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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Version: 5 Date: 29 December 2006

Author's response to reviews: see over
Second Reviewer's report

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.

Version: 4 Date: 6 October 2006

Reviewer: Patricia A Parker

Reviewer's report:

General
The authors appear to have considered the suggestions that were raised in the previous review and have made minor modifications to the manuscript. However, there continue to be some areas of the manuscript that are awkward and unclear and several issues raised by the previous reviewers did not appear to be fully addressed.

Major Compulsory Revisions (that the author must respond to before a decision on publication can be reached).

The identified categories continue to be somewhat ambiguous and some do not seem to match the content described. For example, it is not very clear what the difference is between “information-dependent” and “medically fully informed.” The description and the examples from the patients' comments seem quite similar. It is not clear to this reviewer whether these categories represent meaningful differences in patients' information needs/styles.

The paper has been changed in the paper in the following way: pp 11-12

The third coping strategy is called ‘Medically informed and accepting’. Also these patients appreciated being informed but they came to deal with the information received in another way than did the patients categorized as Information-dependent. While the Information dependent patient followed every single test result most carefully, memorizing every value number, the Medically informed patient never took such an interest in each test taken. They reckoned that they would be informed when there was something they ought to know about. “Actually, you can’t keep it all in your head. It’s too much” (F: 3). “I’m not one of those who checks up the test results. They’ll tell me, I suppose, if there’s something I should know” (G: 11). These patients found the focusing on every test result somewhat tiring and sometimes they were criticising their doctors for being “too medical” or “too focused” on the test values.
figures and numbers. “Too medical … I was unlucky meeting a real medical doctor, so to speak” (D: 3). “Yes … it’s a little too technical” (G: 6). However, of these patients only patient Z was followed into the terminal phase, so it is hard from this study to tell how well these patients held on to their strategy. What was seen in this study was that two of the patients came to change their strategy slightly to the strategy of denying. Patient G, after being told that she had been very close to death, which she had not been aware of (G:9), however, in the next interview she was back as a non-denying patient. On the other hand, patient Z became all the more denying the more her health declined.

More information regarding the participants (e.g., age, gender, education) and disease- and treatment-related (time since diagnosis, current and previous treatments, recurrence status, etc.) characteristics is now provided. However, it is suggested that the authors consider how some of these characteristics might influence the patients’ perspectives.

This has now has been changed in the paper in the following way:

Discussion pp 13-14

One might also have expected that patients with lung cancer diseases and haematological diseases would have reacted somewhat differently to the information given, revealing differences in when and how much patients were informed. But we found people who were well informed and not so well informed in both kinds of patients, though the less well aware patients were more often found among patients with lung cancer. The reasons behind that need to be investigated more.

The age of the interviewees varied, from 37-80 years, the age could then have been of importance for the strategy of the patient’s but this was not found. The youngest patients were categorized differently in relation to each other, as were the oldest patients.

Finally one might have expected gender differences among the patients’ attitudes to information but no such differences were found either.
It would be preferable to have the description about the coding process (e.g., having another reader review the transcripts and interpretations) in the methods' since this is part of the methodology rather than describing it solely in the discussion.

This has now has been changed in the paper in the following way: p 7

Analysis

The study is qualitative, with a hermeneutic approach. The steps taken in the analysis were inspired by Kvale [24] and to some extent also by Graneheim and Lundman [25]. Firstly, all typed material was read through. Then the material not containing information and messages relevant to the purpose of this study was excluded. The remaining material was divided into three domains of investigation: the disclosure of the diagnosis and information during the first treatment, during a second treatment, and terminally. A soon as they were transcribed, all the taped interviews were listened to once again to assure conformity. Then the process of coding started, piece by piece. During the process of coding, a co-reader checked that the codes summed up the text passages. Codes with similar contents, not necessarily confirming each other, were then brought together into different investigation areas. One such area was how the patient came to deal with the information received. Then four possible patterns emerged, four kinds of strategies for coping with information – the four categories.

It is helpful to see the number of interviews for each of the participants. There is such a wide range of the number of interviews for the participants in the diagnosis/treatment 1 phase. However, there is no information/discussion in the paper abut how the interviews may have changed over time (within the diagnosis/treatment 1 phase). It seems that someone who has been interviewed 11 times might express different reactions toward their disease and it would be useful to consider how the number of times participants were interviewed might affect their perceptions.

This has now has been changed in the paper in the following way:

Discussion pp 13-14
As the number of times participants became interviewed differed from 1-14, one might have expected that the number of interviews could have affected the perceptions and reactions of the patients’ toward their disease, making a change to the patient’s strategy for coping with information. As the health of the patients were declining the attitudes to the disease of most patients were changing, but not their attitudes to information. Only on some occasions did two patients change their strategy to the strategy of denying. This, might also indicate that at least some patients had the ability to find “a way out”, when facts were too hard to cope with. Otherwise they all hold on to the strategy they had from start. As soon as the reaction pattern of a patient to information is known, we believe that the physician has a key for further communication with the patient.

Results, p 8:

but as their health started to decline they all, except patient W, were wondering about the reasons behind that. (Z: 4-8, Y: 5-8, X: 8-13, V: 2).

On the other hand as treatment went on the patients came to express an adjustment of being in treatment, which made the fear less for a recurrence of the disease. Now, they thought that they knew what another treatment would be like. “If I will relapse, I will relapse... but that day, that sorrow. It is no big deal if I have to go through it once more” (C: 9). “I do understand that the cancer could come again, but I am not worried if I have to go back to the hospital. Now, I know what it would be like”(E:6).

The conclusions appear to go beyond the data.

This has now has been changed in the paper in the following way: p 17

The result of this study could help to improve health care, if it could make physicians
- more aware of the fact that there are patients whose need for information remains of great importance all through the disease, even in later phases and when life comes near to the end
- more aware that there is sometimes a lack of knowledge among patients, to be recognized and as much as possible minimized.
- more aware that knowing the patient’s strategy for coping with information could probably function as a key for the physician when to communicate with the patient about progressing disease and about death coming near

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Minor Essential Revisions (such as missing labels on figures, or the wrong use of a term, which the author can be trusted to correct)

This has now has been changed in the paper:
P 5: Figure 1
P 6: Table 1
P13: Table 2

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Quality of written English: Not suitable for publication unless extensively edited:

This has been done. Here is a copy of the bill from my translator:

• Alan Crozier

**English Translation**

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Beställare
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Språkgranskning och redigering av
In the shadow of bad messages
2 tim à SEK 440,00/tim 880,00
Moms à 25% 220,00
Öresutjämning 0,00

Att betala
SEK 1100:--
Förfallodag 2006-12-11