	
C1 to C4 (high)	25
C5 to C6 (medium)	57
C7 to C8 (low)	18
Complete motor paralysis below the injury	
Yes	54
No	46
Loss of sensitivity under the lesion	
Yes	41
No	59
Functional Location	
Eating	
Without help	80
With help	20
Getting dressed	
Without help	72
With help	28
Contenance	
No problem	55
Faeces or urine incontinence	29
Faeces and urine incontinence	16
Socio-environmental elements	
Gender	
Man	80
Woman	20
Type of accident	
Public highway accident	56
Sports	27
Domestic	3
Other	14
Family situation at the time of the accident	
In a relationship (union)	35
Not in a relationship (union)	65
A student at the time of the accident	
Yes	22
No	78
Seniority of the accident (in 2006)	
Under 15 years	9
Between 15 and 19	30
Between 20 and 29	40
Over 30 years	21
Professional status in 2006	
Active	20
Not active	80

Sources: *Tétrafigap* 1995 and 2006.
 Data available for download

couple is on average more than ten years (10.2). Unions were formed mainly before 1995: 75% of unions started between the time of the accident and the investigation, and 24% of unions formed after the accident eventually broke down.

What factors impact union formation?

All clinical, functional and socio-environmental variables were tested to check for a possible link with forming a union (Method insert). Then, only significant variables were included in the multivariate analysis. The nature of the paralysis (complete or incomplete) and the level of injury, which are highly relevant elements to describe the severity of tetraplegia, were kept, though they were not significant.

The family network was defined through two sets of variables: the number of people likely to be called upon (parents, siblings, aunts and uncles, cousins, etc.) and

the frequency of meetings. The social network, meanwhile, was made up in the same way, by including friends, neighbors and colleagues...

All things being equal, age and the time elapsed since the accident have no effect. By contrast, women form a union less often. At clinical level, the nature of the motor paralysis (complete or not) has no impact on the probability of forming a union (Table 3). On the other hand, a low lesion level is favorable. After controlling for age and the severity of the injury, the functional elements are not found to be significant, except for autonomy when getting dressed. Socio-environmental elements do exhibit a link with the likelihood of forming a union, both regarding elements dating from the time the accident occurred, such as being a student, and features dating from 2006. Pursuing a gaining activity is the only factor that no longer has influence. The two most sensitive elements to explain union formation seem to be the injured person's networks, whether family or social, but they prove to have opposite effects.

After a spinal cord injury, living at one's parents' home reduces the likelihood of forming a union

Family involvement can certainly be explained by the type of injury. It often involves young victims, who undertake intensive health care (long hospitalization, rehabilitation...). If they do not

T2

Summary of matrimonial situations at each study period (N=521¹)

Situation at the time of the accident							
Singles who have never lived with a partner 334				In a couple 187			
Situation in 1995							
Not in a union 208		Has experienced a union ² 126		In a couple 154		Broken union 33	
Situation in 2006							
Not in a union 166	Has experienced a union ² 42	In a couple 103	Broken union 23	In a couple 133	Broken union 21	In a couple 6	Broken union 27

¹ To simplify the reading of the table, only those in a union and single at the time of the accident are presented, but there was one widow and 21 divorcees at the time of the accident, and 4 persons did not answer the questions about the couple situation in the three periods.

² In a relationship / has broken up.

Sources: Tétrafigap 1995 and 2006.

 Data available for download

T3

Specific effects of different variables on the probability of forming a union between the accident and 2006¹

Variables	Odd ratio	IC
Gender		
Men	1	
Women	0.46	0.2-0.9
Age NS*		
Seniority of the accident NS		
Location of the lesion on the cervical vertebrae		
C1 to C4 (high)	1.3	NS
C5 to C6 (medium)	0.4	0.20-0.94
C7 to C8 (low)	1	
Complete motor paralysis below the injury NS		
Getting dressed		
Without help	1	
With help	0.5	0.2-0.95
Eating NS		
Continenence NS		
Family network		
Low	6.1	2.6-14.2
Moderate	1.7	NS
High	1	
Social network		
No	0.1	0.05-0.4
Moderate	0.6	NS
High	1	
A student at the time of the accident		
Yes	1.9	1.06-3.7
No	1	
Pursuing a gaining activity in 2006 NS		

* NS: Not significant.

