

BMJ - Decision on
Manuscript ID
BMJ.2016.032578

Body: 24-May-2016

Dear Prof. Murray

Manuscript ID BMJ.2016.032578 entitled "Embracing inherent uncertainty in advanced illness"

Thank you for giving us the opportunity to consider this paper, which we discussed at our editorial meeting on Friday 20th May.

We are pleased to make a provisional offer of publication if you are able to revise it to address the points made by the referees and the editors. The referees' comments are available at the end of this letter, and the points raised by the editors are set out below.

1. Editors liked this thoughtful and interesting essay on an important topic. The main feedback from editors was around structure rather than content. The article would benefit from a greater degree of clarity and succinctness. We wonder whether trimming it to, say, under 1500 words would help focus the article and make it sharper?

We hope that you will be able to revise the paper and send it back to us within one month. When you resubmit, could you kindly ensure that you provide:

- (a) A covering letter outlining how you have responded, or not responded and why, to both the referees comments and those of the editors.
- (b) A word count (excluding the references and words in boxes and tables).
- (c) Please check that all the information required in the manuscript (see note below) is included in the revised manuscript.

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I hope you will find the comments useful.

Best wishes

Yours sincerely

Navjoyt Ladher
nladher@bmj.com

***** Present at Analysis meeting: Theo Bloom, Tony Delamothe, Navjoyt Ladher**

INFORMATION TO INCLUDE IN REVISION

Please would you also check that you have provided the following information

* Competing interest statement (in the style explained at <http://www.bmj.com/about-bmj/resources-authors/forms-policies-and-checklists/declaration-competing-interests>)

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* Signed patient consent form(s), if the article gives enough personal information about any patient(s): - (see http://resources.bmj.com/bmj/authors/editorial-policies/copy_of_patient-confidentiality)

Reviewer(s)' Comments to Author:

Reviewer: 1

Recommendation:

Comments:

I liked this article. I think there is a major unaddressed point about uncertainty of prognosis. This is true for cancer as well as non cancer diagnoses. We did a study (ASPECTS) back in 2006 which looked at what people understood about prognosis when making a decision to have palliative chemotherapy. There was very little understanding of extra length of life that might be gained, based on interviews following the discussion about chemotherapy.

The point about finding your 1% is an excellent one. It can be more of an obstacle than a help. I think acknowledging uncertainty and discussing hope for the best and planning for the worst is a better strategy. It is one that needs reviewing as people deteriorate.

It may be worth mentioning treatment escalation plans, particularly in the hospital setting. The discussions are more subtle than DNACPR and are based around what would you want us to do if you become less well. ACP in hospital can be tricky.

The authors may want to consider making recommendations at the end rather than having a box for questions. For example, giving practitioners some specific advice about what to say when acknowledging uncertainty would help.

Additional Questions:

Please enter your name: Julian Abel

Job Title: Consultant in Palliative Care

Institution: Weston Area Health Trust

Reimbursement for attending a symposium?: No

A fee for speaking?: No

A fee for organising education?: No

Funds for research?: No

Funds for a member of staff?: No

Fees for consulting?: No

Have you in the past five years been employed by an organisation that may in any way gain or lose financially from the publication of this paper?: No

Do you hold any stocks or shares in an organisation that may in any way gain or lose financially from the publication of this paper?: No

If you have any competing interests ([please see BMJ policy](#)) please declare them here:

Reviewer: 2

Recommendation:

Comments:

I want to start by saying that I'm sceptical that the slow, expensive, and faulty process of prepublication peer review will add value to this paper. It isn't a paper that could be shown to be "true" or "false." It's an opinion piece, and for me the more quickly it can be published and discussed the better. And you are better qualified than me to decide whether it should be in the BMJ.

The paper covers a subject important to all of us and is clearly written and argued. It has extensive references, and I can't check them all. It's likely that at least some of the 64 references don't say exactly what the authors say they say, but I can't see that that matters.

I enjoyed the bluntness of the key messages and almost agreed with them. I do think, however, that there is a case to be made for continuing to search for "more accurate mortality risk assessment

tools.”

1. I find it uncomfortable to stop any scientific search
2. Although I can accept that such tools may not be valuable to most, some patients and families might like to have a more accurate prediction of when death will occur. Assuming that there are such people, it would be more “person/patient centred” to provide the choice and the information
3. Such a tool if accurate could be useful for those planning and running health services

Other thoughts on the paper...

1. It seems to me that uncertainty is important not just towards the end of life but throughout life. We may choose to try and deny or ignore it, or attempt to overcome it as best we can, but mostly we learn to live with it.
2. And just as the authors argue in the paper, we might find uncertainty uncomfortable, comfortable, or both. Not knowing what is going to happen can be distressing, but uncertainty allows the possibility that the best rather than the worst may happen.
3. I thus wonder if the authors might want to reflect a little on uncertainty in a broader context.
4. I certainly agree that “the perception that uncertainty is an insurmountable challenge and a barrier to appropriate person-centred care” is questionable, but are there really many who don’t question it? Or have the authors set up a straw man (person)?
5. The authors write about “the relatively predictable illness trajectory” of cancer, but hasn’t this changed? I recently saw a presentation from a palliative care physician in which he argued that death from cancer was beginning to follow a trajectory similar to that of frailty—long an uncertain. I have several friends with metastatic cancers that they have had for years. A less predictable trajectory does, of course, mean more uncertainty.
6. There is an irony underlying the article in that Benjamin Franklin’s famous quote says that “In this world nothing can be said to be certain, except death and taxes.” So all else is uncertain, and the phrase that the authors are writing about is more certain than most.
7. Although I tend not to apply the stricture to myself, I believe that almost any piece of writing could be shortened with benefit—and that would be the case here.
8. I wonder too if 64 references are really necessary. Indeed, a shorter’ less scholarly article might attract more readers and prompt more debate.

Richard Smith
Chair, Patients Know Best
Former editor, BMJ

Additional Questions:

Please enter your name: Richard Smith

Job Title: Chair, Patients Know Best; Former editor, BMJ

Institution: Patients Know Bet

Reimbursement for attending a symposium?: No

A fee for speaking?: No

A fee for organising education?: No

Funds for research?: No

Funds for a member of staff?: No

Fees for consulting?: No

Have you in the past five years been employed by an organisation that may in any way gain or lose financially from the publication of this paper?: No

Do you hold any stocks or shares in an organisation that may in any way gain or lose financially from the publication of this paper?: Yes

If you have any competing interests ([please see BMJ policy](#)) please declare them here: I have shares in UnitedHealth, a company that supplies end of life services.

Date Sent: 24-May-2016

