

## QUALITÉ DE VIE ET HANDICAP

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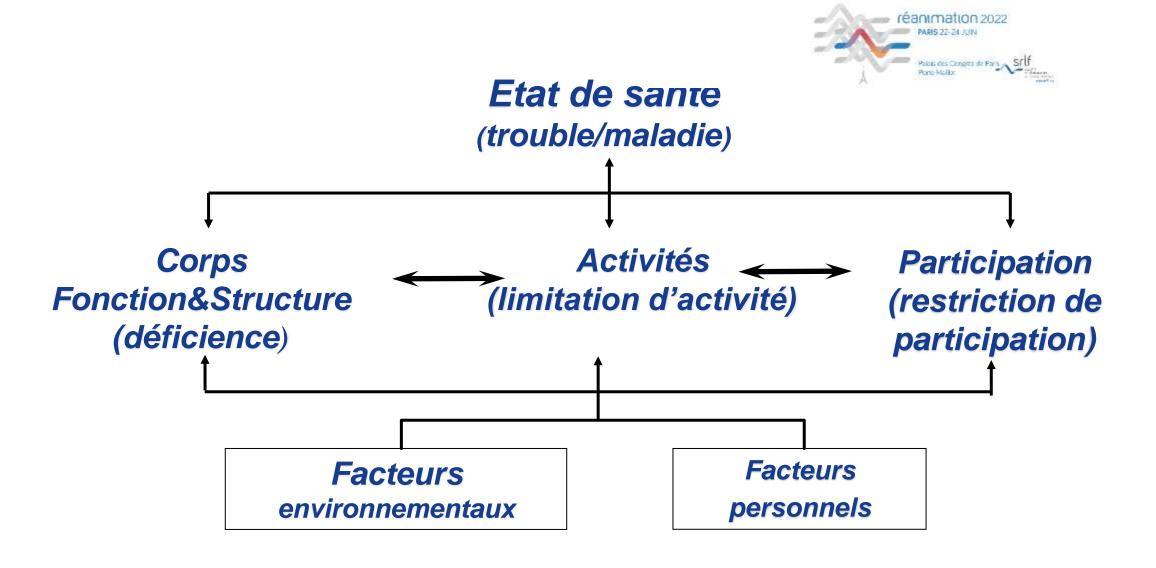
**Orateur: Philippe MARQUE, TOULOUSE** 

☑ Je n'ai pas de lien d'intérêt potentiel à déclarer



- Un service de Neuroréadaptation
- 6 lits de rééducation post-réanimation neurologique depuis 2008 :
  - LIS
  - Tétraplégie Ventilée
  - Polyradiculonévrite aïgue
  - AVC avec craniectomie...
  - Éveil de coma

