PEER REVIEW HISTORY

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This paper was submitted to the JECH but declined for publication following peer review. The authors addressed the reviewers' comments and submitted the revised paper to BMJ Open. The paper was subsequently accepted for publication at BMJ Open.

ARTICLE DETAILS

TITLE (PROVISIONAL)	"Conditional candour" and "knowing me:" an interpretive description study on patient preferences for physician behaviours during end-of-life communication
AUTHORS	Abdul-Razzak, Amane; You, John; Sherifali, Diana; Simon, Jessica; Brazil, Kevin

VERSION 1 - REVIEW

REVIEWER	Dr Karen Detering Austin Health Melbourne, Australia
REVIEW RETURNED	15-May-2014

GENERAL COMMENTS	In the methods section - it would be useful to have interview questions stated. At this stage the first question is stated In the discussion one of your refernces is reference 30, but this is not in your bibliography.

REVIEWER	Daisy J.A. Janssen, MD, PhD CIRO+, Horn, The Netherlands.
REVIEW RETURNED	18-May-2014

GENERAL COMMENTS	The present manuscript addresses an important issue: patient preferences for physician behaviours during end-of-life communication. The research methodology is appropriate. Strength from this study is including patients with malignant and non-malignant disease. The authors use a broad range of criteria to identify patients with a need for end-of-life care communication. The manuscript is well written. I have only a few minor comments. Comments: 1. Abstract: the authors should explain abbreviations the first time (EOL, ACP). 2. Introduction: the authors describe a difference between ACP and in-the-moment decision-making as described by Sudore et al. However, Sudore et al. state that ACP can facilitate in-the-moment decision-making. So, these should not be seen as two different concepts. 3. The authors state that the findings provide practical

	recommendations for improving patient-physician end-of-life communication that can be easily incorporated into a physician's busy practice. Although the authors do provide very important information to improve quality of EOL care communication, the difficulty of providing high-quality EOL communication should not be underestimated. Therefore, easy implementation does not seem reasonable and training in EOL communication is needed. The discussion could benefit from describing the need for training in EOL communication and how the findings of the current study can be implemented. 4. Patients were excluded if they could not recall any previous EOL communication encounters with a physician. It would have been helpful in future studies to also include patients who did not have previous EOL discussions with their physician to explore how they would prefer their physician to initiate these discussions. 5. A few typographical errors should be corrected, for example: discussion, line 3: 'that were felt to beneficial'.

REVIEWER	Professor Anne Wilkinson Edith Cowan University Perth, Australia
REVIEW RETURNED	26-Aug-2014

GENERAL COMMENTS	Very well presented study on an important topic. Very interesting article. Only statement missing is ethics application and approval number.

REVIEWER	Emma Kirby University of Queensland, Australia
REVIEW RETURNED	02-Sep-2014

GENERAL COMMENTS	This paper addresses an important issue, and shows considerable promise in terms of findings, interpretation and implications for practice. I have a number of queries which I hope once addressed will improve the manuscript: - Throughout the paper the focus shifts between ACP and EOL. While of course not mutually exclusive, at times in the background and results sections, the disctinction between these two contexts lacks clarity. More discussion/commentary on the distinction between ACP and EOL is needed. This is particularly the case when dicussiing communication, as issues around acceptance of bad news and family dynamics can play out in a range of ways depending on whether the focus of clinical encounters are focused on issues around EOL (and death and dying) or ACP. - The sentence on data saturation (p8) needs further clarification in meaning. - More information on the project is needed for the methods to situate the qualitative focus. How many participants were approached for the survey? What was the response rate? How many participants were approached to take part in interviews? On what basis were these approached as opposed to others? What was the response rate? - Inclusion of an interview schedule/indicative questions would be useful as a supplementary file. - More information on the focus of the interviews is needed. Were