Red elements: significant to at least p<0.05.

¹ These persons were single at the time of the accident.

Sources: Tétrafigap 1995 and 2006.

 Data available for download

METHOD

Some elements were known at the time of the three dates (at the time of the accident, of the first investigation or of the second one), such as socio-demographic or clinical factors. Others were known at the time of each survey (1995 and 2006), such as the functional elements or some clinical features, and some at a single date, such as education level, resources and family or social network. Information about the pre-accident period, for example, permits to determine the factors that positively or negatively influence the probability of forming a union.

The clinical elements studied are fourfold: the first provide an indication of the severity of the injury (location of the injury, loss of sensation, complete or incomplete injury, head trauma...). Others concern direct consequences, such as continence problems, sweating fits and contractures. Others provide information on consequences caused by the first ones: tracheotomy or bedsore.

Finally, other factors state the medical monitoring level (doctors' visit, nurse, physiotherapist...).

Functional data come under three categories of physical abilities: inability to write or eat, i.e. very low functional capacity. A relatively good physical ability: able to get dressed and wash oneself, to stand or lie down by oneself; abilities related to walking (moving about, type of walking: with or without help).

As for socio-environmental elements, several dimensions are examined: socio-demographic profile (age, gender, occupation and marital status); psychosocial aspects: the level of perceived disability, the estimated well-being and socialization indicators. These indicators have been established to determine whether or not a network (whether social and family) does exist, taking into account the number of people in the network and the frequency of meetings.

CONTEXT

This research, *Questions d'économie de la santé* (Issues in Health Economics), presents the results obtained in the framework of a thesis (Espagnacq, 2008). The thesis was funded by the Francophone International Association of paraplegia entertainment groups (*Association francophone internationale des groupes d'animations de la paraplégie*, Afigap) and the Federative Institute for Research on Handicap (*Institut fédératif de recherche sur le handicap*, IFRH), and was conducted at the French Institute for Demographic Studies (*Institut national d'études démographiques*, INED).

have a partner, the family, especially the parents, provide assistance and support.

Among single injured persons, parents make up the bulk of the family network, whether or not these single persons are living with their parents. To investigate whether dense family network limits union formation, we focused on whether or not the injured were living with their parents in 1995 and 2006¹. In 1995, 30% of single persons at the time of the accident lived with their parents, and the vast majority of them were already living with them before the accident.

In 2006, 16% of those who lived with their parents in 1995 had formed a union,

¹ The living place at the time of the accident is not mentioned in the survey ; it was asked in 1995 and 2006.

against 55% among people who had stated they lived alone in 1995. Moreover, 44% of singles at the time of the accident, who had not formed a union in 2006, live with at least one parent, while the average age of people is over 40 years. Relatively few people living with their parents leave them after the accident (less than a third). However, the severity of the injury does not account for living with one's parents or not, as the people living with their parents have no special features, no particularly adverse clinical or functional limitations. Yet, that particular situation has a high impact because it seems to restrict their social participation as a whole: in 2006, 16.3% of people living with their parents have a job, as against over 26% of those who live alone, regardless of their earlier marital situation.

