Author's response to reviews

Title: In the shadow of bad news - Views of patients with acute leukaemia, myeloma or lung cancer about information, from diagnosis to cure or death.

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

Thank you very much for sending me the comments by the reviewers. I am grateful for their suggestions, which has helped to improve the paper…

Below is a list of the main comments and how the paper has been changed to deal with them. Also a language revision of the manuscript has been taken care of by a native speaker.

The main comments and how the paper has been changed to deal with them.

Reviewer Linda Emanuel:

Comment 1: Abstract. The description of categories is making the reader perplexed rather than intrigued?

The abstract is partly re-written to make the use of the categories more fitting - changed as follows:

Results: All patients described themselves as well informed from start but in later phases of their disease some of them came to express a great uncertainty about the progressing disease and about approaching death. Most of them, regardless of whether they had a haematological malignancy or lung cancer, expressed a wish to be well informed all disease through and even when the messages were bad. Different strategies for coping with information, however, affected how they then dealt with the information received. Four such coping strategies were found: 1) Information-dependent and accepting 2) Information-dependent but denying 3) Medically fully informed and accepting 4) Medically fully informed but denying.

Comment 2: Coping through information as the predominant response to bad news?

The paper has been changed as follows:

Many studies have been written about patients’ coping strategies since the fundamental work of Lazarus & Folkman on stress and coping. In this work, however, we will confine ourselves to coping through information only, which of course is only a small part of the coping process as an entity.

Comment 3: The presentation of three phases of the disease and the imbalance in the focusing the three?

The paper has been changed as follows:

- The recurrent expression three phases of the disease has all through been replaced by “all the disease through”
- A more obvious explanation is now given to the differences in the distribution of interviews:
The intention was to interview the patients with haematological malignancies every fortnight and the patients with lung cancer as they came for treatment three times monthly, but for various reasons the number of interviews came to differ among the patients. Two patients did not get the desired effect of their treatment and died rather soon, patient B only four days after the first interview and patient V after two months. Three patients became excluded from the study. Patient F because wanted to withdraw, A for geographical reason and D as the interview questions seemed to hurt and upset him. Four patients reached the desired state of complete remission, but three of these relapsed and then went on with a second line treatment. Only one patient did not relapse at all during the two years that the patient was followed. Seven patients were followed into terminal phase.

For the distribution of interviews, please see table 1 in the paper.

c) The Results is partly changed in that the order is changed for the presentation of the results. Now, the patients’ views of information is first presented and the description of coping strategies at the end. Secondly, the headings are changed as to: Patients’ views of information, Patients’ views of information – when the disease is in recurrence and Patients’ views of information – in the terminal phase. Thirdly, more quotations have been added to make the imbalance less.

Comment 4:
Methods. Excluding criteria. What is an ‘obvious imbalance’?

This has been changed and is replaced by:
Exclusion criteria were if the patient was unable to give informed consent or understand the questions.

Comment 5:
Analysis. The question of inter-rater reliability of coding?

The paper has been changed in the Discussion – with this sentence added:

During the process of coding, a co-reader checked that the codes summed up the text passages.
…Finally, all through the study, critical researchers, physicians and co-readers have critically read and checked the interpretations made (communicative validity)

Comment 6:
Results. The phases and the four categories do not seem to connect.

How this has been changed is presented above: Please, see, comment 3. Also the title has been changed:

From: In the shadow of bad messages - Reactions of patients with acute leukaemia, myeloma or lung cancer to bad messages in different phases of their disease.

To: In the shadow of bad messages – Views of patients’ with acute leukaemia, myeloma or lung cancer about information, from diagnosis to cure or death.
Comment 7:
Discussion. The norm is to put the study limitations at the end and in a straightforward way… not to switch to first person. 

This has now been changed. The study limitations has been transferred to the end and completed by some more limitations of the study, and the switch to the first person is replaced ‘by the first author’.

Comment 8:
Practical implications as ‘out of the blue’. To this I agree. The suggestion from me is to erase them, leave them out.

Reviewer Patricia A:

Comment 1:
The description of methodology and statistical plan is incomplete.

The paper has now been changed:
  a) Methods: As the patients were diagnosed at Örebro University Hospital, Sweden, they were consecutively asked to join the study…
  b) Ethical considerations: The patients were recruited to the study during their medical visits. As soon as the physicians found it suitable the patients were, from their physician, given both oral and written information about the study.
  c) Methods: The intention was neither to interview the patients as soon as possible after they had received their diagnosis, nor to follow the patients during the whole processes of their dying. The first interview was held from six days to six weeks after the diagnosis had been given the patient and the interviews came to an end as soon as the patients expressed that they knew that they now were to die as no more treatment was possible to stop the progress of their cancer.
  d) A summing up description of the participants and number of interviews is presented in Figure 1, please see Figure 1:

Figure 1 - Study participants and number of interviews

<table>
<thead>
<tr>
<th>Category of patient</th>
<th>Number of interviews</th>
<th>Sex</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>7 Haematologic</td>
<td>44</td>
<td>3 men / 4 women</td>
<td>37–80 years</td>
</tr>
<tr>
<td>5 Lung cancer</td>
<td>44</td>
<td>2 men / 3 women</td>
<td>60–71 years</td>
</tr>
</tbody>
</table>
e) That the differences in the distribution of interviews ought to be explained?

