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## Short Communication

## From armchair to wheelchair: How patients with a locked-in syndrome integrate bodily changes in experienced identity

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## ABSTRACT

Different sort of people are interested in personal identity. Philosophers frequently ask what it takes to remain oneself. Caregivers imagine their patients' experience. But both philosophers and caregivers think from the armchair: they can only make assumptions about what it would be like to wake up with massive bodily changes. Patients with a locked-in syndrome (LIS) suffer a full body paralysis without cognitive impairment. They can tell us what it is like. Forty-four chronic LIS patients and 20 age-matched healthy medical professionals answered a 15-items questionnaire targeting: (A) global evaluation of identity, (B) body representation and (C) experienced meaning in life. In patients, self-reported identity was correlated with B and C. Patients differed with controls in C. These results suggest that the paralyzed body remains a strong component of patients' experienced identity, that patients can adjust to objectives changes perceived as meaningful and that caregivers fail in predicting patients' experience.

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## 1. Introduction

The role of the body in personal identity has been widely discussed in recent work (Baker, 2000; Damasio, 1999; Eilan, Marcel, & Bermudez, 1995; Romagnoli, 2010; Schechtman, 2005; Tsakiris, Prabhu, & Haggard, 2006; Tsakiris, Schutz-Bosbach, & Gallagher, 2007). In particular, the bodily requirements for diachronic identity have been explored – what and how much of the body must remain for someone to be the same and to survive across time? (Coburn, 1960; Lewis, 1976; Nayac, 1968; Parfit, 1971; Penelhum, 1970; Shorter, 1962; Williams, 1960, 1970a, 2008). Diachronic identity refers to the property of any being to remain itself across time. In the case of personal diachronic identity, it seems fairly intuitive that the 31-year old Sophie is in some sense the same person as the 15-year old Sophie, despite the constant cells renewal in her body (Carosella, Saint-Sernin, Capelle, & Sanchez-Sodondo, 2008; Christman, 2004; Damasio, 1999; Gallagher, 2000; Morin, 2006). But would a more radical bodily change impact on Sophie's personal identity?

Most philosophers are interested in constructing a theory of personal identity. They want to determine what it is to be one person over time. They therefore make hypotheses about the ontological conditions required for the diachronic continuity of human identity. In this sort of inquiry, personal identity is something objective that can be determined from the armchair. The question the philosopher might ask with regard to the role of the body in personal identity is: "What degree

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of body/brain continuity is required for anyone's personal identity to be preserved *in itself*?" One way to answer this question is to construct fictional cases involving massive bodily damage to help us – that is, we theorizers with intact healthy bodies – to identify the role of the body in limiting personal identity (Cohnitz, 2003; Williams, 1970b). Philosophers thus imagine cases like the brain-transplant victim (Shoemaker, 1963), the exchange of bodies machine (Williams, 1973), the body duplication or clone case (Nozick, 1981), the teletransportation machine or the divided-mind victim (Parfit, 1984). In the common synopsis of the brain-transplant victim thought experiment, a surgeon removes a patient's brain to transplant it in another body, either another patient's body or a synthetic clone's body. This way, nothing but the brain remains of the initial body. It has been claimed that, after surgery, the patient whose brain was transplanted would still be herself despite this radical bodily change because the bodily continuity was granted by the minimal brain activity supposedly preserved during the surgery. A minimal brain activity would thus be an objective criterion for diachronic identity in persons. That is to say that personal identity is preserved whenever a minimal brain activity is preserved, no matter what degree of other bodily change the person endures.

But this approach is frustrating. First, it does not seem to tell us much about our experience because it relies on fictional cases, both impossible in the current neurosurgery's frame and highly problematic in principle. For instance, where exactly should the surgeon cut the brain: above or under the brain stem? Should he transplant the spine as well to ensure the nervous communication? What about the afferent and efferent nerves, then? As soon as one tries to specify the neurological concrete surgery, these cases reveal the theoretical assumption that the brain, even though physical, is somehow easily separable from rest of the body. Considering the brain as an autonomous recipient for personal identity separable from the 'body', this approach still seems dualist in its presuppositions. It also fails in describing our experience because the criterion of a minimal brain activity equates diachronic identity with our merely being alive – which may get us diachronic identity of a human being but not *personal* diachronic identity. Although this sounds like a perfectly legitimate claim, it is thus not of much help regarding living patients actually enduring major bodily changes that can possibly threaten their personal identity, as experienced from the wheelchair.

