Reviewer’s report

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

Version: 0 Date: 29 Jun 2017

Reviewer: Sabine Salloch

Reviewer's report:

The authors report from a comprehensive, multicentre study on the ADs of patients suffering from hematologic malignancies. The research question has a rather open character "to analyse the content of advance directives written by patients suffering from malignant haemopathies" but the results are clearly presented and give insight in the practice of ADs in France.

Whereas I have several minor remarks my main points of concern refer to

a) the study format,

b) the form of collection of the ADs (which remains unclear to me) and

c) the results concerning the AD format used.

Below I will provide my comments point-by-point.

Abstract

The authors indicate that they adhere to the STROBE statement. STROBE is a reporting guideline for observational studies in epidemiology and does not well fit for a qualitative text analysis as performed in this study. Important points from the STROBE checklist are missing in the article (e.g. "Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers." or "Describe any efforts to address potential sources of bias."). A reporting guideline for qualitative research is the COREQ statement, for example.

Methods

The article first indicates that in CHU Limoges 200 ADs were collected (p. 5). It then says that "All the ADs written by patients being treated for a malignant haemopathy in one of the six sites were included in the study from 01/04/2006 to 15/04/2016." From my perspective the sample size then should be much bigger than the 35 ADs actually analyzed for the article.
It is also written that "we were informed of the ADs collected punctually by a physician or a nurse in the five hospitals quoted" (p. 7). This stands in contrast to "All the ADs written by patients being treated for a malignant haemopathy in one of the six sites were included in the study from 01/04/2006 to 15/04/2016."

Why did you create the two main subgroups of myeloid pathologies and lymphoid pathologies and in how far did this influence your data analysis? (p. 5) Is this really an important distinction with respect to the content of ADs?

Research ethics: The authors indicate that "According to French health regulations no written informed consent is required as the research is a retrospective observational study on registered data." In the article, however, they declare that their research is a "prospective, multicentre, qualitative, descriptive study." (Abstract). The authors also describe active interventions performed with the patient: "The patient is given the information after being diagnosed and a model AD is made available to him/her in free text, in keeping with legislation." (p. 5) etc. From my perspective this is more than a descriptive study. More exact information about the study type to assess the research ethics would be important.

Results

"Nearly all the patients died at the hospital or in another institution with only 5.7% dying in their homes (n=2/35)." (p. 8) Did you only include deceased patients' ADs?

The article says that the Limoges patients received an "AD form of the free text kind" (p. 5). Later it is indicated that "Most of the patients wrote their ADs on blank paper (n=22/35, 62.9%)." (p. 8). As 24 of 37 ADs were coming from Limoges (p. 8) this is hard to understand. In general the recruitment process in the six centers is not describes so clearly that it could be easily understood. It even does not become clear whether the study has a prospective or retrospective design.

The quotes from the ADs and their interpretations are not always easy to follow. The following quote is used, for example, to demonstrate how patients are referring to euthanasia or assisted suicide: "I want the doctors to prevent me from suffering morally as well as physically, and that they help me pass away in all dignity." (p. 11) From my perspective, it is far from being clear that the patient is referring to euthanasia or assisted suicide here; best palliative care could be meant as well.

Discussion

The sentence starting with "Of the 35 ADs"(p. 18) should be better placed in the results section.
"The main limit of the study is that it was conducted in a predominantly rural population." (p. 23) In the methods section the authors indicated that "The qualitative study was therefore carried out in six hospital sites in various rural and urban locations" (p. 6). A more consistent description of the study context would be helpful.

"a substantially higher number were collected from the two sites which have procedures specifically providing information about ADs - Limoges (n=24) and Libourne (n=5) - than from sites with an institutional procedure (n=6)." (p. 8) It did not become clear to me (in this and other passages) what was the difference between the two groups of sites, namely between "procedures specifically providing information about ADs" and "institutional procedures".

p. 19 ff: There are long text passages which still report study results. From my perspective this should be omitted in the discussion section but either removed or integrated in the results section.

p. 20: There are several passages in the results and the discussion section where the authors discuss distribution and impact of blank paper ADs versus standardized forms. They also report, however, that a great share of their sample was provided a specific format of AD ("AD form of the free text kind", p. 5) via an institutional procedure. Against this background I think any interpretation of patients' choice of specific AD format is very limited and the respective sections should be either better discussed or removed.

Future developments

The authors might consider including more recent developments for advanced decision-making (such as Advance Care Planning) in their concluding sections.

Language / formal aspects of the article:

A language proof by a native speaker would be advisable for this article. Please find below some examples for mistakes or rather odd wordings.

,,careers" (Abstract)  
There are unclear numbers (references ?) in abstract and text, for example "The median age of the patients was 69 [48,85]."

"United-States" (p. 4)  
"whether they be chronic or acute" (p. 4)  
"In background," (p. 4)
"two of which were excluded as they had not been filed," (p. 8); do you mean "filled"?

**Are the methods appropriate and well described?**
If not, please specify what is required in your comments to the authors.

Yes

**Does the work include the necessary controls?**
If not, please specify which controls are required in your comments to the authors.

Unable to assess

**Are the conclusions drawn adequately supported by the data shown?**
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Yes

**Are you able to assess any statistics in the manuscript or would you recommend an additional statistical review?**
If an additional statistical review is recommended, please specify what aspects require further assessment in your comments to the editors.

I recommend additional statistical review

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Please indicate the quality of language in the manuscript:

Needs some language corrections before being published

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