Author's response to reviews

Title: Strategies for effective goals of care discussions and decision-making: Perspectives from a multi-centre survey of Canadian hospital-based healthcare providers

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Version: 3
Date: 7 July 2015

Author's response to reviews: see over
July 6th, 2015

Dear Dr. Seymour:

**RE: MS: 2145284480152598 - Strategies for effective goals of care discussions and decision-making: Perspectives from a multi-centre survey of Canadian hospital-based healthcare providers**

Thank you for your decision letter, dated April 28th 2015, regarding our above named manuscript. Please find below a point-by-point response to the reviewers’ comments. (Note that all page numbers, paragraphs, noted in our responses below are in reference to the revised manuscript file with changes tracked). We have modified our manuscript based on the reviewers’ feedback, and have uploaded both a clean and tracked changes version of the manuscript to the manuscript submission website. We hope that the revised manuscript will be acceptable for publication in *BMC Palliative Care*.

Sincerely,

Amanda Roze des Ordons, MD FRCPC MMed
Critical Care Medicine, Palliative Medicine
Clinical Assistant Professor, University of Calgary
Reviewer's report

Title: Strategies for effective goals of care discussions and decision-making: Perspectives from a multi-centre survey of Canadian hospital-based healthcare providers

Version: 2 Date: 23 March 2015

Reviewer: M. Jeanne Wirpsa

Reviewer's report:

Major Compulsory Revisions

Comment 1: Given the central role played by chaplains, psychologists, and social work in helping patients and families align values with medical plan, initiate goals of care conversations, facilitate advance care planning/advance directives, and address barriers to communication among families and between pt/family and medical team, it is unclear why these disciplines were not included in your study of healthcare providers' perspectives. A more complete picture of currently effective strategies for goals of care discussions as well as ideas for overcoming barriers would emerge if these disciplines were included. For example, recent literature highlights the central importance of attending to spiritual needs and religious frameworks in goals of care discussions, especially at the end-of-life. This aspect does not emerge in your qualitative findings, perhaps because the discipline most responsible for focusing on this area of care (chaplains) were not included.

Response: We recognize that there are many healthcare providers who communicate with patients in hospital. We chose to focus upon nurses, residents and physicians for reasons of feasibility and because these providers are involved in the clinical care of every patient in a medical teaching unit, while other providers may or may not be involved, depending on a patient’s needs. We recognize this is a limitation of the study, and have now acknowledged this limitation explicitly in the “Participants” section of the Methods and “Limitations” section of the Discussion.

While many healthcare providers communicate with patients in hospital, we chose to focus upon nurses, residents and physicians for reasons of feasibility and because these providers are involved in the clinical care of every patient in a MTU while other providers are less frequently involved, depending on a patient’s needs. [Lines 122 – 126, p.5]

Another limitation is our focus on physicians and nurses in the hospital setting; community-based practitioners, social workers, counselors, and spiritual care providers would likely identify different approaches and ideas. Their views, as well as a greater number of free-text responses from attending physicians in the study, may have allowed for a broader range of perspectives on the issues. [Lines 400 – 405, p.18]

Discretionary Revisions

Comment 1: Although your study does not specifically focus on ICUs, it seems an oversight to not include well-developed body of literature from this setting. Reference literature on shared decision making model, strategies for improvement from critical care, intensive care settings including (but not limited to):

T Osborn, J Curtis, et al, “Identifying Elements of ICU Care that families report as important but unsatisfactory,” CHEST 2012; 142(5):1185-1192


Response: We acknowledge the ICU literature has contributed important knowledge to the field of shared decision-making and thank the reviewer for sharing some of these references; we have now included two of these references (references 6 and 25). As other fields within and outside of medicine have also contributed important knowledge, word counts for publications are limited, and the focus of our study was on the medical wards, where there is also an appreciable amount of literature, we chose to focus on describing the literature that reflected the medical ward setting specifically.

Comment 2: The low rate of response from attending physicians in the free text section of your study (16.5% v. 53.1% nurses, 31.6% residents) merits further exploration or explanation in limitations of study section of paper.

Response: We agree that this is a limitation of our study. Potential reasons include fatigue at the end of a long questionnaire, a lack of ideas, or the perception that they had sufficiently expressed their opinion in the closed-ended section of the questionnaire. We have added the low physician response rate as a limitation of our study.

Another limitation is our focus on physicians and nurses in the hospital setting; community-based practitioners, social workers and spiritual care providers would likely identify different approaches and ideas. These perspectives, as well as a greater number of free-text responses from attending physicians in the study, may have allowed for a broader appreciation of the issues. Response to free-text questions was optional; we cannot discern from our data why physicians were more inclined not to respond to these questions than nurses or residents. Potential reasons include fatigue at the end of a long questionnaire, a lack of ideas, or the perception that they had sufficiently expressed their opinion in the closed-ended section of the questionnaire. [Lines 400 – 409, p.18]

Comment 3: Figure 2: “All of the themes in DECIDE correspond to one of the categories in the ACCEPT study, with the exception of interprofessional communication; an analogous theme from a patient perspective could be represented as patient-family communication.” While the other themes represent helpful correlates, this analogy seems forced or at least it unclear how it was derived. Pt/family comments on lack of coordination of care among providers or mixed messages from the medical team or the importance of daily goals of care discussions with the interdisciplinary team would better correspond to the theme of interprofessional communication rather than communication challenges between pt and family members. Pt-family communication issues would more appropriately correspond to patient/family factors in your diagram.