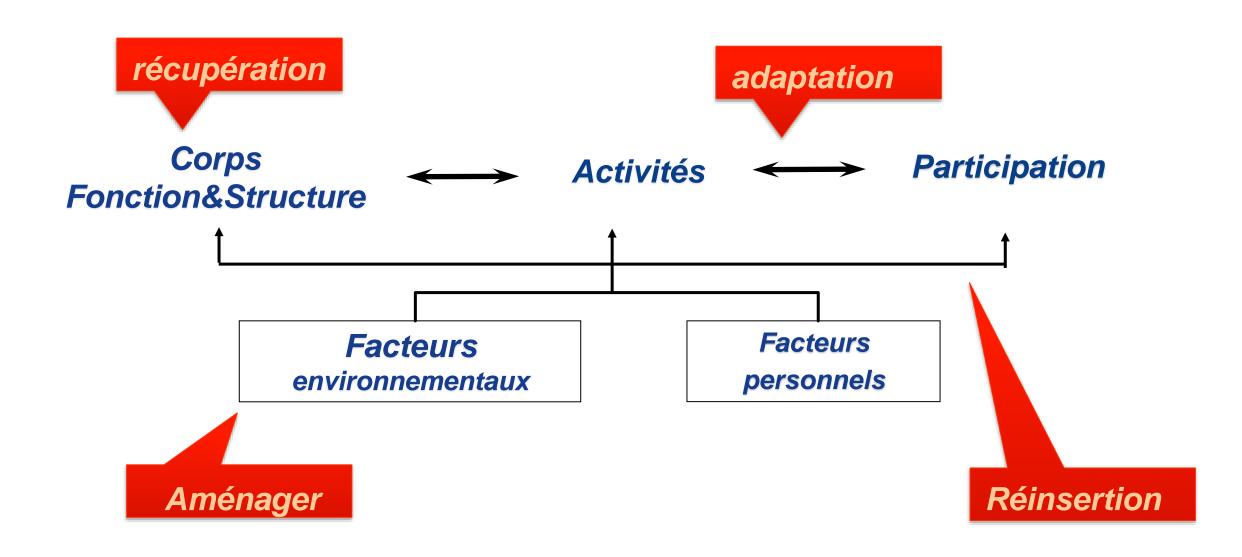




Interaction des concepts CIF 2001



#### Réadaptation





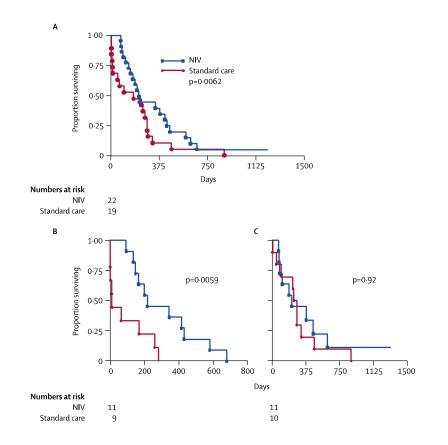
#### • Qualité de vie liée à la santé :

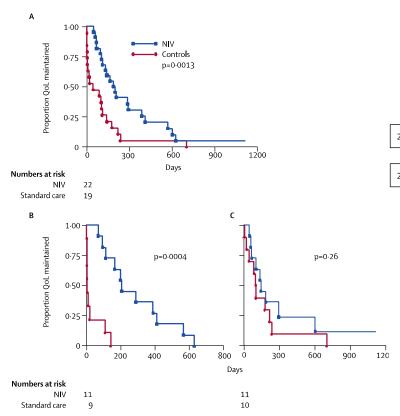
- Perception de son état de santé : déclaratif
- Evaluation par des échelles : SF36
- Echelles génériques, échelles spécifiques
- Plusieurs dimensions : douleur, ADL, relationnel, professionnel, psychisme, communication, mobilité
- Souvent utiliser comme évaluation de la participation
- Qualité de vie : bien être (Albrecht 1996)
- Qualité de vie comme capacité à exercer un role social (Levine 1994)

### **QUALITÉ DE VIE**

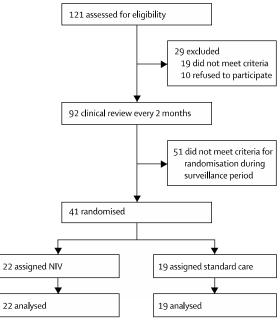
# Effects of non-invasive ventilation on survival and quality of life in patients with amyotrophic lateral sclerosis: a randomised controlled trial

Stephen CBourke, Mark Tomlinson, Tim L Williams, Robert EBullock, Pamela JShaw, GJohn Gibson









# Qualité de Vie patients BM hauts

cine and the American Academy of Physical Medicine and Rehabilitation

From The Northern California Regional Spinal Injury System, Santa Clara Valley Medical Center (Dr. Hall, Mr. Wright, Dr. Werner), and Silicon Valley Independent Living Center (Ms. Knudsen), San Jose, CA; The Rocky Mountain Regional Spinal Cord Injury System, Craig Hospital, Englewood, CO (Ms. Charlifue); and Baylor College of Medicine, The Institute for Rehabilitation and Research, Houston, TX (Dr. Graves).

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subgroup. Only in the last 20 years has the ibeen sufficient to begin evaluating the chargroup separately from all persons with SC from individuals with C5 through C8 leve reported the incidence of C1 to C3 spinal ir million per year, and C4 level incidence as year. Neurologically complete tetraplegia mately 17.5% of all SCIs.<sup>7</sup>

Complete tetraplegia caused by SCI a

There was greater need for personal assistance services in the VA group, as expected, and they more often hired RN and LVN level care than the VI group, and more paid than unpaid assistance. They also had more turnover in help. The individual with SCI is most often the person training attendants. This speaks to the need to intensively train inpatients and continue

Table 11: Responses to Question "What Changes Would Improve the Quality of Your Life?"

