Author’s response to reviews

Title: Advance directives from haematology departments: the patient’s freedom of choice and communication with families. A qualitative analysis of 35 written documents.

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Author’s response to reviews:

Limoges, France, September 14 2017,

Dear Editor,

We would like to resubmit our manuscript entitled “Advance directives from haematology departments: patient’s freedom of choice and intrafamilial communication?: a qualitative analysis of 35 written documents.” for publication in BMC Palliative Care.

You will find enclosed a detailed response to each point raised by the reviewers. All changes to the manuscript are highlighted in the text in blue.

We would like to thank the reviewers for their valuable comments and suggestions which have allowed us to improve our manuscript.
Reviewer 1: Ms Sabine Salloch

1. Abstract:

- We have removed the reference to STROBE statement and preferred to note that we adapted our methodology to a COREQ statement (consolidated criteria for reporting qualitative research dedicated to interviews and focus group) because it is not entirely conform with the checklist, even if the majority of the items are in accordance with our qualitative analysis. (Abstract, line 29, page 2).

2. Methods:

- We have reworked the methods section to clarify the methodology used (Method, line 80-88, page 4/ Sample selection, line 91-93, page 4/ The Limoges University Hospital’s department, line 124-130, page 5-6/ Qualitative analysis, line 142-143, page 6).

- We develop a more consistent description of the study context (Method, line 96-117, page 4-5)

- We have simplified the drafting in 2 steps because in the first step we did not have 200 ADs but only 6 ADs collected retrospectively from 200 medical records in the Limoges site. In order to have a sufficient number of ADs, we have decided to include the 6 ADs found in these medical records in our sample.

- We analysed the content of the ADs collected retrospectively and prospectively with the same methodology.

- We have corrected the sentence and clarified the fact that we did not collect all the ADs but only ADs written by patients being treated for a malignant haemopathy in one of the six sites were included in the study from 01/06/2008 to 15/04/2016, whether the document was given directly by the patient to a healthcare professional or had been filed in the patient's medical records. (Method, line 91/93, page 4).

- We have taken into account your remarks on the subgroups of pathologies and removed this distinction as the qualitative analysis of the ADs did not reveal any difference in content.

3. Research ethics:
• We have specified that the Ethics Committee of the University Hospital of Limoges approved the study (Ethics, line 589, page 24). The research is indeed a descriptive study because the clinical research engineer does not intervene in the process of writing the ADs. Her mission is to inform the patient about the legal formalism and specify the ADs’ role and scope. (Method, line 129-130, page 6). As indicated and according to French health regulations no written informed consent is required as the research is an observational study on registered data. Research applies to evaluate routine care. Patients were duly informed and oral consent was obtained prior to the research from all the participants.

4. Results:

• We included all the ADs collected by the healthcare professionals of the 6 sites or found in medical records and in the case of the deceased patients, we identified their places of death. We have added a sentence to clarify this point: “Among the 14 patients/35 deceased (40%), nearly all of them died either in hospital or in another institution while only 2 died (5.7%) at home.” (Results, line 175-177, page 8)

• We have corrected the sentence, and qualified our interpretation in the light of our remark: “although this expression could mean a wish of best palliative care” (Results, line 259-260, page 11).

5. Discussion:

• We place the sentence starting with ‘of the 35 ADs” in the results section (Results, line 199-203, page 9).

• We add that the size, the geographic location has no influence on the way patients write their ADs (Discussion line 491-492, page 20)

• We clarify the hospital’s admission procedure and the internal procedures (Method, line 107-114, page 5).

• We have taken into account your remarks on the discussion and place a paragraph in the results section (Results, line 191-196, page 8)

6. Future developments:
- We have added a paragraph about Advance Care Planning to support our results on the emerging role of the ADs to communicate messages within the family (Discussion, line 545-551, page 22-23)

7. Language/formal aspects of the article:

- A native English speaker has read the revised manuscript.
- We have made the necessary corrections which are highlighted in blue.

Reviewer 2: Mr Joan Liaschenko

1. Title:

- We have chosen a new title, more reflective of the findings in the context of French law: “Advance directives from haematology departments: patient’s freedom of choice and intrafamilial communication?: a qualitative analysis of 35 written documents.”.

2. Background:

- We have taken into account your remarks on the importance to develop the context of French law rather than what is done in the U.S. We clarify the formalism and value of ADs in France. (Background, line 51-69, page 3)

3. Abstract:

- We wanted to talk about the healthcare professionals.

4. Methods:

- We have reworked the methods section to clarify the methodology used (Method, line 80-88, page 4/ Sample selection, line 91-93, page 4/ The Limoges University Hospital’s department, line 124-130, page 5-6/ Qualitative analysis, line 142-143, page 6).
- We have simplified the drafting in 2 steps.
• We clarify the aim and method (Background, line 77-78, page 4).

• We develop a more consistent description of the study context (Method, line 96-117, page 4-5).

• We know that patients were alive two years later because data relating to patient survival was updated on 15/05/2016. (Method, line 140, page 6 and Table 3).

• We choose not to compare practices between the sites because no difference was observed in terms of the ADs content between one site and another. According to our sample a comparison between the sites did not seem relevant.

5. Sample selection:

• We clarify the dates within which we collected the data (01/06/2008 to 15/04/2016) (Method, line 91, page 4) and dates within which patients wrote ADs (01/04/2006 to 15/04/2016) (Results, line 167-168, page 7).

6. Discussion:

• We clarify the implications for practice and for the patient care: “Furthermore, the new restrictive nature of ADs should have an impact on the doctor-patient relationship and the decision-making process. However mentalities must evolve because some physicians indicate that ADs will not have any influence on their decisions. This dichotomy between ADs and medical care has been demonstrated by several studies. The binding nature of ADs deserves to be explained to doctors because it changes the decision-making process.” (Discussion, line 532-537, page 22)

• We have completed the discussion and the references with the articles cited comparing French and English/American models.

Yours faithfully,

Ms. S Trarieux-Signol