Author's response to reviews

Title: Are elderly people with co-morbidities involved adequately in medical decision making when hospitalised? A cross-sectional survey

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Author's response to reviews: see over
Dear Editor Rachel Neilan,

Thank you very much for considering publishing our article: MS: 1335967199517034 “Are elderly people with co-morbidities involved adequately in medical decision making when hospitalised? A cross-sectional survey”. Anne W Ekdahl, Lars Andersson, Ann-Britt Wirehn and Maria Friedrichsen

We think that all the referees have made very good comments and suggestions and we have now addressed them all below and highlighted all changes in the manuscript. We also think that, thanks to the referees, we have now made our findings a bit clearer (that more elderly with co-morbidity are not having their preferred role in medical decision making and would have preferred a more active role) and hope that the manuscript still will be interesting for BMC to publish.

As to your request all authors have declared no financial or non-financial interests in relation to this manuscript this is included in the manuscript after the conclusion section – I hope this is what you asked for?

Kind regards

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Referee 1: Shaun O'Keeffe

Reviewer's report

Title: Are elderly people with co-morbidities involved adequately in medical decision making when hospitalised? A cross-sectional survey
Version: 1 Date: 4 April 2011
Reviewer: Shaun O'Keeffe

Reviewer's report:

Dear Editor,

This is an informative and well written study of an important topic. The use of the Degner scale seems well suited to this subject. The statistical analysis is appropriate. There is a useful and well-referenced discussion to put the results into context.

The authors acknowledge the main limitation which is the low response rate. This is probably unavoidable in such a study. I have two minor points to make. The authors might wish to discuss whether assessment of people while in-hospital might improve the response rate.

We are sure that assessment while in hospital would have approved the response rate – and (as I pointed out to reviewer 3) it would probably also been better to have a shorter time between getting the list of names through the local register of care to the attempt to interview – and we should have done so if we should have made this study again. One of the reasons for not doing the survey in hospital was to diminish the risk of the patients feeling afraid of giving negative feed-back while still in hospital and dependent of good care perhaps thinking that we should inform of bad or poor information and participation (although we of course would ensure the patient that we where not involved in their care).

Secondly, the percentage noted to have dementia (4%) is low: formal assessment of cognition and of comprehension skills in future studies will reveal the degree to which this may contribute to
difficulties with providing information.

You are perfectly right. In my answer to referee 3 (Jan Florin) I have explained our considerations about the low degree of dementia which should be around 20% in this population. I cite from my answer: “We did not do any screening for dementia or other neuropsychological diseases – but when we during an interview suspected that a patient answered without understanding the questions, we asked more questions to decide whether the answers were logic and tried to judge whether the patient understood the questions properly or not. As you can see from the results only few patients (4%) were excluded for that reason (dementia) – and too few according to the prevalence of dementia. In our opinion (working with dementia in a daily care basis) it is important to ask even persons with dementia of their preferences and they can often provide good answers if you take your time and effort to explain and understand. We have added this text to the discussion in the article top p. 14:

There was a very low reported prevalence of dementia in our study population (4%) but probably elderly with mild dementia could answer the questionnaire without problems and probably there were a high proportion of patients with moderate or severe dementia among the patients that declined to participate.

Level of interest: An article of importance in its field
Quality of written English: Acceptable
Statistical review: Yes, and I have assessed the statistics in my report.
Declaration of competing interests:
No to all

Referee 2: Hirono Ishikawa

Reviewer's report

Title: Are elderly people with co-morbidities involved adequately in medical decision making when hospitalised? A cross-sectional survey
Version: 1 Date: 31 May 2011
Reviewer: Hirono Ishikawa

Reviewer's report:

Thank you for the opportunity to review this manuscript.
This paper studied the role that elderly people with co-morbidities wish to play with regard to information and participation in medical decision making, and perceived barriers to participation.
General comments: There have been many studies investigating patients’ preferred and actual levels of information and participation in medical decision making, concordance between the preferred and actual levels, and barriers to participation. Although few studies targeted the oldest age groups as the authors noted, the novelty of the findings of this study is not clear to me. Also, the age effect and cohort effect should be considered in interpreting the results. (i.e. Are the findings generalizable to future oldest age population as well, or is it somewhat specific to this cohort?)