	the interviews organised around particular themes/domains? If so, what were these and why? - A short overall introduction to the results would better ground the following subsections. - The predominant concern I have relates to the presentation of data within the results section. There are a number of assertions made within the results which immediately follow data excerpts, however such assertions do not appear to be reflected in the data presented. (for example, p.13 "In effect, participants conveyed that they were part of a close network of loved ones....". Is there data available to include which supports this, as with other claims?) Further, the majority of the data (particularly in the early results sections) appear not to be about preferences for physician communication. The data presented in the 'acknowledging family roles' section might infer physician preference, but at present does not actually show patient preferences for physician communication. Rather, the data shows patient preferences in terms of ACP and EOL according to family/relational context. As such, some of the claims are not strictly supported by the data. More discussion of this is needed for clarity. - p.14. The second paragraph does not seem to relate to the point made above/linked to it. This needs to be reworked. Further, it is unclear whether the sentence following the colon (line 10) is commentary or paraphrased data. (Perhaps just remove the colon). - Participant quotes could be identified (for example by numbering participants) for further context (ie - are each of the data segments from different participants?) Also, gender and age range could be included with each quote without compromising the anonymity of participants. - Overall, more clarity of discussion and interpretation is needed in the results section. Frequently, the interpretation of the data presented is somewhat lacking. - More engagement with the literature on communication and breaking bad news would be useful (for example Back et al. have a number of pertinent papers on the topic), particularly in relation to the section on appropriate delivery of information. - Re: p.19/20, "It may be helpful to view the patient as a group of people". The authors may find my previous work (Kirby et al. 2014, Mortality) useful in further discussing this point (in terms of physician communication with family as well as patient in breaking bad news/EOL talk). - I disagree with the assertion that the main strength of the paper lies in strategies to ensure rigour. I think the papers substantive findings are a principal strength. I also note that the sample is relatively small, even for a qualitative study, so discussion of sample size within the limitations sections seems necessary. - More clarity in the final paragraph, to relate these findings to recommendations for practice would be useful.

VERSION 1 – AUTHOR RESPONSE

Reviewer # 1 Comments (Dr. Karen Detering)
Comment #1:
In the methods section - it would be useful to have interview questions stated. At this stage the first question is stated
Response:
Thank you for your constructive feedback. Initially, we started with only one open-ended question, as stated in the text of the manuscript. The development of the interview schedule was an iterative process, with questions being added based on concepts that emerged from previous interviews. We have added a table with sample questions (please see table 2, on p.11 of revised and highlighted manuscript), and have elaborated on the iterative development of the interview schedule in the manuscript (please see p.10, last paragraph of revised and highlighted manuscript).
Comment #2:
In the discussion one of your references is reference 30, but this is not in your bibliography.
Response:
Thank you for noticing this error, we have corrected the reference number, it is now reference 23.

Reviewer #2 Comments (Dr. Daisy J.A. Janssen, MD, PhD)
The present manuscript addresses an important issue: patient preferences for physician behaviours during end-of-life communication. The research methodology is appropriate. Strength from this study is including patients with malignant and non-malignant disease. The authors use a broad range of criteria to identify patients with a need for end-of-life care communication. The manuscript is well written. I have only a few minor comments.
Comment #1:
Abstract: the authors should explain abbreviations the first time (EOL, ACP).
Response:
We have revised the abstract such that there are no acronyms for ease of reading.
Comment #2:
Introduction: the authors describe a difference between ACP and in-the-moment decision-making as described by Sudore et al. However, Sudore et al. state that ACP can facilitate in-the-moment decision-making. So, these should not be seen as two different concepts.
Response:
Thank you for your feedback, and we agree that ACP and in-the-moment decision making, as described by Sudore et al, are interrelated concepts and that indeed ACP has been described as facilitating in-the-moment decision making. However, we find it helpful to distinguish somewhat between these two concepts, as they occur at different time points: ACP (should) occur prior to in-the-moment decision making . Furthermore, the content of ACP discussions, such as discussing values and preferences for health care or assigning a surrogate decision maker in the event that one is too sick to speak for herself, is different than in-the-moment decision making topics, such as deciding on specific interventions during an acute illness and/or hospitalization. We wanted to be clear that in our study, we have broadly defined end-of-life (EOL) communication as including these interrelated activities. However, in order to address your valid concern, we have modified the text in the introduction (please see p.6, paragraph 1 of revised and highlighted manuscript).