The paper has partly been changed as a more obvious explanation is now given to the differences in the distribution of interviews:

The intention was to interview the patients with haematological malignancies every fortnight and the patients with lung cancer as they came for treatment three times monthly, but for various reasons the number of interviews came to differ among the patients. Two patients did not get the desired effect of their treatment and died rather soon, patient B only four days after the first interview and patient V after two months. Three patients became excluded from the study, patient F because she wanted to withdraw, A because for geographical reason and D as the interview questions seemed to hurt and upset him. Four patients reached the desired state of complete remission, but three of these relapsed and then went on with a second-line treatment. Only one patient did not relapse at all during the two years that the patient was followed. Seven patients were followed into terminal phase. (For an overview of the distribution, please see Table 1 in the paper).

e) The questions about Data collection / Verbatim transcriptions / More descriptions are needed about the interview-process?

To make this - the paper has got (as before) an appendix 1; with interview questions to the very first interview with each patient. Depending on what the patient was telling and what happened to the patient, new questions emerged. Most interviews started with a short recapitulation of the previous interview and then followed the questions, appendix 2:

1) What has happened to you since we last met?
2) How are you today? What is to worse? What is to better?
3) What is there to tell about the treatment you are getting?
4) Any news in the information given to you?
5) What now?

Each interview consisted of 5–7 questions.

Verbatim transcriptions?
As before: All interviews, except for those with one patient, were tape-recorded, conducted and transcribed verbatim by the first author.

c) Accuracy?
The paper has got two sentences added at the end of the Discussion:

The intention was to follow as closely as possible the words of the patients, but there is always the possibility of misinterpretations or over-interpretations. To minimize such risks most interviews started with a short recapitulation of the previous one held. Checking questions were also used (dialogic validity). A soon as they were transcribed, all taped interviews were listened to once again to assure conformity. During the process of coding a co-reader checked that the codes summed up the text passages. Finally, all through the study, critical researchers, physicians and co-readers have critically read and checked the interpretations made (communicative validity).
Comment 2:
More information is needed regarding the participants?

Please, see above Comment 1/ Figure 1

For the differences in the distribution of interviews?
Please, see above Comment 1/. Table 1

The differences in the distribution of interviews is to be explained?

This has been changed this way in the paper:

The intention was to interview the patients with haematological malignancies every fortnight and the patients with lung cancer as they came for treatment three times monthly, but for various reasons the number of interviews came to differ among the patients. Two patients did not get the desired effect of their treatment and died rather soon, patient B only four days after the first interview and patient V after two months. Three patients were excluded from the study, patient F because wanted to withdraw, A for geographical reasons and D as the interview questions seemed to hurt and upset him. Four patients reached the desired state of complete remission, but three of these relapsed and then went on with a second-line treatment. Only one patient did not relapse at all during the two years that the patient was followed. Seven patients were followed into terminal phase.

Comment 3:
More information is needed about how the categories were created?

Analysis: The paper has now been changed from: through the work with codes the analytical categories and themes of the patients were obtained to as follows:

Codes with similar contents, not necessarily confirming each other, were brought together into different investigation areas. **One such area was how the patients came to deal with the information received. Then four possible patterns emerged, four kinds of strategies for coping with information - the four categories.**

The individual statements are not enough brought together?

This has partly been changed in the paper. The presentations of Results has got a new order in that patients’ views of information is first presented and the description of coping strategies at the end. Secondly, the headings are slightly changed to: Patients’ views of information, Patients’ views of information – when the disease is in recurrence and Patients’ views of information – in the terminal phase. Thirdly, more quotations have been added to make the imbalance less.
Reviewer Lidia Schapira:

Comment 1:
To change the title?

The title of the paper has now been changed
From: In the shadow of bad messages…
To: In the shadow of bad news….

Comment 2:
To change one expression?

The expression is now changed in the paper
From: when death is coming close
To: as death approaches

Comment 3:
A visualization how the patients were distributed among the four categories?

This has been changed in the paper, through a table, Please, see Table 2:

<table>
<thead>
<tr>
<th>Patient</th>
<th>1 Information dependent and accepting</th>
<th>2 Information dependent but denying</th>
<th>3 Medically fully informed and accepting</th>
<th>4 Medically fully informed but denying</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B</td>
<td>(X)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C</td>
<td>X</td>
<td></td>
<td></td>
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<tr>
<td>D</td>
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<td></td>
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<td>Y</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
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<tr>
<td>Z</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>
Comment 4
Only a small number of patients were interviewed as they were disoriented or were near death?

This has now been explained more clearly in the paper, through the added lines:

Methods: … The intention was neither to interview the patients as soon as possible after they had received their diagnosis nor to follow the patients during the whole processes of their dying. The first interview was held from six days to six weeks after the diagnosis had been given the patient and the interviews came to an end as soon as the patients said that they knew that they were about to die as no more treatment was possible to stop the progress of their cancer.

The paper has got a table of distributions, Please see table 1 in the paper, but now also a description of the differences in the distributions of interviews.

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In addition a number of minor changes have been made. I enclose a new version of the paper where the changes have been inserted.

Yours sincerely,
Lena Hoff