	VI	VA
None	10 (15)	2 (13)
Spouse, family, SO support	14 (21)	4 (25)
-		

#### 70% qualité de vie bonne ou excellente

Etes vous heureux d'être en vie? 76/82 OUI

IIGH TETRAPLEGIA, Hall

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Table 8: Days Out of the House per Week

VI VA

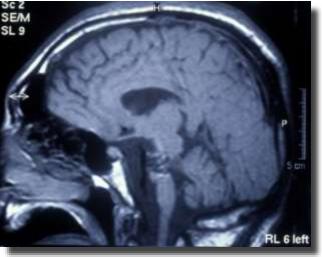
# Quality of life in patients with locked-in syndrome: Evolution over a 6-year period

Marie-Christine Rousseau<sup>1,2\*</sup>, Karine Baumstarck<sup>2,3</sup>, Marine Alessandrini<sup>2</sup>, Véronique Blandin<sup>4</sup>, Thierry Billette de Villemeur<sup>5</sup> and Pascal Auguier<sup>2,3</sup>

- Qualité de vie (ACSA) plutôt bonne :
  - Moins bonne que les traumatisme cervicaux (coup de fouets)
  - Meilleures que les prothèses faciales ou Maladie alzheimer au moment du diagnostic
- Une qualité de vie stable sur la période
- Une qualité de vie non corrélée au handicap physique
- Un rôle majeur de la communication













Social Science & Medicine 48 (1999) 977±988

#### The disability paradox: high quality of life against all odds

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University of Illinois at Chicago, School of Public Health, 2035 West Taylor Street, Chicago, IL 60612, USA

Le paradoxe du handicap



 N'est pas corrélée à l'intensité du déficit moteur ou de la dépendance physique (Simmons Z et al, 2000 Neurology 55:388-392; Laureys S, 2005 Prog Brain Res 150:495-510)

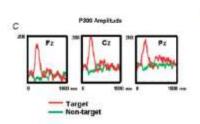
- Facteurs influençant la qualité de vie :
  - La douleur
  - La dépression
  - La communication => BCI & LIS
  - Les interactions sociales

LA QUALITÉ DE VIE













## CHRONIC PAIN, DEPRESSION AND QUALITY OF LIFE IN INDIVIDUALS WITH SPINAL CORD INJURY: MEDIATING ROLE OF PARTICIPATION

Rachel MÜLLER, PhD<sup>1,2</sup>, Gunther LANDMANN, MD<sup>3</sup>, Markus BÉCHIR, MD<sup>4</sup>, Timo HINRICHS, MD<sup>5</sup>, Ursina ARNET, PhD<sup>1,2</sup>, Xavier JORDAN, MD<sup>6</sup> and Martin W. G. BRINKHOF, PhD<sup>1,2</sup>, for the SwiSCI Study Group

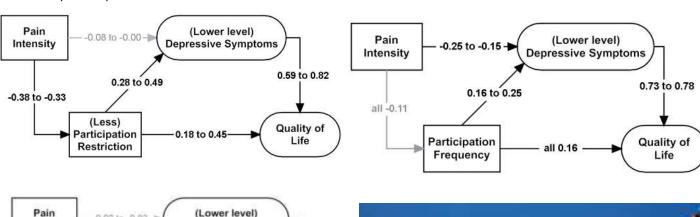
From the ¹Swiss Paraplegic Research (SPF), Nottwil, ²Department of Health Sciences and Health Policy, University of Lucerne, Lucerne, ³Centre for Pain Medicine, Swiss Paraplegic Centre, ⁴Department of Intensive Care, Pain and Operative Medicine, Swiss Paraplegic Centre, Nottwil, ⁵Division of Sports and Exercise Medicine, Department of Sport, Exercise and Health, University of Basel, Basel and ⁵Spinal Cord Unit, Clinique Romande de Réadaptation SuvaCare, Sion, Switzerland

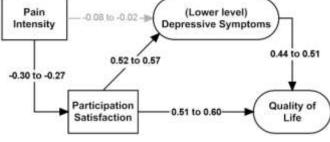
**Table III.** Pearson correlation between outcome participation, depressive symptoms and quality of life (n = 834)

				· · ·		
	PI	PF	PR	PS	D	QoL
Pain intensity (PI) Participation	1.000					
frequency (PF)	-0.111**	1.000				
Participation restrictions (PR)	-0.254**	0.496**	1.000			
Participation satisfaction (PS)	-0.203**	0.345**	0.506**	1.000		
Depressive symptoms (D)	-0.188**			0.566**		1 000
Quality of life (QoL)	-0.271**	0.324**	0.462**	0.640**	0.631*	1.000

<sup>\*</sup>Correlation is significant at the 0.05 level (2-tailed).

J Rehabil Med 2017; 49: 489-496







<sup>\*\*</sup>Correlation is significant at the 0.01 level (2-tailed).



- Elle peut être bonne
- Ne dépend pas du handicap moteur et de la dépendance physique
- Nécessite la redéfinition d'un équilibre entre le corps, l'esprit et l'environnement
- Éviter de se projeter

Qualité de vie et handicap



### **MERCI!**