Comment #3
The authors state that the findings provide practical recommendations for improving patient-physician end-of-life communication that can be easily incorporated into a physician’s busy practice. Although the authors do provide very important information to improve quality of EOL care communication, the difficulty of providing high-quality EOL communication should not be underestimated. Therefore, easy implementation does not seem reasonable and training in EOL communication is needed. The discussion could benefit from describing the need for training in EOL communication and how the findings of the current study can be implemented.

Response #3
Thank you for your insightful feedback. We agree that the provision of high-quality EOL communication is a challenging task and we have modified the discussion to reflect this fact. We have also included a discussion about how the study findings could be implemented in training curricula as well as used as part of a complex intervention study focused on improving EOL communication (see p.30, last paragraph of revised and highlighted manuscript as well as “article summary” on p.5).

Comment #4
Patients were excluded if they could not recall any previous EOL communication encounters with a physician. It would have been helpful in future studies to also include patients who did not have previous EOL discussions with their physician to explore how they would prefer their physician to initiate these discussions.
Response #4
We agree that this is a limitation of the study and have included this in the discussion section (see p. 29, last paragraph of revised and highlighted manuscript). In addition, we have further clarified that when participants did not have a lot of experience in EOL communication with a physician, they were allowed to speak of scenarios where they were caring for a seriously ill loved one and engaged in EOL communication (along with their loved one) with a physician in that capacity. This has been clarified in the methods section, the results and in the discussion.
Comment #5
A few typographical errors should be corrected, for example: discussion, line 3: 'that were felt to beneficial.'
Response #5
Thank you for noting this, we have corrected the typographical errors.

Reviewer # 3 (Professor Anne Wilkinson)
Comment #1
Very well presented study on an important topic. Very interesting article. Only statement missing is ethics application and approval number.
Response #1
Thank you for your kind feedback. We have included the ethics approval numbers for both institutions in the methods section of the manuscript (see p.7 paragraph 2 in revised and highlighted manuscript).

Reviewer # 4 (Emma Kirby)
This paper addresses an important issue, and shows considerable promise in terms of findings, interpretation and implications for practice. I have a number of queries which I hope once addressed will improve the manuscript:

Comment #1
Throughout the paper the focus shifts between ACP and EOL. While of course not mutually exclusive, at times in the background and results sections, the distinction between these two contexts lacks clarity. More discussion/commentary on the distinction between ACP and EOL is needed. This is particularly the case when discussing communication, as issues around acceptance of bad news and family dynamics can play out in a range of ways depending on whether the focus of clinical encounters are focused on issues around EOL (and death and dying) or ACP.
Response #1
Thank you for your astute observation. We have noted the use of the term “ACP” a few times in the manuscript and we have corrected these instances to state “EOL communication,” as more accurately reflects our definition and focus. We agree that high quality communication may look different for ACP versus EOL issues. In this study, we are interested in a broad definition of EOL communication, which may include more upstream, iterative ACP-related activities (e.g., discussing values, and preferences

for health care, assigning a surrogate decision maker, completing an advance directive) as well as more immediate “in the moment” decision making, and related activities such as prognostic disclosure. We have referenced an article by Sudore et. al. in the introduction section of the article, as these authors have previously discussed the interrelated activities of ACP and “in the moment” decision making (please see p.6, paragraph 1). We have also further clarified our definition of EOL communication in this paper.

Comment #2

The sentence on data saturation (p8) needs further clarification in meaning.

Response #2

We have elaborated on the rationale behind this sentence in the text (please see p.10, paragraph 2 of revised and highlighted manuscript). Interpretive description methods has been developed out of the applied health sciences field (nursing specifically), with a purpose that is reflective of the unique needs of this discipline. The main focus is on findings that can be applied in practice. As Thorne, the researcher who coined the term “interpretive description” and has written a book and methodology papers on this method explains, patients may each have their own unique experience with health care, and it can be impossible to claim that all variations have been captured. Instead, the focus should be on capturing a variety of experiences but remaining aware of the fact that other perspectives may exist that have not been included in the work. If interested, please see Dr. Thorne’s book on interpretive description, especially chapters one and five (Thorne S. Interpretive Description. Walnut Creek, CA: Left Coast Press; 2008).