Secondly, this strategy relying on fictional cases might get it wrong about what it would be like to *actually* wake up in a very different body. These thought experiments rely on our having intuitions *from the armchair* about what the experience would be like. Parfit justifies the use of fictional cases thusly: "This criticism [against fictional cases] might be justified if, when considering such imagined cases, we had no reactions [...] By considering these cases, we discover what we believe to be involved in our own continued existence, or what it is that makes us now and ourselves next year the same people. We discover our beliefs about the nature of personal identity over time. Though our beliefs are revealed most clearly when we consider imaginary cases, these beliefs also cover actual cases and our own lives." (Parfit, 1984). However, these beliefs may as well be wrong. When relying on fiction, no belief about personal identity can be tested or verified through empirical research.

These remarks lead us to adopt two methodological constraints on our theory. In this survey, we investigate how bodily changes are integrated in the personal identity of *real* patients (*vs* fictional cases) and we question these *in situ* patients about their *actual* experience of personal identity (*vs* intuitions from the armchair). We want to determine, in real life, how far someone's body can objectively change and her *experienced identity* be preserved. Our main concern in this survey is what it is like for a person to feel the same or different over time when enduring a massive bodily change. It should be noted that a person's psychological experience about their relationship to earlier conditions may not hold implication for whether their objective identity has been preserved. Therefore a patient can describe a *feeling* of discontinuous identity, meaning that she does not recognize herself in a new condition, without her objective identity to be discontinuous. We shall call *in situ* the patients' self-report of experienced identity *from the wheelchair* – as opposed to the exterior perspective of philosophers or caregivers on patients' actual experience, which we shall call *from the armchair*.

We choose to investigate the integration of massive bodily changes in patients with a locked-in syndrome (LIS). Classical LIS patients<sup>1</sup> offer us a unique opportunity to study this matter as they suffer from a full-body paralysis with preserved cognitive functions (Bruno, Bernheim, Schnakers, & Laureys, 2008; Bruno, Pellas, Schnackers et al., 2008; Gosseries, Bruno, Vanhauzenhuysse, Laureys, & Schnakers, 2009; Laureys, Perrin, & Bredart, 2007; Schnakers et al., 2008). LIS often results from a vascular accident touching the brain stem (Laureys et al., 2005) and is characterized by complete awareness and the ability to communicate using vertical eye movements or blinking while being paralyzed and voiceless (American Congress of Rehabilitation Medicine, 1995). Notice that LIS patients have lost motor control but have preserved sensations, at various levels<sup>2</sup>. Therefore, the massive bodily changes investigated in this survey impact on the sense of agency (Schechtman, 2005; Tsakiris et al., 2006) rather than the sense of embodiment (O'Regan, Myin & Noë, 2005). Knowing that these patients have endured an objective massive bodily change, we raise three questions. (A) Do they feel like the same person as before the accident? (B) Do they recognize these 'new' bodies as theirs? and (C), if they do, on what criterion then relies their subjective feeling of a preserved personal identity?

A three parts questionnaire – adapted from the McGill Quality of Life questionnaire (Cohen, Mount, Strobel, & Bui, 1995) and the Coma Science Group ALIS questionnaire (Bruno et al., 2011; Association of the Locked-In Syndrome-ALIS, France,

<sup>1</sup> It is important to stress that, at present, there are very few case reports of complete LIS (i.e. communicating solely via electroencephalography signals; Schnakers et al., 2009) and hence a study as the one here presented is currently impossible in this condition. Therefore, the closest we can get to test our hypothesis is the study of classical LIS patients.

<sup>2</sup> The role of the body in patients with neither motor control nor sensation is to be investigated in a forthcoming survey.

