

Attitudes towards Personhood in the Locked-in Syndrome: from Third- to First- Person Perspective and to Interpersonal Significance

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Abstract Personhood is ascribed on others, such that someone who is recognized to be a person is bestowed with certain civil rights and the right to decision making. A rising question is how severely brain-injured patients who regain consciousness can also regain their personhood. The case of patients with locked-in syndrome (LIS) is illustrative in this matter. Upon restoration of consciousness, patients with LIS find themselves in a state of profound demolition of their bodily functions. From the third-person perspective, it can be expected that LIS patients might experience a differential personal identity and may lose their status as persons. Howev-

er, from the patients' perspective, it is uncontested that they retain their personal identity and that they consider themselves to be persons. We here include results from a survey with patients with LIS aimed at identifying the primary expectations of patients for their care by non-medical professionals. Based on these first-hand reports, we argue that personhood in LIS is progressively regained as the widening circle of others recognizes them as persons.

Keywords Personhood · Locked-in syndrome (LIS) · Self · Attitudes · Identity

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Background

The Locked-in Syndrome

The locked-in syndrome (LIS) is a clinically rare acquired condition characterized by severe motor disability with preserved non-verbal capacity to communicate [1]. LIS is usually caused by lesions at the pons of the brainstem and it is primarily of vascular etiology, although it is also observed at the end-stage of amyotrophic lateral sclerosis (ALS), a motor-neuron disease [2]. Based on patients' motor abilities, LIS can be subdivided into (1) classic, which describes tetraplegic and aphonic patients using coded communication by vertical eye movement or blinking, (2) incomplete, wherein patients have remnants of more voluntary movements other than oculomotor ones, and (3) total, which refers to patients with complete motor

immobility, including eye movements [3]. LIS patients with pure brainstem lesions have preserved cognitive functions, as assessed by standard neuropsychological testing [4], and report a good quality of life even in total LIS, using brain-machine interfaced communication [5]. For healthy individuals, such severe restrictions of independent and physical function may appear as a frightening scenario which leads to questions of whether a “life is worth living” after severe brain injury [6]. This is mainly due to an estimated lower quality of life which is tightly linked to perceptions about severe disability [7]. By and large in disability, quality-of-life instruments assess health and wellbeing in terms of physical functioning, mental, and emotional dimensions of experience [8]. Therefore, if quality of life is based on the perceived value of physical and mental functioning, it is possible that healthy individuals can underestimate the quality of life that patients with chronic disabilities lead. Studies show that indeed when partners or caregivers rate patients’ quality of life, the questionnaire scores are significantly lower than when patients do it for themselves [9–12]. The puzzling effect of patients’ high self-ratings on quality of life measures in the presence of disability is known as the “disability paradox” [13], and it can be partially explained by the way people adopt different perspectives on perceived quality-of-life.

Physical functioning is, therefore, considered critical for oneself. From the theoretical point of embodiment, sensorimotor skills shape cognition, selfhood and subjectivity [14]. According to the theory, an organism is considered a self when: a) it possesses volume in space (localized within bodily boundaries), b) it recognizes a global body representation (the body is perceived as a whole as opposed to localized body parts and isolated movements), and c) it possesses a visuospatial frame of reference/egocentric model of reality. These properties are respectively referred to as self-location, self-identification and a first-person perspective [15]. In the extreme case when all three aspects of selfhood are disturbed, as can happen in cases of neurologic patients, illusory global own body perceptions come about, such as out-of-body experiences (i.e., patients seeing their own body in extracorporeal space, while they localize and identify themselves with this new representation [16]). It has been suggested that the experience of being the author of our own actions and being able to selectively control our body actions (agency) also enables selfhood [17]. In that case, physical function is implicated because the subjective sense of agency depends on