Comment #3

More information on the project is needed for the methods to situate the qualitative focus. How many participants were approached for the survey? What was the response rate? How many participants were approached to take part in interviews? On what basis were these approached as opposed to others? What was the response rate?

Response # 3

Thank you for your helpful feedback. We did not include details of the quantitative survey work as this will be submitted as a separate manuscript in which we will discuss the overall mixed methods study. However, we agree that it may help to situate the qualitative work. We have included more information about the number of participants approached for the quantitative strand (survey) and the response rate in the methods section (see p.8, paragraph 1 of revised and highlighted manuscript). Unfortunately we did not collect information about the number of participants approached to take part in interviews and the response rate, but we are not accustomed to seeing this information included as a routine part of the results or methods section of qualitative work. We have included information about the purposive sampling strategy (maximum variation sampling) in the methods section, which is supported by the literature as discussed (please see p.9, paragraph under table 1 of revised and highlighted manuscript).

Comment # 4

Inclusion of an interview schedule/indicative questions would be useful as a supplementary file.

Response # 4

Another reviewer has also made a similar recommendation, and we have responded by include a sample interview schedule in the manuscript (please see table 2, p.11 of revised and highlighted manuscript).

Comment #5

More information on the focus of the interviews is needed. Were the interviews organized around particular themes/domains? If so, what were these and why?

Response #5

The interview schedule developed in an iterative fashion, with only one open-ended question at the beginning. This question was based on the overall objective of the study. Additional questions were then added based on concepts that emerged from previous interviews. These additional questions were also relevant to the overall purpose of the study, but tended to have a narrower focus. We did not organize the interviews on pre-existing themes or domains, as we tried to maintain a purely inductive process. Please see the bottom of page 10 of the highlighted and revised manuscript for further information on the interview process.

Comment # 6

A short overall introduction to the results would better ground the following subsections.

Response # 6

Please find our introduction to the results on page 15, paragraph one. We have also included a brief summary statement of the findings in the discussion section (p. 25, paragraph 1 of revised and highlighted manuscript) but attempted to avoid unnecessary redundancy.

Comment # 7

The predominant concern I have relates to the presentation of data within the results section. There are a number of assertions made within the results which immediately follow data excerpts, however such assertions do not appear to be reflected in the data presented. (for example, p.13 "In effect, participants conveyed that they were part of a close network of loved ones....". Is there data available to include which supports this, as with other claims?) Further, the majority of the data (particularly in the early results sections) appear not to be about preferences for physician communication. The data presented in the 'acknowledging family roles' section might infer physician preference, but at present does not actually show patient preferences for physician communication. Rather, the data shows patient preferences in terms of ACP and EOL according to family/relational context. As such, some of the claims are not strictly supported by the data. More discussion of this is needed for clarity.

Response #7

We thank you once again for this insightful point. We agree that some of the data presented may not clearly relate to the interpretations, especially in relation to the first theme ‘knowing me.’ As such, we have replaced some of these excerpts with data that is more clearly relevant. More specifically, in the subtheme ‘acknowledging me’ we have replaced an excerpt (and text) about the heavy weight some participants place on family members’ opinions in their EOL decisions (which shows patient preferences in terms of EOL communication according to a relational context) with an excerpt that clearly relates to physician behaviours. In this excerpt, we have provided an example of a communication encounter that was perceived poorly from the participant perspective—a scenario in which a physician attempted to exclude family members during a ‘breaking bad news’ situation (please see p.16-17 of revised and highlighted manuscript). In addition, in the subtheme ‘respecting one’s background’ we have also replaced a data excerpt with two others that more directly reflect the claims made (please see p.18 of revised and highlighted manuscript). Once again, we have included text to elaborate on the interpretation as requested. Upon review of the second theme, ‘conditional candour,’ we feel that the data excerpts here more clearly represent the theme, subthemes, and interpretive claims.

Comment #8

p.14. The second paragraph does not seem to relate to the point made above/linked to it. This needs to be reworked. Further, it is unclear whether the sentence following the colon (line 10) is commentary or paraphrased data. (Perhaps just remove the colon).