* * *

The results of this study show spinal cord injury is a major obstacle to tetraplegics' forming a union. In France, people with a health problem are four times more likely to be single than in the general population (Banens *et al.*, 2007), whereas the population studied is about seven times more affected. While, in the general population, about 7% of men will never form a stable union (Prioux, 2003), half of tetraplegics remains permanently single. However, spinal cord injury does not completely preclude union forming since

the other half of single people at the time of the accident does form a union. The average age at the time of first living as a couple is relatively high (31 years) while, in France, it is about 25 years (Prioux, 2003). Such postponement of forming a union can be explained in part by the hospitalization and rehabilitation period. But other phenomena have an impact: it takes longer to find a partner, and it is more difficult to find a stable one... We also find that functional issues are an unfavorable factor to find a spouse; yet being self-sufficient does not makes it easier to form a union.

Ultimately, the most influential factors on the probability of forming a union after the accident are socio-environmental elements. Staying at their parents' home may limit the injured person's opportunities of finding a partner. This finding is to be linked with the work on the transition to adulthood in the general population. They show that leaving the parents' home is no longer directly associated with forming a union. Union formation occurs once the person is financially independent and has left home (Galland, 1995; Villeneuve-Gokalp, 1997). However, a significant proportion of tetraplegics had their accident when about to step into adulthood, thus interrupting the process of leaving the parental home, thereby slowing down the set of mechanisms that lead people to form a union. ♦

FOR FURTHER INFORMATION

- Banens M., Marcellini A., Le Roux N., Fournier S., Mendès-Leite R., Thiers Vidal L. (2007). « L'accès à la vie de couple de personnes vivant avec un problème de santé durable et handicapant : une analyse démographique et sociologique ». *Revue française des affaires sociales*, N.2, p. 57.
- Daguet F., Niel X. (2010). « Vivre en couple : la proportion de jeunes en couple se stabilise », *Insee Première*, n° 1281, février.
- Espagnacq M., Albert T., Boyer F.C., Brouard N., Delcey M., Désert J.F., Lamy M., Lemouel M.A., Meslé F., Ravaut J.F. (2011). "Predictive factors of long-term mortality of persons with tetraplegic spinal cord injury: An 11-year French prospective study", janvier, *Spinal Cord*. 9 (6) p.728-35.
- Espagnacq M. (2008). « Mortalité à long terme et devenir social des blessés médullaires tétraplégiques. Études à partir des enquêtes Tétrafigap 1995 et 2006 ». Thèse de démographie, décembre, 276 p.
- Galland O. (1996). « L'entrée dans la vie adulte en France. Bilan et perspectives sociologiques ». *Sociologie et société*, p. 37.
- Prioux F. (2003). « L'âge à la première union en France : une évolution en deux temps », *Population*, /4 (Vol. 58), p. 6223-644.
- Ravaut J.-F., Delcey M., Desert J.-F. et le groupe Tétrafigap (2000). "The Tétrafigap survey on the long-term outcome of tetraplegic spinal cord injured persons: part II Demographic characteristics and initial cause of injury". *Spinal Cord* vol 38 (3) p.164-172.
- Ravaut J.-F., Désert J.-F.; Boulongne D., Delcey M., Peleducq J.-P., Trambly M., Cayot-Decarte A. Papa A., Maury M. et le groupe Tétrafigap (1998). "The Tétrafigap survey on the long-term outcome of tetraplegic spinal cord injured individuals : part I protocol et methodology". *Spinal Cord* 1998, vol 36 (2) p. 117-124.
- Villeneuve-Gokalp C. (1997). « Le départ de chez les parents : une définition d'un processus complexe ». *Economie et statistique*, n° 304-305 p. 149.

IRDÉS

INSTITUT DE RECHERCHE ET DOCUMENTATION EN ÉCONOMIE DE LA SANTÉ •
117bis rue Manin 75019 Paris • Tél. : 01 53 93 43 02 • Fax : 01 53 93 43 07 •
www.irdes.fr • Email : publications@irdes.fr •

Director of the publication: Denis Raynaud • Technical senior editor: Anne Evans • Associate editor: Anna Marek • Translator: Dominique Macabies •
Layout compositor: Damien Le Torrec • ISSN : 1283-4769.