Thank you for this very good comment. You can of course discuss about the novelty. The study shows (as in many earlier studies) that you must have an individual focus even in the oldest age-groups when considering participation in medical decision making. In Sweden it is often said (by health care providers) that elderly do not want so much participation but our study actually showed that generally the patients were less active in medical decision making as preferred. We could not find a correlation to
education as in several earlier studies. That could be a cohort effect as more the elderly gets more and more educated – but we would not dare to make such a conclusion from our study. So our point is: “Invite the elderly just as much as younger patients to participation in medical decision making” – which is not the case at least in Sweden today. I have pointed this out further in the discussion underlined in the manuscript p. 12:

The results of the present study confirm findings in other patient groups (12, 24-26). Almost half of the patients preferred to play a passive role in decision making, while 35% had a more less active role than preferred, and 21% a less more active role. In most studies, being older, being a woman, and being less educated are related to the preference for a more passive role, although this relationship is not constant (18, 21, 27, 28). We did not find any such relationship in our study, just opposite our study showed that generally the patients were less active in medical decision making as preferred. Not finding correlation between education and preferred role in medical decision making could be a cohort effect as elderly is not so well educated as younger in Sweden and the study was to small to show any significances.

Specific comments:

# Abstract
The purposes of the study are not clearly stated in the abstract.

I have made underlined changes in the abstract p. 2:

The main objective of the study was to investigate the preferences of degree of control elderly people with co-morbidities wish to assume with regard to participation in medical decision making

# P.7: The response options for the patient’s preferred and actual information seeking roles
What were the leading questions for these response options? How the questions and response options were developed and validated? They do not seem to fully measure patient “preference” or “actual role” for information seeking. The response options are not on a single axis and not mutually exclusive.

You are perfectly right and seen in retrospect we are not pleased of our questions of information seeking. We have taken away the word “role” and changed to preferred and actual ways of information seeking. We have not tried to make any conclusions about degree of congruence and we have not calculated any kappa values about information seeking. If our questions had been better constructed more with your considerations in mind, we could have made a more detailed interpretation as we did with the CPS-scale and thus have gotten more valuable information.

**Level of interest:** An article of limited interest
**Quality of written English:** Acceptable
**Statistical review:** No, the manuscript does not need to be seen by a statistician.
**Declaration of competing interests:**
I declare that I have no competing interests.
Reviewer's report

Title: Are elderly people with co-morbidities involved adequately in medical decision making when hospitalised? A cross-sectional survey

Version: 1 Date: 5 June 2011

Reviewer: Jan Florin

Reviewer's report:

Major compulsory revisions

Objective

The objective of the study does not fully cover the reported findings. The objective is about the roles that patients wish to play, but the findings report also from what role patients actually played regarding information and participation in medical decision-making.

Exactly as you have stated we have not fully covered the objective. We now have added some extra text (underlined p 5) there to get a better coverage.

Method

2. The modification of the Control Preference Scale is more comprehensive than adding an item regarding actual participation. That should be presented in the text, at least briefly. The original scale use a card sort technique with the cards presented in a specific order, often responding by ordering all of the response alternatives.

You are perfectly right and we are aware of the trouble just adding a question to a well validated instrument. Nevertheless we found this question so important (about not being invited at all to participate) that we chose to add it to the questionnaire. Degners Control Preference Scale was developed as a card sorting technique as you write – but is has been used in many studies without this technique. I have now added text where I write about the reason why choosing “our” technique. (underlined at the bottom p. 6 and above on page 7)

3. The items identified for information-seeking role. What is the origin to those questions?

The questions arose from the authors and originated from the items found in our qualitative study (ref 16).

Describe the response options available.

It is written in detail after the options for CPS (with the letters ABC on page 7 and 8).

Further, the items for actual.

Again it was from our qualitative study and with inspiration from the CPS with the model of a preferred and an actual role.

information-seeking role does not actually pin point a role, rather an end result.

You are right and we have taken away the word “role” and changed to preferred and actual ways of information seeking.

