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

Vanessa Charland-Verville [a,*], Zulay Lugo [a,1], Jean-Pierre Jourdan [b,2], Anne-Françoise Donneau [c,3], Steven Laureys [a,*]

[a] Coma Science Group, University and University Hospital of Liège, GIGA-Research B34, Avenue de l'hôpital 1, Sart Tilman, 4000 Liège, Belgium
[b] International Association For Near Death Studies, Avenue Flourens Aillaud 28, 04700 Oraison, France
[c] 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.

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 (V. Charland-Verville), steven.laureys@ulg.ac.be (S. Laureys).
[1] Fax: +32 4 3668449.
[2] Fax: +33 6 73393034.
[3] 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); paroxistic 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 exits 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; Schwaninger, 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 $\geqslant 7$; 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 ± 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 $\geqslant 7$; 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).

Table 1
Demographical information of patients with NDE in LIS vs. patients with "classical" NDEs.

	"LIS NDEs" $n = 8$ (%)	"Classical NDEs" $n = 23$ (%)	p Value
Gender – female	5 (63)	12 (52)	.890
Etiology	7 brainstem CVA (88)	20 supratentorial CVA (87)	.968
	1 brainstem trauma (12)	3 supratentorial trauma (13)	
Age at NDE (mean in years ± SD)	31 ± 6	31 ± 14	.959
Time since NDE (mean in years ± SD)	19 ± 9	19 ± 9	.732

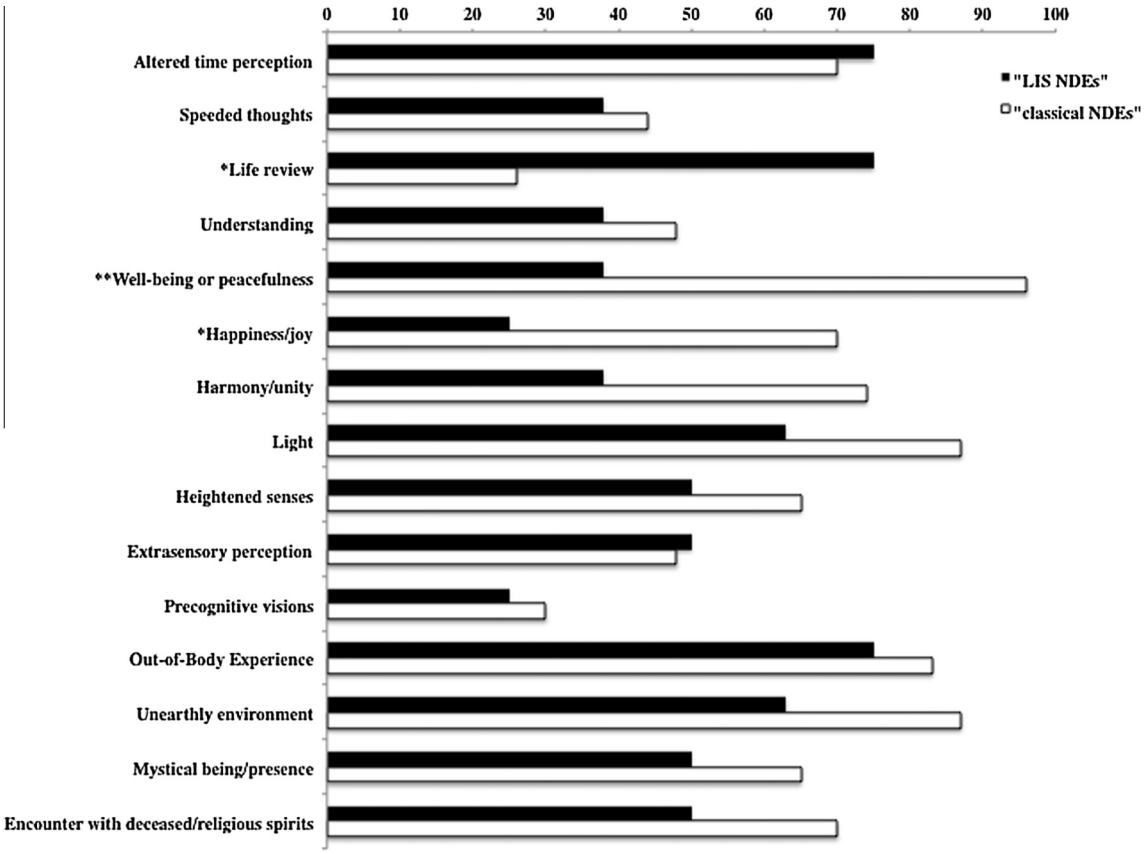

Fig. 1. Frequency of reported Greyson NDE scale items in patients with locked-in syndrome (LIS; $n = 8$) and "classical NDEs" after coma ($n = 23$); *uncorrected $p < .05$; **corrected $p < .05$.