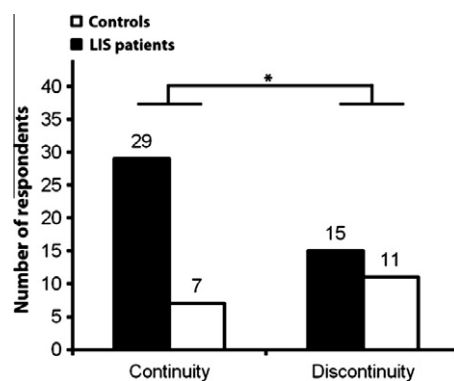
<http://www.alis-asso.fr>) – was constructed to address these questions: (A) experienced personal identity, (B) body representation and (C) experienced meaning in life. In the first part, (A) experienced personal identity, we want to determine if such a massive bodily change can be integrated in the patients' subjective identity. If it does, we expect the patients to report a continuous experienced identity, namely they feel like the same person as before the accident. If not, a discontinuous experience should appear with reports such as "I am not the same person anymore". In the second part, (B) body representation, we want to determine if their new bodies are still part of their experienced identity. If it is so, we expect the patients to have a positive attitude toward their bodies, reporting a sense of ownership (Damasio, 1999; Tsakiris et al., 2007). If not, a discontinuous experience should again appear with reports such as "This is not me, I am trapped into this body". We focus here on the conscious experience of being a body (De Preester, 2007) rather than on a theoretical body targeted by most of the models of body representation (Carruthers, 2008) or body schema (Gallagher, 2005). In the third part, (C) experienced meaning in life, we want to test the hypothesis that, no matter the degree of objective bodily change, whether the *experienced* identity is reported as continuous by the patients is correlated to their experiencing a meaningful life. We borrow this concept from the fifth part of McGill quality of life test entitled "Degree of experienced meaning and purpose in life". If this is true, we expect patients reporting a continuous identity in part A to report a correlated quality of life in part C.

When investigating the experience of the patients *in situ*, it is a closely related issue to determine whether there is a difference between the patients' self-report and the caregivers' from the armchair prediction. Indeed, if the actual experience matters in the criteria of personal identity, then it is possible for persons like caregivers or medical teams to form false judgments on their patients' feelings – which is obviously a great ethical concern regarding non-communicative patients. From an exterior point of view, it seems difficult to endure such a handicap without failing in experiencing a continuous self. When asked if they themselves would accept to be kept alive in such a situation, medical teams often answer that they would not, predicting a negative experience for the patients (Demertzi et al., 2011; Lule et al., 2009). Most of the patients, on the contrary, report a positive wellbeing (Bruno, Pellas, Bernheim et al., 2008; Bruno et al., 2011). We therefore add a control group of healthy medical professionals, well acquainted with the clinical syndrome of LIS, in this survey to compare patients' report and controls' prediction on the integration of bodily changes in the experience of personal identity.

Our questionnaire was distributed to 168 LIS patients (members of ALIS) and 20 healthy medical professionals (Avicenne Hospital, France) matched for gender and age. Each part of the questionnaire was scored separately (sum of the five items). An additional global score (sum of 15 items' score) was used to evaluate an overall experience of the self in the context of an important physical change. Half of the items were presented in a negative form ("I don't recognize myself") and half in a positive form ("I still am the same person") in order to avoid response biases for positive responses (Fiske, 2008). A total number of 15 items (five for each dimension) were included in the questionnaire. The responses were given on a four-point Likert scale ("Totally agree, Agree, Disagree, Totally disagree"). Responses to each item should be interpreted as follow: positive scores (+1, +2), reflect a "continuity profile" (meaning the patient experiences a continuous sense of self before and after the LIS); negative scores (−1, −2), reflect a breach in identity or "discontinuity profile" (meaning the patient reports a discontinuous experience of herself before and after the LIS).

A redundant item was added from the Coma Science Group ALIS questionnaire ("At home, I keep a role fulfilling my needs and those of my family"). Patients answered the same question twice in two different questionnaires. A strong correlation in their answers is hypothesized to reflect a good reliability of the questionnaire towards the patients' attitude.