4. The items for preferred role and actual role regarding information-seeking role
is not fully equivalent. There is a slight change in focus, for e.g. the preference “I would like to receive more information about my treatment without having to ask” compared to an actual experience of “I would liked to have had more information”. The part about “without having to ask” is missing, leading to a much broader question in the latter case. The shift of focus is even more obvious in the third item regarding difficulty asking questions about treatment vs Do not want to know about my medical treatment. The reason for the shift of focus between preferences and actual experience is unclear to the reader.

You point is perfectly correct and a weakness of the article. We have not tried to make any conclusions about degree of congruence and we have not calculated any kappa values about information seeking. We have just used simple descriptive statistics. If our questions had been better constructed more with your considerations in mind we could have made a more detailed interpretation as we did with the CPS-scale and thus have gotten more valuable information.

5. The change in focus for barriers to participation in medical decision making in the method section to barriers to communication in Figure 2 in the result section needs to be addressed.
Further, the first two items are displayed differently in figure 2 than in the preceding text. The first item is changed from “take part in the medical decision making” into “to communicate”. The second item is changed from “too many doctors were deciding about your treatment” into “doctors with different treatment strategies leaving the patient confused”. The descriptions regarding posed questions and responses ought to be more coherent.

We have changed the text in the figure according to your suggestions for better coherence. The main reason for the different expressions was to shorten the text, but you are perfectly right it leaves the reader confused.

6. The process of developing the questionnaire could be described in more details. How many healthy individuals answered the questionnaire? How many persons participated in the expert panel, and what kind of process did they have? Any statistical measures for e.g. agreement?

Text have now been added to the article to explain the process a little better p. 8.

Discussion
7. a mis-interpretation of the discrepancy-score is present in the beginning of the discussion. It was 35 % that had a more passive role than preferred and 21% that had a more active role than preferred.

You have pointed out a very important mis-interpretation. It is as you write – so we have changed the text in the discussion. I can not explain why we made this shift in interpretation – the results taken into account – but as a bad excuse the problem of being “homeblind” for your own writing when you have seen it to many times.

Minor essential revisions
Methods
8. A definition of “elderly people with experience of hospitalization” is provided twice (page 4 and 6). It is sufficient to present it only once, preferably in the background.
9. The number of questions regarding barriers to participation is described in the text as being five (page 7), while only four questions are described in further details.

Corrected

10. The short description that patients that did not understand the questions and subsequently failed to provide answers were excluded is not clear to the reader.

We have now added a few words p 8. We did not do any screening for dementia or other neuropsychological diseases – and when we during an interview suspected that a patient answered without understanding the questions, we asked more questions to decide whether the answers were logic and tried to judge whether the patient understood the questions properly or not. As you can see from the results only relative few patients were excluded for that reason (dementia) – and too few according to the prevalence of dementia. In our opinion (working with dementia in a daily care basis) it is important to ask even persons with dementia of their preferences and they can often provide good answers if you take your time and effort to explain and understand.

RESULTS
11. The reasons reported for why patients choose not to participate/respond could be described more clearer. It is a bit unclear if the reasons are potential participants’ descriptions why they did not want to participate in the study, or if it is a condition identified by the interviewer. In case of the latter, it is more a question about exclusion criteria or internal loss.

We have clarified in the text p 10.

This notion is supported by the text on page 10 by the sentence in the result section “when we excluded the patients describing themselves as “too ill”….”. Apparently you used the data as part of the statistical analyses at some point in time. How, and by whom, were the reasons identified? E.g. dementia, was it the patient that identified the barrier, or the interviewer, and if so, using what method? The same goes for too ill to participate, hearing problem, inability to speak Swedish.

As for this section it is merely when the patient describes him- or herself as “too ill to participate in medical decision-making during last hospitalisation” – not too ill to participate in the survey. We made kappa-statistics for “correlation” or concordance between preferred and actual role in medical decision making – but we could not see any differences whether we removed the group “being too ill to participate” or not. I just moved the sentence with kappa-statistics to one sentence later and perhaps it now seems a bit clearer?

12. The sentence on page 9: “The reasons for not responding were most often related to...” should more correctly be phrased “The reasons for not participating in the study were most often related to...”. But again, it is a question about who identified the reason? Was it the patient himself before making an informed consent or was it the interviewer making a decision that this person is not able to respond adequately enough to the questions.