successful prediction of sensory consequences of action [18]. Based on this framework, imprecise sensory predictions can lead to mental disorders, where patients need to rely strongly on external cues in order to predict their environment [19]. For example, in the case of schizophrenia patients experiencing their actions as having external rather than internal causes. Interestingly, though, agency is not a constitutive condition for the phenomenal aspects of selfhood. This follows from clinical observations of impaired motor control like the alien hand syndrome [20] and like, in our case, the LIS. In the former case, patients experience their limb performing seemingly purposeful acts without their intention, often interfering with the actions of their normal limb. In the latter case, patients are fully paralyzed even to the point of eye movements, while they remain fully conscious in their impaired bodies. In both cases, the subjective experience of a unified self remains. Therefore, although the paralyzed body remains a strong component of patients’ experienced personal identity, patients adjust to objective changes by perceiving them as meaningful, while caregivers fail in predicting these patients’ experiences [21].

Third-Person Perspectives on LIS

It is usually easy to evaluate a third person’s situation by directly asking him or her what it is like being in a particular condition. In the case of patients with severe disabilities such evaluation may be hindered as a result of inefficient communication, physical constraints or due to the inability to get in contact with these patients in the first place. Therefore, qualitative estimations can be inferred by observing behavioral output or by empathic mechanisms – as if one is in “someone else’s shoes”. A recently conducted survey among physicians, clinicians and other non-medical professionals, illuminated third-person attitudes towards medical and ethical issues surrounding the LIS [22]. In terms of pain perception, it was found that a vast majority (90%) considered that patients in LIS feel pain, which is in accordance with what patients generally self-report [e.g., 8]. Interestingly, 9% of respondents negated pain perception in patients in LIS which corroborates the frequent misunderstandings around the syndrome [23]. Indeed, public information can be fraught with misconceptions even for more widely known conditions, such as the vegetative state/unresponsive wakefulness syndrome (VS/UWS) [24]. The VS/UWS is a clinical condition

of unconsciousness wherein patients are awake but show only reflexive movements denoting no perception of themselves and their environment [25]. In the case of the complete LIS, therefore, it can be that a conscious but paralyzed patient can be mistaken for an unconscious one, if signs of consciousness (other than communication) are not detected. When LIS was compared to VS/UWS, the same survey showed that the majority of participants considered it to be worse than being unresponsive. A possible explanation could be that since LIS patients are aware of their condition, in contrast to unresponsive patients who do not reach this level of self-awareness, the situation may be judged as worse as a function of retained consciousness. In that sense, greater sentience could mean a greater ability to feel both pain and suffering from being in a severely compromised state [26].

It terms of end-of-life options in LIS, it has been found that the majority (75%) of respondents were opposed to stopping treatment, i.e., artificial nutrition and hydration and invasive ventilation [22]. To disagree with treatment withdrawal in LIS seems reasonable, if one considers that patients retain cognitive and emotional function [4]. These results corroborate what patients report for themselves, that although suicidal thoughts can be present in the initial stages of the syndrome, with the passage of time they generally report a satisfactory wellbeing [9, 22]. Interestingly, one quarter of the surveyed participants considered that treatment can be stopped in patients with chronic LIS. Surprising as it may seem to endorse the possibility for conscious patients to hasten death, the presence of consciousness alone might not always work in favor of patients' best interests because it jeopardizes the patients' autonomy, dignity, and suffering [27]. Autonomy especially seems of great value to one's wellbeing. As stated by the Belmont report [28] individuals should be treated as autonomous agents, and persons with diminished autonomy in particular are entitled to protection. In the same line, the American Academy of Neurology [29] recognizes that adult patients with severe and permanent paralysis have the right to make decisions regarding their own healthcare and to accept or to refuse life-sustaining therapy.