4. Discussion

Our data show that patients with LIS who retrospectively report a NDE subsequent to an acute brainstem lesion of ischemic or traumatic origin, experience this event as less positive as compared to "classical NDEs" following coma after supratentorial brain damage. The most frequently reported core NDE feature in the "classical NDEs" group was the feeling of well-being or peacefulness, corroborating previous studies on NDEs after acute anoxic or traumatic coma (Charland-Verville et al., 2014; Greyson, 2003; Nelson et al., 2006). NDEs with negative emotions have been previously documented but only in about 1–2% of retrospectively collected reports (Charland-Verville et al., 2014; Greyson & Bush, 1992). "*Negative*" NDEs still remain understudied and possibly also underestimated perhaps due to the possible individuals' reluctance to disclose them (Greyson & Bush, 1992).

It is important to stress that the present convenience sample of patients with LIS who recounted memories of their coma period might not be representative due to a possible selection bias. In addition, the intensity of NDE core features seem to differ when comparing retrospective and prospective study designs (Charland-Verville et al., 2014; Mobbs & Watt, 2011), highlighting the need for controlled prospective collection of NDE memories and neuroimaging data. Our data do not permit to draw any conclusions on the overall incidence of NDEs in patients with LIS and no high-resolution structural imaging analyses could be performed.

The observed lower proportion of patients with LIS experiencing peacefulness (and the possible trend towards the increased frequency of autobiographical life review and lesser experienced joy) could be related to an altered connectivity in (para)limbic systems secondary to the acute pontine brainstem dysfunction (Baxter & Murray, 2002), similar to what can be observed in REM sleep intrusions and nightmares (Hobson, Stickgold, & Pace-Schott, 1998; Nelson et al., 2006). Some authors have indeed postulated that positive emotions and autobiographical memory flashbacks in NDEs could be linked to mesiotemporal dysfunction (involving amygdala and hippocampi) (Mobbs & Watt, 2011). The presence of "life review", usually one of the least reported features by NDE experiencers (Charland-Verville et al., 2014; Greyson, 2003; Nelson et al., 2006), was here reported in 6/8 patients with LIS. It could be hypothesized that the specific ventral pontine brainstem lesions causing the LIS and their potential repercussion on afferent and efferent pathways with (para)limbic/midbrain structures and neurotransmitters systems (Blackmore & Troscianko, 1988; Nelson et al., 2006) could account for the observed differences in NDEs content. Thus, when brain lesions occur at the infratentorial level, individuals might experience less positive emotions – and possibly more memory flashbacks.

Alternatively, it could be argued that finding oneself in a paralyzed body might account for the potential diminished positive phenomenology and the presence of possibly negative or frightening emotions associated with the experience. A parallel could be made with the pharmacologically induced LIS that can exceptionally be encountered in general anesthesia when patients receive muscle relaxants together with inadequate amounts of anesthetic drugs. Testimonies from these patients relate that the worst aspect of the experience was the anxious desire to move or speak while being unable to do so (e.g., Sandin, Enlund, Samuelsson, & Lennmarken, 2000). Although previous studies have suggested that experiencing a NDE in the course of a life threatening event might produce a positive effect on patients' well-being and diminish psychological distress (Greyson, 1997), experiencing a negative NDE could lead to the formation of post-traumatic stress disorder symptoms and lead to a lower quality of life, pointing to the importance of a psychological follow-up (Greyson, 1997).

5. Conclusions

We here report that patients with NDEs following an acute brainstem lesion and subsequent LIS, less frequently recount positive emotions. Further studies should disentangle whether the emotional valence of NDEs have a specific neuroanatomical substrate (i.e., could be related to an altered limbic/pontine connectivity) or should be seen in light of the specific emotional distress caused by motor paralysis and residual conscious awareness.

Competing interests

None.

Authors' contributions

The authors declare they have participated in the study: Concept and design: SL, VCV; Acquisition of data: ZL, VCV; Statistical analyses and interpretation of data: VCV, SL, AFD; Drafting of the manuscript: VCV, SL; Critical revision of the manuscript for important intellectual content: VCV, SL, JPJ, ZL, AFD. All authors have seen and approved the final version.

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