

Peer Review History

A survey on self-assessed wellbeing in chronic locked-in syndrome: happy majority, miserable minority

BMJ Open-2010-000039

Reviewer 1: Solari, Alessandra

Alessandra Solari
Foundation IRCCS Neurological Institute C Besta, Unit of Neuroepidemiology

The Study	Yes	No
Is the research question clearly defined?	✓	
Is the overall study design appropriate and adequate to answer the research question?	✓	
Are the participants adequately described, their conditions defined, and the inclusion and exclusion criteria described?	✓	
Are the patients representative of actual patients the evidence might affect?		✓
Are the methods adequately described?	✓	
Is the main outcome measure clear?	✓	
Are the abstract/summary/key messages/limitations accurate?	✓	
Are the statistical methods described?	✓	
Are they appropriate?	✓	
Is the standard of written English acceptable for publication?	✓	
Are the references up to date and relevant? (If not, please provide details of significant omissions below.)	✓	
Do any supplemental documents e.g. a CONSORT checklist, contain information that should be better reported in the manuscript, or raise questions about the work?	✓	

If you answered No to any of the above, please supply details below.

Selection bias is possible, but the authors acknowledge this limitation.

RESULTS AND CONCLUSION (For articles reporting research findings only)	Yes	No
Do the results answer the research question?	✓	
Are they credible?	✓	
Are they well presented?	✓	
Are the interpretation and conclusions warranted by and sufficiently derived from/focused on the data?	✓	
Are they discussed in the light of previous evidence?	✓	
Is the message clear?	✓	

REPORTING AND ETHICS	Yes	No
Is the article reported in line with the appropriate reporting statement or checklist (e.g. CONSORT)?	✓	
Are research ethics (e.g. consent, ethical approval) addressed appropriately?	✓	
Is the article free from any concerns about publication ethics (e.g. plagiarism, fabrication, redundant publication, undeclared conflicts of interest)?	✓	

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I'm almost enthusiastic about this manuscript. The limitations (selection bias, response bias and acquiescence biases) have been clearly commented by the authors in the discussion. An interesting paper that deserves publication in the journal.

Reviewer 2: León-Carrión, José

José León-Carrión

Center for Brain Injury Rehabilitation , Dept.of Research, Development and Innovation

The Study	Yes	No
Is the research question clearly defined?	✓	
Is the overall study design appropriate and adequate to answer the research question?		✓
Are the participants adequately described, their conditions defined, and the inclusion and exclusion criteria described?		✓
Are the patients representative of actual patients the evidence might affect?		✓
Are the methods adequately described?	✓	
Is the main outcome measure clear?	✓	
Are the abstract/summary/key messages/limitations accurate?	✓	
Are the statistical methods described?	✓	
Are they appropriate?	✓	
Is the standard of written English acceptable for publication?	✓	
Are the references up to date and relevant? (If not, please provide details of significant omissions below.)	✓	
Do any supplemental documents e.g. a CONSORT checklist, contain information that should be better reported in the manuscript, or raise questions about the work?	✓	

If you answered No to any of the above, please supply details below.

The methodology is biased in terms of the numbers of patients selected and studied. The patients selected are not representative of chronic LIS patients. Patients with very severely constrained communication were invited by letter to fill out a questionnaire on socio-demographic, clinical and quality of life variables.

The English is acceptable, but lacks clarity and fluidity in many parts of the text. A native English speaker would help make the text an easier reading experience.

RESULTS AND CONCLUSION (For articles reporting research findings only)	Yes	No
Do the results answer the research question?	✓	
Are they credible?		✓
Are they well presented?	✓	
Are the interpretation and conclusions warranted by and sufficiently derived from/focused on the data?	✓	
Are they discussed in the light of previous evidence?	✓	
Is the message clear?	✓	

If you answered No to any of the above, please supply details below.

The results are not fully credible because of the methodological problems mentioned above.

REPORTING AND ETHICS	Yes	No
Is the article reported in line with the appropriate reporting statement or checklist (e.g. CONSORT)?	✓	
Are research ethics (e.g. consent, ethical approval) addressed appropriately?	✓	
Is the article free from any concerns about publication ethics (e.g. plagiarism, fabrication, redundant publication, undeclared conflicts of interest)?	✓	

Comments

If you have any further comments for the authors please enter them below.

1. I recommend that the title be modified to read as follows:
"A survey on self-assessed well-being in a group of patients in chronic Locked-in Syndrome: happy majority, unhappy minority".
2. The authors clearly describe the bias in their study, and state that their results may not be representative of chronic LIS patients in general. They also note that given the dependence of LIS participants on the help of a caregiver for communication of their answers, social desirability may be high in patients' responses.
3. State of misery is a very strong term to use with this kind of patient; I do not recommend its use in reference to patients of any kind, for the conflict and negative impact it could produce in the future.

Authors Response to Decision Letter for (BMJ Open-2010-000039)

A survey on self-assessed wellbeing in chronic locked-in syndrome: happy majority, miserable minority

January 6th 2011

Dr Trish Groves
Editor in chief , Responsible for editorial policy direction

Mr. Richard Sands
Managing editor, Responsible for peer review procedure and manuscript decisions

REF: Revised MS Manuscript ID BMJ Open-2010-000039

Dear Editor,

Please find herewith our revised MS entitled "A survey on self-assessed wellbeing in chronic locked-in syndrome: happy majority, miserable minority", which we would like to submit electronically for publication in BMJ open.

We thank the reviewers for their constructive comments and have changed the MS according to their concerns. We hope it will now be acceptable for publication in your journal. Thanks for your time and effort in considering this MS.

Please find below our responses to both reviewers.

Reviewer 1 :

"I'm almost enthusiastic about this manuscript. The limitations (selection bias, response bias and acquiescence biases) have been clearly commented by the authors in the discussion. An interesting paper that deserves publication in the journal."

We thank the Reviewer for these positive comments.

Reviewer 2 :

Comment 1

"I recommend that the title be modified to read as follows: A survey on self-assessed well-being in a group of patients in chronic Locked-in Syndrome: happy majority, unhappy minority."
We have changed the title as requested it now reads: "A survey on self-assessed well-being in a cohort of patients in chronic Locked-in Syndrome patients: happy majority, unhappy minority."

Comment 2

"The authors clearly describe the bias in their study, and state that their results may not be representative of chronic LIS patients in general. They also note that given the dependence of LIS participants on the help of a caregiver for communication of their answers, social desirability may be high in patients' responses."

We agree and have added this even more explicitly in the revised MS. It now reads:

"It is important to stress the discussed possible biases in our study. The observed results may hence not be representative of chronic LIS patients in general. It should also be noted that given the dependence of LIS participants on the help of a caregiver for communication of their answers, social desirability might have confounded patients' responses."

Comment 3

"State of misery is a very strong term to use with this kind of patient; I do not recommend its use in reference to patients of any kind, for the conflict and negative impact it could produce in the future."
We agree and have replaced "state of misery" by "unhappiness" throughout the MS.