Response: The analogous “Patient-family communication” theme was a proposal and not derived empirically. Our reasoning for pairing this proposed theme with the “Interprofessional collaboration” theme derived from our study is that “Interprofessional collaboration” represents processes within the healthcare team and “Patient-family communication” represents processes within the family.

To clarify, our study involved healthcare providers only and the ACCEPT study involved patients/families only. The patient-family-healthcare provider communication theme from our study therefore represents comments from healthcare providers. In Figure 1, we are relating healthcare provider perspectives (our study) to patient/family perspectives (the ACCEPT study), such that we would not pair the “Interprofessional collaboration” theme with the “Patient-family-healthcare provider communication” theme, as both were derived from our study. We believe that the “Patient-family-healthcare provider communication” theme from our study describes factors related to interactions between patients/families and the healthcare team, which would be analogous to the “Access to and interaction with physicians” theme from the ACCEPT study.

We feel that the “Patient/family factors” theme from our study reflects intrinsic patient/family values that go beyond communication, which is why we considered this theme as analogous to the “Person values and experiences” theme from the ACCEPT study.
Level of interest: An article whose findings are important to those with closely related research interests

Quality of written English: Acceptable

Statistical review: No, the manuscript does not need to be seen by a statistician.

Declaration of competing interests: I declare that I have no competing interests.
Reviewer's report

Title: Strategies for effective goals of care discussions and decision-making: Perspectives from a multi-centre survey of Canadian hospital-based healthcare providers

Version: 2 Date: 28 April 2015

Reviewer: Linda Emanuel

Reviewer's report:

General:
Comment 1: Limited significance due to preponderance of nurses and trainees over physicians.

Response: We agree that a higher physician response rate may have provided additional insights. However, the richness of the responses from nurses and residents adds considerable value to the literature in this field. The DECIDE study deliberately captured responses from physicians, nurses, and residents in recognition of the role that each professional group plays in end of life discussions, both individually and as a member of a team. While physicians may be the ultimate decision makers on the provider side of the equation, the literature describes nurses’ and residents’ important roles in initiating and facilitating these conversations (Gorman, Singer, Hamric, Iasevoli), roles in which they often struggle.

References:


Comment 2: More information is needed about the frequency of themes and how often respondents came up with multiple suggestions, especially if they thought that multi-modality was important.

Response: Thank you for your comment. Our approach to data analysis and reporting is in keeping with tenets of qualitative research and thematic analysis (Denzin, Braun). As described by Denzin et al. “A qualitative approach emphasizes the qualities of entities, processes and meanings that are not experimentally examined or measured in terms of quantity, amount, intensity or frequency.” We worry that attempting to quantify qualitative data would lead readers to misinterpret the significance of the results, as statistical analysis cannot be applied, and an issue identified by a few people may have the same or greater impact that one recognized by the majority.

Also, we reviewed all of the original open-ended responses in our dataset and did not note any responses that indicated that a multi-modality approach would be required. Multiple suggestions by the same respondent were coded to the appropriate theme or themes, if a single comment spanned multiple domains.

References:

Specific:

*Line 41:* ‘Open-ended’ is redundant; all questions were open ended. Or if it is the case (implied later – bring some of what is in line 316 and on up front), explain that this report is the qualitative part of a mixed open and closed-ended survey.

*Response:* The reviewer is correct, this report is the analysis of the qualitative section of a mixed open and closed-ended survey. The original wording in Line 41 was: “A cross-sectional survey about goals of care communication and decision-making was administered to healthcare providers in 13 centres in six Canadian provinces. The survey included open-ended questions asking for (1) suggestions for overcoming barriers encountered in discussing goals of care, and (2) currently effective practices. Thematic content analysis was used to analyze responses to the open-ended questions.”

We have modified this line to read:

“A cross-sectional survey composed of closed- and open-ended questions about goals of care communication and decision-making was administered to healthcare providers in 13 centres in six Canadian provinces. We analyzed a portion of the open-ended survey questions, specifically (1) suggestions for overcoming barriers encountered in discussing goals of care, and (2) currently effective practices. Thematic content analysis was used to analyze responses to the open-ended questions.” [Lines 37-42, p.2]

*Line 43:* Later the response rate of physicians in reported at >70%. Note here the difference between closed and open ended item response rates, or do something so that the reader is not puzzled.

*Response:* The Participants section of the Results has been revised to read:

“Questionnaires were returned by 1,256 of 1,617 eligible healthcare providers, with an overall response rate of 78% for the larger survey that included both the open and closed-ended responses (512 of 646 nurses [79%], 484 of 634 residents [76%], 260 of 337 physicians [77%]). A free-text response to Question 1 and/or Question 2 (the open-ended survey questions) was provided by 468 (37%) of the 1,256 healthcare providers who responded to the larger survey (272 of 512 nurses [53.1%], 153 of 484 residents [31.6%], 43 of 260 physicians [16.5%], Figure 1). [Lines 171-177, p.2-3]

*Line 85:* The longer trajectory of chronic illness and possibilities for living with disability add to the complexity and prominence of the issue. Goals of care are relevant for all illness care, not just near the end of life.