Response # 8

This comment relates closely to the previous one, and we agree that this data excerpt is not readily interpreted as being related to the point linked to it. We have deleted this paragraph and replaced it with another data excerpt (please see response #7).

Comment #9

Participant quotes could be identified (for example by numbering participants) for further context (ie - are each of the data segments from different participants?) Also, gender and age range could be included with each quote without compromising the anonymity of participants.

Response #9
We have responded to this suggestion by providing participant numbers, gender, age range and diagnosis type (cancer versus non-cancer diagnosis) below each quote.
Comment #10
Overall, more clarity of discussion and interpretation is needed in the results section. Frequently, the interpretation of the data presented is somewhat lacking.

Response #10
We have added more interpretation in the results section to help clarify the perceived meaning of certain quotes (please see pp.16-17, interpretation related to “acknowledging family roles,” p.19,”respecting one’s background,” p.22, “being invited to the conversation”). However, much of the discussion/relation to literature has been reserved for the discussion section of the paper—and we have added to the discussion based on your suggestions below as well.
Comment #11
More engagement with the literature on communication and breaking bad news would be useful (for example Back et al. have a number of pertinent papers on the topic), particularly in relation to the section on appropriate delivery of information.
Response #11
We have discovered that this month Anthony Back and colleagues have published a paper that heavily discusses the importance of following the delivery of bad news (specifically being told no further chemotherapy is available) with what they have called “actionable offers.” We have included a discussion of this paper as it complements the subtheme ‘appropriate delivery of information,’ especially with relation to following the delivery of bad news with a discussion of what can be offered(please see p. 28, paragraph 1). In addition, we have referenced a paper by Baile et al on the SPIKES method for delivering bad news, as these authors discuss concepts such as the need to ask patients how they would like information to be shared, which relates to the subtheme ‘being invited to the conversation.’ This paper also addresses the benefit of discussing what is possible to accomplish (e.g., symptom control) as a way to maintain or reframe hope, which relates to our subtheme ‘appropriate delivery of information’ (please see p. 27 last paragraph).

Comment #12
Re: p.19/20, "It may be helpful to view the patient as a group of people". The authors may find my previous work (Kirby et al. 2014, Mortality) useful in further discussing this point (in terms of physician communication with family as well as patient in breaking bad news/EOL talk).
Response #12
We have reviewed this work and included some discussion of how our findings relate to the findings in the article stated above (please see p. 26 of revised and highlighted manuscript). More specifically, the above study recruited physicians, which provides an interesting complementary understanding, and also provides a slight variation as it relates to the perception of what it means to be a “supportive family.”
Comment #13
I disagree with the assertion that the main strength of the paper lies in strategies to ensure rigour. I think the papers substantive findings are a principal strength. I also note that the sample is relatively small, even for a qualitative study, so discussion of sample size within the limitations sections seems necessary.
Response #13
We agree that the substantive findings are a main strength of this paper and have modified the discussion to reflect this (please see p.28, last paragraph of revised and highlighted manuscript). Although our qualitative sample may be considered to be relatively small, we have made no claims to understand all variations in patient perspectives on physician behaviours during EOL communication. As such, we feel that the sample size is reasonable to allow the researchers (and readers) to gain

some insight into the topic of interest. As discussed in the methods section, when using interpretive description to ask questions in the applied health sciences, the researcher understands that not all variations in perspectives can be captured, and we remain aware that other perspectives may exist. We have added this explanation to the discussion section of the text as well (see p.25, paragraph 1).
Comment #14
More clarity in the final paragraph, to relate these findings to recommendations for practice would be useful.
Response #14
Another reviewer has provided similar comments, and we have included further discussion (please see p. 30 paragraph 2).

VERSION 2 – REVIEW

REVIEWER	Dr. Daisy Janssen CIRO+, The Netherlands
REVIEW RETURNED	21-Sep-2014

GENERAL COMMENTS	The authors addressed my comments appropriately and I have no further comments.

REVIEWER	Emma Kirby University of Queensland, Australia
REVIEW RETURNED	22-Sep-2014

GENERAL COMMENTS	The reviewer's comments have been comprehensively addressed; it is my view that the revised paper is suitable for publication.