The aforementioned survey further identified a dissociation between third-person and first-person perspectives in attitudes. Specifically, it was found that a great proportion (56%) of respondents would decide

differently about end-of-life if they were in LIS themselves by refuting staying alive if they imagined themselves in this condition [22]. This is consistent with previous studies where physicians decide differently if they are in a professional role deciding for others than if they are in an existential role deciding for themselves. Such results suggest that clinical decision-making can be fundamentally different when one decides for oneself or gives advice to others. One explanation could be that the preference not to undergo life-prolonging treatment stems from the fear of a profound identity change due to modified body image. In other words, when healthy individuals would imagine their bodies severely paralyzed, they would report a discontinuity in their personal identity after the imagined acute loss of motor control [21]. However, patients' bodies continue to live after their accidents, implying that identity in patients in LIS is primarily socially constituted [30]. As such, the loss of independent function, control, and mobility, which eventually may lead to social isolation, could also have been the reasons that the respondents refused more frequently to be kept alive if they imagined themselves in a chronic LIS.

Taken together, these data suggest that respect for persons partly relies on the fact that respected entities have a moral status or moral agency, but also that they have worth and value for others. This relational (or contextual) understanding of respect for persons, therefore, entails that the urge for respecting the person is not based on the person's capacities, but instead on the obligation towards others, respect for human relationship, and respect for what a person was before the injury [31]. Therefore, an interpersonal approach to LIS may shed more light on the issue of personhood in severe motor disability.

First-Person Perspectives: Personhood as an Interpersonal Status

Previous studies have shown a noteworthy difference between the actual experience of LIS patients in the first-person perspective and the experience that caregivers and third parties predicted LIS patients would have [21, 22]. Because of this discrepancy, it is important to explore the experience of personhood from the patients' standpoints. A recent study, presented during the 2016 SOFMER congress by Seguin, adopted this focus and found that the two major contributors to patients' feelings who were treated as a person were

quality of communication and quality of human environment [32]. For instance, addressing the patient directly, rather than talking *about* the patient to their present caregiver, contributed to (re)establishing the patients' personhoods. These findings are consistent with a notion of personhood as interpersonal status [33]. In this sense, individuals achieve the status of person when and only when others recognize them as persons. This concept of personhood, thus, focuses on a socio-phenomenological experience, constituted through interpersonal attitudes. In the case of LIS patients, the attitudes of others towards them can contribute to establishing or demoting personhood.

Here, we report qualitative findings from a survey initiated by a patient with LIS who contacted other LIS patients. With these results our purpose was to emphasize our assumption about the interpersonal dimension of personhood rather than exhaustively quantifying this issue. The survey's initial aim was to identify the expectations of patients for their care by non-medical professionals (homecare assistants). While the survey did not explicitly target interpersonal factors, the analysis here centered on interpersonal attitudes that contribute to reinforcing personhood, namely the willingness to listen and communicate, the consideration of LIS patients as able-minded persons, and the respect of their rights and abilities to make decisions for themselves. The study was originally presented during the 2016 annual ALIS workshop (Boulogne Billancourt, March 25) and later published in the association's magazine (*La Lettre d'ALIS*, 28, October 2016). The study was approved by the ethics committee of the University of Liège. Completion of the questionnaire was voluntary, anonymous, and was considered to be consent for participation in the survey.

Methods

Participants

Originally, 36 patients were contacted and 30 patients responded (83% response rate), either electronically or in person between January and March 2015. The sample comprises 13 females and 17 males, mean age = 49y ± 9 (range = 35–66), with LIS mean duration = 13y ± 8 (range = 3–32); 29