For LIS patients, the survey was conducted at home in presence of a caregiver who was facilitating the response procedure – but was told not to influence it. Patients selected their responses matching a communication code following the instruction: "Determine for each item if you totally agree, agree, disagree or totally disagree. Blink the suitable number of time to choose the answer. For "Totally Agree", blink once; for "Agree", blink twice; for "Disagree" blink three times and for "Totally disagree", blink four times." For controls, the survey was conducted at the Avicenne Hospital (AP-HP Paris, France) after a



**Fig. 1.** Mean continuity scores (i.e., the experience of a continuous sense of self before and after the LIS) and discontinuity scores (i.e., the experience of a discontinuous sense of self before and after the LIS) in 20 controls (in white) and 44 LIS patients (in black). More patients self-reported a continuity (vs discontinuity) in their personal identity after the acute loss of motor control, as compared to third-person views from healthy caregivers.

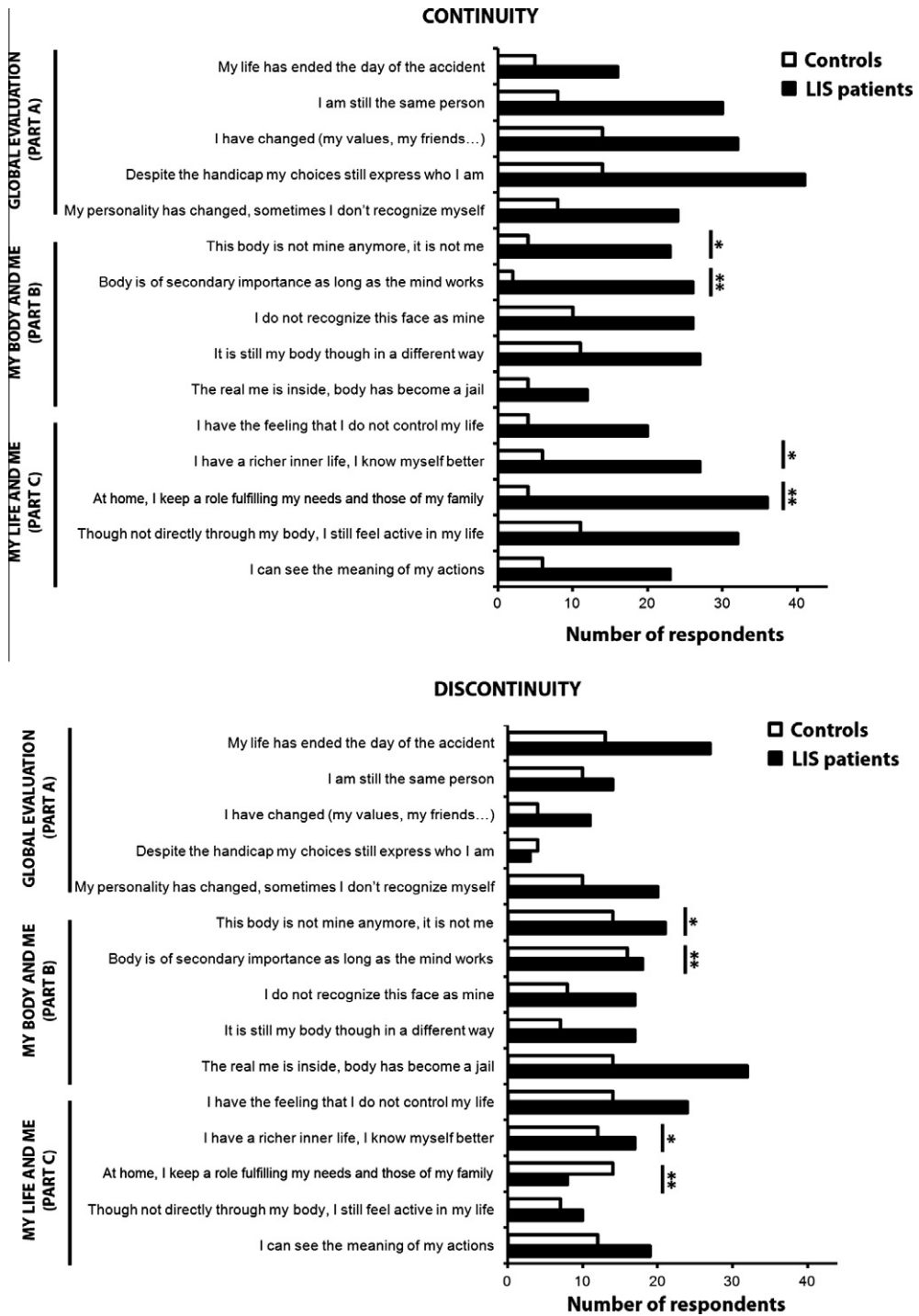


Fig. 2. Continuity and discontinuity of personal identity as formulated by the questionnaire items in LIS patients (n = 44) and healthy controls (n = 20; chi square tests, \*p < .05, \*\*p < .001).

short reminder of the definition of LIS as: “The locked-in syndrome is characterized by preserved awareness, relatively intact cognitive functions and by the ability to communicate while being paralyzed and voiceless. Five criteria are present: sustained eyes opening and preserved vertical eye movement, preserved higher cortical functions, aphonia or severe hypophonia, quadriplegia or quadriparesis and primary mode of communication that uses vertical eye movement or blinking”

**Table 1**

Correlation coefficient matrix (Kendal's tau) among the partial scores A, B, and C of the questionnaire for the LIS patients.

|                            | Global evaluation (Part A) | My body and me (Part B) | My life and me (Part C) | Mean B–C |
|----------------------------|----------------------------|-------------------------|-------------------------|----------|
