



## Near-Death Experiences in patients with locked-in syndrome: Not always a blissful journey



Vanessa Charland-Verville<sup>a,\*</sup>, Zulay Lugo<sup>a,1</sup>, Jean-Pierre Jourdan<sup>b,2</sup>,  
Anne-Françoise Donneau<sup>c,3</sup>, Steven Laureys<sup>a,\*</sup>

<sup>a</sup> Coma Science Group, University and University Hospital of Liège, Cyclotron Research Center, GIGA-Research B34, Sart Tilman, 4000 Liège, Belgium

<sup>b</sup> International Association For Near Death Studies, Avenue Flourens Aillaud 28, 04700 Oraison, France

<sup>c</sup> Department of Statistics, School of Public Health, University of Liège, Avenue de l'Hôpital 3, 4000 Liège, Belgium

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### ABSTRACT

Memories of Near-Death Experiences (NDEs) most often are recounted as emotionally positive events. At present, no satisfactory explanatory model exists to fully account for the rich phenomenology of NDEs following a severe acute brain injury. The particular population of patients with locked-in syndrome (LIS) provides a unique opportunity to study NDEs following infratentorial brain lesions. We here retrospectively characterized the content of NDEs in 8 patients with LIS caused by an acute brainstem lesion (i.e., “LIS NDEs”) and 23 NDE experiencers after coma with supratentorial lesions (i.e., “classical NDEs”). Compared to “classical NDEs”, “LIS NDEs” less frequently experienced a feeling of peacefulness or well-being. It could be hypothesized that NDEs containing less positive emotions might have a specific neuroanatomical substrate related to impaired pontine/paralimbic connectivity or alternatively might be related to the emotional distress caused by the presence of conscious awareness in a paralyzed body.

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### 1. Introduction

In 1975, the term “Near-Death Experience” was coined to describe memories reported by some individuals who had recovered consciousness after coma (Moody, 1975). Near-Death Experiences (NDEs) are classically associated with positive emotions like peacefulness, well-being, happiness and joy (Charland-Verville et al., 2014; Greyson, 2003; Nelson, Mattingly, Lee, & Schmitt, 2006). To date, few NDEs reports containing negative emotions have been documented (Greyson & Bush, 1992). Although NDEs classically arise in the context of a coma caused by a severe acute brain insult (e.g., cardiac arrest, trauma), their associated memories are reported as being phenomenologically very rich and detailed (Thonnard et al., 2013). NDEs can also be reported in non-life-threatening situations (e.g., stressful events, childbirth, fever, concussion, sleep

*Abbreviations:* LIS, locked-in syndrome; NDE, Near-Death Experience; CVA, cerebrovascular accident; IANDS, International Association for Near-Death Studies.

\* Corresponding authors. Fax: +32 4 3668449.

*E-mail addresses:* [vanessa.charland-verville@ulg.ac.be](mailto:vanessa.charland-verville@ulg.ac.be) (V. Charland-Verville), [steven.laureys@ulg.ac.be](mailto:steven.laureys@ulg.ac.be) (S. Laureys).

<sup>1</sup> Fax: +32 4 3668449.

<sup>2</sup> Fax: +33 6 73393034.

<sup>3</sup> Fax: +32 43662596.

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or meditation; e.g., see Charland-Verville et al., 2014). In the past 40 years, both psychological and physiological explanations have been suggested (for review see Facco & Agrillo, 2012; Greyson, 2013). Proposed hypotheses have focused on the possible influences of cultural background (Kellehear, 1993); depersonalization (Greyson, 2013) and other personality traits such as the tendency for dissociation (Greyson, 2000); false memories (Braithwaite, 2008; French, 2001) and the expectancy of an incoming death causing an altered mental state (Appleby, 1989; Blackmore & Troscianko, 1988; Britton & Bootzin, 2004). Neurobiological theories have discussed the potential role of pharmacological factors (e.g., acting on NMDA receptor systems such as ketamine; Jansen, 1989); neurotransmitter imbalances (e.g., endorphin release; Carr, 1981); altered blood gas levels (Klemenc-Ketis, Kersnik, & Grmec, 2010) and retinal ischemia (Blackmore, 1996); paroxysmic temporal lobe disorders (Blanke, Landis, Spinelli, & Seeck, 2004; Britton & Bootzin, 2004; Hoepner et al., 2013) and REM-sleep intrusions (Nelson et al., 2006). To date however, no satisfactory evidence-based explanatory model exists to fully account for the rich phenomenology of NDEs following a severe acute brain damage (Mobbs & Watt, 2011).