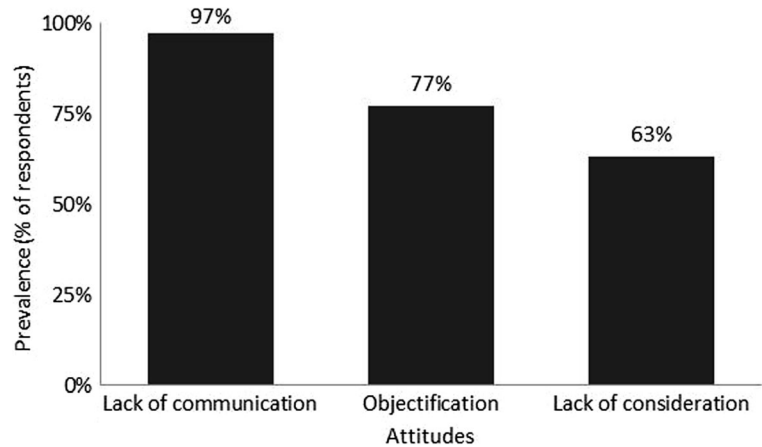
patients had suffered a pontine stroke and 1 patient infectious disease; 18 respondents were in a classical LIS, 11 were in an incomplete LIS, and 1 did not respond as to the type of LIS.

Four demographic questions (gender, age, duration of LIS, and housing) and nine open-ended questions were addressed:

- Who helps you for everyday actions?
- How many helpers do you have and over how many hours (day/night)?
- What are 3 things you expect from the person helping you?
- What are the skills required to help you (gestures and technical know-how)?
- What feels unacceptable?
- Would you like to share a relevant anecdote on this point?
- Is there a specific point you would like to stress about that?
- Imagine the ideal helper: how is she/he?
- According to you, what is creating problems and what could solve them?

Data Analysis

We conducted qualitative descriptive analysis of the responses to the open-question section of the survey. Responses were analyzed in three phases. The first two authors coded the data qualitatively, by assigning each statement a label capturing its general theme. For instance, the answer “did not try to learn the communication code” was coded as “lack of communication”. Likewise, the response “pretended not to hear or understand” was coded as “avoid communication”. Coders were blind to each other's coding. In a second phase, the coding categories were consolidated across coders, and a final code was attributed to each answer. For instance, the two previous statements were both categorized as “lack of communication”. Last, we analyzed the three most prevalent categories, relevant in the context of our discussion of personhood: lack of communication, objectification, and lack of consideration (Fig. 1). These three categories encompass several concrete ways in which personhood can be promoted or demoted interpersonally.

Fig. 1 Interpersonal attitudes impact experienced personhood

Results

Lack of Communication

Of the 30 respondents, 29 (96.7%) reported that the (un)willingness to communicate was the primary factor shaping their experience of personhood in their interactions with homecare assistants. Respondents systematically reported feeling that they were not treated as persons when others “pretended not to hear or understand”, “did not try to learn the communication code”, “did not listen or respond”, “ignored or interrupted the person”.

On the other hand, making the effort of understanding the patient by learning the communication code, asking the patient for their input and waiting for the answer, demonstrating friendliness and patience in listening to the patient and taking their comments into account in everyday care were perceived and highlighted as appropriate behavior by 23 respondents (76.7%). This data suggests that adopting the proper attitude in communicating with LIS patients is core to their sense of personhood.

Objectification

A large majority of respondents ($n = 23$; 76.7%) described interactions that left them feeling “not respected as persons” but rather “treated as objects”. Descriptions of such situations included care providers engaging in long phone calls or text conversations with others during their shift rather than engaging with the patient, speaking of the patient in front of them, or caring for the patient with headphones on to listen to music;

“pretending they haven’t heard [what I said]”, “ignoring me”, “pretending they understood”, “treating me like a piece of furniture”, “making decisions for me”, or looking at patients “as curiosities rather than human beings”. Several respondents highlighted their yearning for “human contact and communication above and beyond technical tasks of assistance”, describing that helpers sometime “go too fast”, treating their time with the patient as a succession of technical gestures rather than a relation with another person, which was described as “treating us like cattle”. The lack of certain attitudes also contributed to feeling objectified, such as talking to the patient, sharing games, humor, discussions, being friendly.