| Global evaluation (Part A) | –                          | –                       | –                       | –        |
| My body and me (Part B)    | 0.305*                     | –                       | –                       | –        |
| My life and me (Part C)    | 0.288*                     | 0.364**                 | –                       | –        |
| Mean BC                    | 0.362**                    | 0.725**                 | 0.736**                 | –        |

\*  $p < .05$ .\*\*  $p < .01$ .

(American Congress of Rehabilitation Medicine, 1995). Controls were instructed to imagine being LIS themselves in order to evaluate their predictive judgments while not being in the actual situation themselves.

Data were analyzed using SPSS v.14 (SPSS Inc., Chicago, 2005). Correlation analyses (Kendall's tau) and chi-square tests were ordered. Results were considered significant at  $p < .05$ .

## 2. Results

In controls, from the 20 distributed questionnaires, 20 were returned; none were excluded due to missing data (6 women, mean age 48, from 26 to 64 years old). From the 168 distributed questionnaires in LIS patients, 53 were returned (response rate 32%). Nine questionnaires were excluded from the analysis due to missing data (44 LIS patients, 14 women, mean age 53, from 27 to 75 years old).

In LIS patients, the mean global score was positive ( $3 \pm 7$  SD) whereas in controls, the mean global score was negative ( $-1 \pm 6$  SD). Significantly more LIS patients reported a continuity (vs discontinuity) in their experienced identity when compared to healthy controls ( $\chi^2 = 3.8, p = .048$ , Fig. 1).

Partial scores (Part A, B and C) are summarized in Fig. 2. Significant differences between LIS patients and controls were observed in scores of Part C ( $t = 3.64, p = .001$ ). Four items focused on the most important difference between patients and controls: B1, "This body is not mine anymore, it is not me" ( $\chi^2 = 4.6; p = .03$ ); B2, "Body is of secondary importance as long as the mind works" ( $\chi^2 = 11.9; p < .001$ ); C2 "I have a richer inner life, I know myself better" ( $\chi^2 = 4; p = .045$ ); C3, "At home, I keep a role fulfilling my needs and those of my family" ( $\chi^2 = 10.9; p < .001$ ).