Corrected as your suggested on p 10 – and clarified in the text about who that makes the judgement of what.
13. Table 1: I presume that the figure about special accommodation for the elderly is wrong. If it is 15 persons out of 156, it makes 6 %, not 90%.

I so sorry: It should be 90% for community dwelling and 10% for special accommodation – no other alternatives asked for.

Additionally, the reader is curious what housing facilities the rest of the respondents had, so the categories for housing could be summed up to 100%. The top of the table displaying mean age might be mistaken for a heading because of the underscore. Could you alter the table to reduce the risk for that initial misreading?

Corrected. Hope this is more clear?

14. Unclear what statistical analyses that are behind the result that there were no relationships between age group, gender, and education and the preferred and actual roles in information-seeking (page 11, 2nd section). Presumably chi-square test was used, which could be stated under statistical methods.

Corrected.

15. page 11, 3rd section: “The greatest barrier to...”. Isn’t it more a question of “most common barrier”?

Corrected.

Also the use of the term “important” seem a bit odd. The respondents have responded to a question on a scale of little/somewhat/ a lot. The answer to that is more about The importance is perceived on another scale according to my thinking.

You are right – I have not made changes in the text, but I get your point.

Discretionary revisions
16. The information that the answers from the 42 patients reporting that they were not asked for an opinion were not included in the kappa statistics should preferably be described under statistical methods and not in the result section.

You are right, but I would rather not change this because I think it would make it more difficult for the reader to understand.

17. Some additional information about the respondents medical conditions would be beneficial, without going into too much details of course. But some brief descriptions of the group might be useful for the reader in order to deepen the understanding.

Some short lines in top of p. 14 inserted

18. Table 3. Why use one decimal in the table, but describe in the text without decimals? I suggest you drop the decimals in the table. Further, since you describe the result in such details (each item) one can wonder how much information table 3 adds. Could you just describe it in text?

I have taken away table 3
Discussion

19. Why not use the collapsed categories describing passive/collaborative/active participation role often used in studies using CPS?

We were considering that but – as you can see – ended up with this description amongst others to be able to make a meaningful kappa-statistics. We could of course have used CPS as you suggested.

20. The connection to the literature regarding barriers for participation in decision making could have been more elaborate. Now you only use a previous study by the same research group (reference 16) for identifying potential relevant barriers, and also confirming the importance of own previous findings.

This is totally correct and one of the weaknesses of the study.

21. Page 12, in the middle of the page. New results are presented in the discussion section. Here you combine several barriers (multifunctional decline and doctor’s speaking Swedish with an accent) and state that this affects a third barrier (difficulty understanding medical information). This ought to be part of the result using proper statistical methods to analyze such relationships.

You are right we could have done so.

22. Page 13 at the top. The information about time between interview and last hospital experience should be mentioned in the Method section. Is there a risk for recall bias? A lot of things can happen with our memory during three months. A description of time between last hospital stay and answering the questionnaire would increase the understanding.

I have added some lines in the method section (top at p 6 before “participants”). Of course the time period between hospitalisation and interview did play a role. As a matter of fact we noticed that the time period between when we got the list of patients to we made the interview played a role for the response rate. Should we have done this survey again in this fragile patient group, we would probably have chosen to get shorter list and several lists to make it possible for us to make the interview within 2-3 weeks after discharge – both for more correct answers and for better response rate (before the patients could decline further and being too ill to participate or pass away).

23. You could have more of a discussion regarding your use of CPS as a contrast to the original use.

It was for the reason of convenience and recourses which I of cause could have discussed more in detail. We have added some text on p 7.

24. Reference no 5: Isn’t it better to refer to it as Health care Act. It is a more exact description instead of just legislation.

25. Figure 1: In the text the term “prefer” is used, and so also in the heading of figure 1. Why use the term “desire” inside figure 1? To me desire and preference is not the exact same thing. Use the terms more consistent.

Corrected

**Level of interest:** An article of importance in its field
Quality of written English: Acceptable
Statistical review: No, the manuscript does not need to be seen by a statistician.
Declaration of competing interests: 'I declare that I have no competing interests'