Lack of Consideration

Finally, the third most prevalent category encompassed behaviors denoting a lack of consideration, and 19 respondents (63.4%) underscored their impact on experienced personhood. These behaviors covered a range of situations. For instance, a respondent described: “Some people associate ideas such as: he cannot speak so he cannot hear and when they talk to you, they can’t help shouting”. Another such situation was described as follows: “There are some who speak pidgin French, and others who make you believe they have a lot of esteem for you, asking questions and not waiting for the answers.” Several respondents reported that lack of consideration could manifest as “treating me like a vegetable”, “taking me for simple minded”, “talking to us like babies”, “infantilizing me”, “treating me like I am stupid”, or as if the patient was senile, calling the patient “Old-timer or Grandpa”, and invariably contributed to

weakening their experienced personhood. A respondent erupted: “I’m not 15 years old!” and another echoed: “My head works just fine!!!”

Discussion

With these results, we aimed at illustrating the role of interpersonal attitudes in promoting or demoting personhood in LIS patients. Indeed, respondents listed social skills as the most important aspect of a caregiver’s interaction with them, even when answering questions about know-how and technical gestures.

Establishing Personhood through Communication

Communicating with someone in LIS is a challenge of both expression and comprehension. Individuals may use different codes, which must be learned by any new homecare assistant to allow communication. These codes often rely on lengthy processes, such as reciting the alphabet for the patient to spell words by selecting one letter at a time through blinking. Furthermore, re-establishing communication at an early stage is often delayed by multiple factors: absence of deliberate movements (60%), a potential deliberate movement which was not used (16%) and patients’ impressions that could achieve a movement which has not yet been seen (4%). The yes-no code which is used most frequently by families (85%) is used less frequently by therapists and nursing staff. Since this type of communication is necessary for proper care, neglecting it therefore has repercussions on the LIS person’s experience and future history.

Yet communication is crucial to personhood because it allows for a sense of agency. Even more so for LIS patients, who have lost the ability to act upon and manifest their will through a physical action, communication becomes the only channel to agency. It is not surprising then that respondents often connected the unwillingness of their homecare assistant to learn their communication code to an experienced loss of agency: not communicating with the LIS patient soon would turn into “answering or deciding for me”, “acting on me without asking”, “not asking for my opinion”, or “not respecting my choices and habits”.

Restoring communication through the use of improved communication protocols is therefore likely to result in reinforcing the sense of personhood of LIS patients. In line with this importance of communication

to maintain the experience of personhood through interpersonal attitudes, a LIS person reported: “When I use my eye-controlled computer, the handicap is forgotten for a while; the machine becomes a space of freedom where I can do what I want, when I decide to... even though a computer will never replace the spontaneity of a conversation”. Another LIS person said: “So, is there some tip to feel better? I think it’s all very personal but, my recipe would be for sure: it’s better to have a good homecare assistant and an efficient communication computer, then the method is up to you!”

Establishing Personhood through Interpersonal Attitudes

Beyond communication, attitudes from others can grant or demote personhood. Patients highlighted the negative effects of a lack of consideration in their relationship with care providers. From the results, it seems that the root of these behaviors lies in a misunderstanding of what LIS is. A respondent explains that “some people rely on my physical appearance and make remarks, thinking I don’t understand them”. Others may think that a LIS person is not cognitively competent: “I am handicapped, says a LIS respondent, but I am of sound mind”, paralleling the response of another participant “We’re not brain handicapped”. Specific education of homecare assistants may help alleviate the effects of this misconception, and in turn remedy the behaviors that are perceived as lack of consideration for the patient.

Like the unwillingness to communicate, the erroneous assumption that the LIS person does not understand human interactions leads to an array of objectifying behaviors that diminish the patients’ sense of personhood. If it is assumed that the LIS patient does not understand their environment, it becomes possible to act around and upon them as we would do around objects. Namely, homecare assistants with this implicit bias were reported by respondents to pick up their phones and have private conversations while on duty at the patient’s home, to disregard the patient’s desires and family rules/habits, and to become lax with the respect of patients’ privacy. They would make decisions without consulting the patient and act as if the patient was not there. Respondents reported that such attitudes would make them feel “like a piece of furniture” or “like cattle”. A respondent expressed as their main concern the need for the homecare assistant to “treat me as a person and not an object”.