For LIS patients, the correlation coefficient matrices (Kendal's tau) are summarized in Table 1. The correlation between global evaluation (Part A) and the mean score of body representation (Part B) and experienced meaning in life (Part C) was significant ( $\tau = 0.36, p < .01$ ) implying that the questionnaire targets one and the same concept of self. The correlation between global evaluation (Part A) and body representation (Part B) was significant ( $\tau = 0.31, p < .05$ ), implying that the body representation is an important component of personal identity. The correlation between global evaluation (Part A) and experienced meaning in life (Part C) was significant ( $\tau = 0.29, p < .05$ ) implying that the experienced meaning in life is an important component of personal identity.

## 3. Discussion

We here aimed to investigate how massive bodily changes can be integrated in real patients' experienced identity from an *in situ* point of view. Our question was "How far can someone's body objectively change in real situations and *her subjective experienced personal identity* be preserved?" and not "What degree of body objective continuity is required for anyone's personal identity to be preserved *in itself*?"

We found that the massive bodily changes resulting in a full-body paralysis except for the eye movements in LIS was most of the time well integrated in our patients' experienced identity, most of the patients reporting a continuous profile in part (A) – items targeting the experienced identity only – and a positive global score – including items targeting their body representation and overall experienced meaning in life. As for our first question, most of our LIS patients enduring a massive bodily change do feel the same as before the accident, which seems to indicate that such an objective change, in real life, can be integrated in one's experienced identity. It should be noted, however, that the low response rate might introduce a bias even if the communication difficulties in LIS patients also account for this (Bruno et al., 2011).

This is not to say that the body is of secondary importance for experienced identity though. Indeed, we found that the body constituted a major element of the experienced identity and remained so even after a massive motor incapacity. Not only did the patients recognize these new and very different bodies as theirs – from scores in part (B) – which answers our second question (Do they recognize these 'new' bodies as theirs?), but their report of experienced identity (A) was significantly correlated to their experience of the body (B), thus suggesting that patients tend to report a continuous identity when they accept their body changes and tend to report a discontinuous experienced identity when they reject the new body. This finding suggests that even if the objective body can undergo massive changes, the *body representation* is the component of the experienced identity that matters *from the wheelchair*. Medical recommendations may be driven from these results. For example, considering the role of the body representation in real patients' experienced identity, we might



consider increasing the body-related care at the hospital, not only for rehabilitation but also to reinforce the patients' sense of body-ownership through ergotherapy, psychomotricity care, massages, physical therapy and relaxation based on passive mobilization for instance.

Additionally, LIS patients reported a better preserved identity when their life, no matter how objectively different, kept its subjective meaningfulness. These findings are due to our focus on the *in situ* or *wheelchair-view*, which emphasizes the psychological sense of identity. Though we have not been focusing on the philosophical theory of personal identity in itself, these results might be of some interest regarding the fictive cases such as the brain transplant. If real patients can adjust to massive bodily changes because of a psychological meaningfulness in their life, then personal identity might be as plastic as brain plasticity: no matter how important the objective bodily change is as long as the patient acknowledges it as meaningful. In this sense, our findings are in accordance with contemporary models of experienced identity as a subjective process of adjustment to changes (Morin, 2006) partially based on what we called here experienced meaning in life (Bernheim, 1999). Further research could develop the dimension of experienced meaning in life as constitutive of the experienced identity.

Finally, we found that predictions of the control group did not match the report of the *in situ* patients regarding the experienced meaning in life. This result is hypothesized to reflect a bias in the *armchair-view* that can be avoided by accessing the patients' *wheelchair-view* whenever it is possible (Albrecht & Devlieger, 1999). Especially in the case of non-communicative patients, it is important to stress the role of technological devices enabling medical teams and caregivers to reach to the patients' report for obvious ethical reasons.

In conclusion, the new strategy adopted here – that is, to investigate the role of massive bodily changes in the experienced identity in *real cases* rather than fictional cases and by asking patients about *what it is actually like* rather than relying on intuitions from the *armchair* – seems to be of significant interest both for caregivers and medical teams from an ethical point of view, in so far as it stresses the importance of the patients own report about her experience, and for philosophers from a theoretical point of view in so far as it questions the accuracy of theoretical intuitions about phenomenal experiences when detached from any empirical survey.

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