*Response:* We agree that the term “Goals of Care” applies more broadly. For this study, the focus was specifically on goals of care for medical interventions in the context of serious illness; we have now clarified this in our Abstract and Methods sections.

Communication gaps impact the quality of patient care. Previous research has focused on communication barriers rather than seeking solutions. Our aim was to identify strategies for effective communication and decision-making about goals of care for medical interventions in serious illness, from the perspectives of hospital-based healthcare providers. [Lines 32 – 36, p.2]

This cross-sectional study, conducted from September 2012 to March 2013, involved a self-administered questionnaire about effective goals of care communication and decision-making in relation to medical interventions desired in serious illness... [Lines 109 – 111, p.5]
In addition, we have moved the definition of “Goals of care” used for the study from the Introduction to the Methods section.

The following definition was given to survey participants: “We define communication and decision-making about goals of care as a conversation in which, ideally, a patient or family member and the healthcare team establish the goals of treatment (e.g., cure, prolongation of life, comfort) and agree upon the types of life sustaining technology that will (or will not) be used to achieve those goals (e.g., CPR, mechanical ventilation, dialysis, intensive care unit admission, feeding tubes, or intravenous hydration).” [Lines 136-142, p. 6]

**Line 90:** Missing word changes the meaning to the opposite of intended. ’or they approach…”

**Response:** Thank you for noticing this oversight. We have now inserted the word “they”. [Line 89, p.4]

**Line 89/90:** Did this second sentence get included in the definition that was given to survey participants? Be explicit.

**Response:** We had included our definition of goals of care decision-making in the Background section of the manuscript. To clarify that this same definition was provided to survey participants, we have moved the definition to the Methods section, using the exact wording of the definition provided to participants. The definition is now included under the subheading “Study procedures”.

“The following definition was given to survey participants: “We define communication and decision-making about goals of care as a conversation in which, ideally, a patient or family member and the healthcare team establish the goals of treatment (e.g., cure, prolongation of life, comfort) and agree upon the types of life sustaining technology that will (or will not) be used to achieve those goals (e.g., CPR, mechanical ventilation, dialysis, intensive care unit admission, feeding tubes, or intravenous hydration).” [Lines 136-142, p.6]

**Participants Lines 114/120:** Explain why chaplains and social workers or counselors were not included

**Response:** Please see the above response to Reviewer #1, Mandatory Revisions Comment #1.

**Study procedures:** Need more detail so the reader understands – especially the low response rates for physicians. The goal was to get provider opinions, but mostly you have nurse and trainee opinions.

**Response:** Please see the above response to Reviewer #1 Discretionary Revisions Comment #2, and the response to Reviewer #2 General Comment #1.

**Line 164:** Rounding up in the abstract but not here makes the reader confused.

**Response:** Thank you for identifying this inconsistency. We have removed decimals from the Participants subsection of the Results section of the manuscript.

Questionnaires were returned by 1,256 of 1,617 eligible healthcare providers, with an overall response rate of 78% for the larger survey that included both the open and closed-ended responses (512 of 646 nurses [79%], 484 of 634 residents [76%], 260 of 337 physicians [77%]). A free-text response to Question 1 and/or Question 2 (the open-ended survey questions) was provided by 468 (37%) of the 1,256 healthcare providers who responded to the larger survey (272 of 512 nurses [53%], 153 of 484 residents [32%], 43 of 260 physicians [17%], Figure 1). [Lines 171-177, p.7-8]
**Line 334-337:** Bring this up into the background section.

**Response:** We agree that it is important for readers to be aware of the ACCEPT study to set the stage for our study findings, and have modified the manuscript to make reference to the ACCEPT study in the Background section.

This study of healthcare provider experiences follows our previous exploration of patient and family perspectives on barriers and facilitators to advance care planning (the Audit of Communication, CarE Planning, and DocumenTation (ACCEPT) study.[17] [Lines 102-105, p.4-5]

**Lines 368-374:** Ditto

**Response:** The reviewer suggests that we move the passage about tools to support shared decision making about goals of care from the Discussion into the Background section. We are concerned that describing tools to support shared decision making in the Background section may distract from the focus of our work, and might suggest to the reader that the authors are attempting to pre-emptively suggest solutions. The purpose of our study was to identify ideas and potential solutions to barriers, such that a discussion of decision support tools flows nicely from our Results, hence our decision to retain this in the Discussion section. We have added a sentence indicating that our future work will assess the impact of implementing these potential solutions in the clinical setting.

**Lines 388 – 390:** Low physician response rate must be addressed, as must absence of input from chaplains, social workers, counselors/psychologists, etc.

**Response:** Please see the response to Reviewer #1 Discretionary Revisions Comment #2, and the response to Reviewer #2 General Comment #1.