Objectification, indeed, is the direct negation of personhood, or in Mounier's words: "The person is not an object. It is actually that, which in each man cannot be treated as an object" [34]. Indeed, when personhood is compromised in interpersonal attitudes, the LIS person may come to feel as the exact opposite of a person, and come to feel as an object.

Limitations

Due to the methodology of this project, a few limitations must be acknowledged. First, the data was collected by an inexperienced researcher. The questions as well as the motivation for the survey, came from several conversations among LIS patients about their subjective experience with home caregivers. The patient with LIS who initiated the survey was involved in the training of home caregivers, and wanted to raise awareness about the subjective experience of LIS patients in these interpersonal contexts. This organic, rather than theory-informed, process offers both strengths and weaknesses. To the first, it is rooted directly into the subjective experience of patients, thus reflecting the most salient aspects of their experience in a way that may elude a purely theory-driven approach insofar as the disability paradox highlights divergence between the first- and third-person perspectives. To the latter, this data merely illustrates the importance of these topics and our descriptive analysis aims at providing a proof of concept and encouragement to investigate how these behaviors interact with perceived personhood in the LIS. A second limitation is the small sample size, which is frequent in such populations. However, the very high response rate suggests that this topic was particularly engaging for the respondents. The high response rate is even more meaningful in response to open questions, which increase the communication burden for LIS patients, compared to multiple choice questionnaires or Likert scales. Finally, a third limitation comes from the descriptive and exploratory nature of this analysis. We do not propose inferential statistics or a predictive model here, but rather describe qualitatively factors relevant to personhood experienced from the first-person perspective.

Implications

Although preliminary, these findings may contribute to improving the care of LIS patients in three ways. First, this is a type of data which is understudied and bears

important information. The first-person, qualitative nature of the data anchors our reflexion at a level of analysis which is directly relevant to the patients. Given the frequent discrepancy between the first- and the third-person perspectives, it is important that the field take into account subjective reports from the patients to inform our theoretical models of personhood in LIS. As scientists, investigating direct, subjective reports of perceived personhood, in addition to objective measures of personhood assessed by a proxy (like legal considerations), may precisely be what it means to treat LIS patients as persons. Second, these results provide concrete recommendations for caregivers to turn away from attitudes that tend to damage experienced personhood in LIS patients. Specifically, caregivers should watch for the following behaviors in their interactions with LIS patients: not answering the patient or making decisions for the patient, acting without asking the patient first or not waiting for the patient's answer, and not respecting the patient's answer when expressed. Additionally, caregivers should be mindful of their implicit bias, such as assuming that the patient is mentally ill, incapacitated, senile, or immature because of the visible, physical impairment. Third, this data has implications for the way we evaluate the quality of caregiving services. Currently, the criteria used to assess the quality of services do not systematically include direct consideration of the behaviors and implicit attitudes that impact the experienced personhood of LIS patients. Future studies could propose a new assessment tool and investigate how current quality assessment methods compare to the new one, thus contributing to improving the standard of service quality assessment for the care of LIS patients.

Conclusions

Personhood is ascribed on others, such that interpersonal attitudes from third parties can reinforce or demote its sense. For LIS, third-person perspectives can encompass erroneous implicit beliefs, such as thinking that LIS patients are cognitively incompetent or unwilling to communicate. This often leads to an array of specific behaviors that may result in LIS patients losing their statuses of person when interacting with others. From the patients' perspective, when third parties are willing to learn their communication codes and show a genuine interest in learning the patients' own thoughts and desires, it greatly contributes to reinforcing the patients'

experience of personhood. Based on first-hand reports from LIS patients, we think that personhood of LIS patients is progressively regained as a widening circle of others recognize the patient as a person.

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