The scientific study of the neural correlates of NDEs represents a major challenge since the genuine subjective experience occurring during coma cannot be replicated in controlled settings. Empirical studies of NDEs after life threatening situations have mostly been conducted in cardiac arrest survivors (French, 2005; Greyson, 2003; Klemenc-Ketis et al., 2010; Parnia, Waller, Yeates, & Fenwick, 2001; Schwanager, Eisenberg, Schechtman, & Weiss, 2002; van Lommel, van Wees, Meyers, & Elfferich, 2001) and much less after severe brain injury of traumatic or other origin (Hou, Huang, Prakash, & Chaudhury, 2013). We recently observed that the etiology of coma (i.e., anoxic, traumatic or other) does not seem to significantly influence the intensity or content of NDEs (Charland-Verville et al., 2014). To the best of our knowledge, however, no studies could correlate specific features of NDEs with the spatial location of the acquired brain damage that caused the coma or loss of consciousness. As a first step towards that aim, we here compared the phenomenology of NDEs in patients who survived a coma caused by an *infratentorial* lesion (i.e., damaging the brainstem and classically causing a locked-in syndrome; LIS) with a group of “classical NDEs” occurring after *supratentorial* lesions.

## 2. Material and methods

In collaboration with the French Association for Locked-In Syndrome (ALIS; <http://alis-asso.fr>), patients who had an acute acquired brain stem lesion and subsequent LIS who retrospectively recalled memories from their coma period were referred to our research team. They were invited to fill in a structured questionnaire, aided by a proxy. The questionnaire included demographic and clinical information (age, gender, duration and etiology of LIS) and the Greyson NDE scale (Greyson, 1983). The scale was introduced by the question “Do you recall any memories from the coma/unconsciousness period associated with your accident?”. In the affirmative, the patient was invited to fill the Greyson NDE scale. The scale consists of a validated 16-item multiple-choice tool (i.e., scores ranging from 0 to 32) used to characterize the experience’s content (items are related to 16 NDE core features; Lange, Greyson, & Houran, 2004). For each item, the scores are arranged on an ordinal scale ranging from 0 to 2 (i.e., 0 = “not present”, 1 = “mildly or ambiguously present” and 2 = “definitively present”; Lange et al., 2004). For statistical analyses, a feature was considered present when participants scored an item as 1 or 2. Patients with LIS whose experience did not meet the accepted criteria of NDE (i.e., Greyson NDE scale’s total score  $\geq 7$ ; Lange et al., 2004) were excluded from further analyses.

“LIS NDEs” (i.e., coma-survivors post *infratentorial* brain lesion) were compared to patients with “classical NDEs” (i.e., coma-survivors post *supratentorial* brain lesions). The latter cohort was recruited in collaboration with the International Association for Near-Death Studies (IANDS France and IANDS Flanders) and the Coma Science Group (University of Liège, Belgium). Completion of the anonymous questionnaire was voluntary and taken as consent for participation in the survey. The study was approved by the ethics committee of the Faculty of Medicine of the University of Liège.

Differences between “LIS NDEs” and “classical NDEs” groups were assessed using Student’s *t*-test (age and time since insult) and with Fisher’s exact test for qualitative variables. Results were considered to be significant at the 5% critical level ( $p < .05$ ) and were expressed as mean  $\pm$  standard deviation (SD) for quantitative variables and as counts and proportions (%) for qualitative variables. To correct for multiple comparisons with the 16 Greyson NDE scale items, we applied a Bonferroni correction setting the criterion for statistical significance at  $p < .003$ . Data analysis was carried out using SPSS (Statistical Package for the Social Sciences, version 22.0, SPSS Inc., Chicago, IL, USA).

## 3. Results

14 patients with LIS recalled having had memories of their coma period. 8 (57%) qualified as a NDE according to the Greyson NDE scale criteria (i.e., total score  $\geq 7$ ; Lange et al., 2004). Table 1 reports the demographic information of the “LIS NDEs” and “classical NDEs”.

There were no significant differences in age and interval since NDE, as well as for gender and etiology ratios (i.e., vascular cerebral accident (CVA) vs. trauma). The content (i.e., NDE scale features) of reported NDEs differed between both groups. As compared to the “classical NDEs” group, “LIS NDEs” reported less frequently feelings of peacefulness or well-being (96% vs. 38%, respectively,  $p = .0018$ ). The comparison between the two groups did not show significant differences on any other item of the Greyson NDE scale – note that at a less conservative uncorrected threshold, “LIS NDEs” less frequently showed life review (26% vs. 75%;  $p = .031$ ) and joy (70% vs. 25%;  $p = .083$ ), as compared to the “classical NDE” cohort (see Fig. 1).

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