Author’s response to reviews

Title: Breaking Silence: A Survey of Barriers to Goals of Care Discussions from the Perspective of Oncology Practitioners

Authors:

Katrina Piggott (katrina.piggott@medportal.ca)
Ameen Patel (patela@mcmaster.ca)
Arthur Wong (arthur.wong@medportal.ca)
Leslie Martin (leslie.martin@medportal.ca)
Alexandra Patel (alexandra.patel@mail.utoronto.ca)
Matthew Patel (matthewpatel@rcsi.ie)
Yudong Liu (yliu2364@uwo.ca)
Sukhbinder Dhesy-Thind (dhesy@hhsc.ca)
John You (jyou@mcmaster.ca)

Version: 1 Date: 14 Dec 2018

Author’s response to reviews:

December 14, 2018

Dr. Linda Gummlich
Editor, BMC Cancer

Dear Dr. Gummlich:

Thank you for your decision letter dated December 3, 2018 regarding our original research article entitled “Breaking Silence: A Survey of Barriers to Goals of Care Discussions from the Perspective of Oncology Practitioners”.

Please find below a point-by-point reply to the reviewer comments. We have attached a revised version of the manuscript with changes tracked. Please also note that in the revised submission we have corrected the spelling of the name of one of our co-authors, Bindi Dhesy: her full name is Sukhbinder Dhesy-Thind.

We hope that the revised version will be acceptable for publication.

Sincerely,

Katrina Piggott, MD, FRCPC
Department of Geriatric Medicine
University of Toronto

Reviewer 1

Major comments

Comment #1

While the authors provide clinically important findings, I'm afraid the majority of the findings have already been demonstrated in previous studies (e.g., reference 20). The authors used questionnaires based on reference 20, and reached very similar conclusions. Although they focused on cancer patients this time, the rational for having selected cancer patients only is not very clear.

Response

We agree with the reviewer that the findings from our current study are incremental in nature, building upon what has previously been published, as opposed to being completely new.
However, we believe that our findings merit publication for several reasons. First, there are appreciable differences between patients who have cancer and patients who do not have cancer and we thought that these differences in clinical context may also influence the relative importance of different barriers to goals of care discussions. Specifically, patients who have advanced cancer have a more predictable prognosis with a more linear decrease in performance status compared to non-cancer patients with multiple chronic illnesses (e.g., congestive heart failure, COPD, diabetes) who typically have fluctuations in their functional status even in advanced stages of disease. As a result, despite having an equally short life expectancy, patients who have advanced cancer are more easily recognized as having “terminal” illness compared to patients with advanced non-cancer illness. Therefore, barriers related to prognosis might be hypothesized to be less important in the oncology context and it was interesting that our study found that these barriers were of similar importance in non-cancer and cancer settings. Second, most research and knowledge discovery is incremental in nature, rather than disruptive. Therefore, we believe it is still an important part of the research process to conduct studies to determine whether findings in one setting are indeed transferable to another. Indeed, our earlier study (reference 21 in our revised manuscript: You J, Downar J, Fowler R, et al. Barriers to Goals of Care Discussions With Seriously Ill Hospitalized Patients and Their Families: A Multicenter Survey of Clinicians. JAMA Internal Medicine. 2015 Apr 1;175(4):549-56.) that elicited barriers to goals of care discussions from the perspectives of hospital-based practitioners on medical wards drew criticism about lack of generalizability when it was under peer-review before its ultimate publication in JAMA Internal Medicine. Specifically, each of the 2 peer reviewers had the following comments:

JAMA Internal Medicine Reviewer 1:
“Limitations: It should be noted that the findings may not be generalizable to healthcare settings which differ from those included in the study: hospitals outside of Canada, non-teaching hospitals, non-medical inpatient units, outpatient settings, etc.”

JAMA Internal Medicine Reviewer 2:
“Consider mentioning that all of the data is from academic institutions. It is unknown whether barriers would be different in community hospital settings.”

To respond to these concerns from peer-reviewers, we strengthened the language about these limitations in the final published version of that manuscript in JAMA Internal Medicine (reference 21 in our revised manuscript) to read as follows:
“Our study also has limitations. First, despite the high response rate and multi-center design of our study, our findings may not be representative of other settings, such as hospitals outside of Canada, non-teaching hospitals, non-medical inpatient units, or outpatient settings.”

Finally, from a knowledge translation perspective, it may be difficult to persuade practicing oncologists to consider changes in their communication practices based on findings published in non-cancer journals on non-oncology populations. Therefore, to enable practice change in oncology, we believe that it is important to document that the findings of the earlier study in other populations hold true in the oncology setting. Moreover, the observation that barriers were of similar importance in the cancer and non-cancer setting suggests that disease-specific interventions to improve goals-of-care communication may not be necessary and that disease-agnostic strategies could be effective.

To respond to this reviewer’s comment, we have added the following text to the Discussion on page 13 to acknowledge the incremental nature and generalizability of our findings:

“However, our findings were remarkably similar to findings from a multi-center survey of practitioners (response rate 78%) that we conducted on hospital medical wards. Therefore, our study confirms that the findings of our earlier study are generalizable to the oncology setting, suggesting that barriers to goals-of-care discussions during serious illness may be similar regardless of the specific disease state and that disease-agnostic interventions to improve communication during serious illness may be useful.”

Comment #2

As the authors mentioned in the limitation, the response rate is very low, especially nurses (26%) including only one APN. Given the nature of a single center survey, the low response rate markedly impairs the generalizability. Were there any differences in baseline characteristics between responders and non-responders?

Response

First, since the non-responders, by definition, did not consent to participate in the study, we did not collect any data on the non-responders so are not able to comment on whether there were important differences between responders and non-responders.
We agree with the reviewer that, in isolation, the low response rate and the single center nature of the study may each impair the generalizability of our findings. However, as discussed above and as pointed out by Reviewer #1 above (see response to Comment #1), our findings were remarkably similar to the earlier, larger, multi-center survey we conducted with hospital-based general medical practitioners and that achieved a response rate of 78% (reference 21 in revised manuscript). Therefore, we believe that, taken together, these studies show that these barriers may indeed be generalizable across different clinical settings.

Comment #3

The participants were overall young, and might not have sufficient experiences in oncology clinic. In particular, 5.9-week (mean) inpatient subspecialty oncology experiences of resident physicians might not be enough for them to reasonably assess the clinical situations and implications of the vignette case, and their understanding may be different from that of other oncology clinicians with years of actual experiences.

Response

It is true that the resident physicians in our study sample had only a mean of 5.9 weeks experience on inpatient oncology services. However, as discussed above, despite these potential limitations, our findings were very consistent with the earlier, larger, multi-center survey in a different clinical setting (hospital-based medical practitioners). It is also important to note that, before beginning their oncology residency training, these learners would have already had 1 to 2 years of clinical experience at the end of their undergraduate MD degree and a further 3 years of clinical experience in residency training (e.g. internal medicine). During this time, they would undoubtedly have had experiences caring for many patients with serious, life-limiting illnesses, including advanced cancer. Nonetheless, we agree with the reviewer that the relatively younger mean age of our study population would have been another potential limitation to the generalizability of our findings and have added the following text to the Discussion section on page 13 to reflect this point:

“There are several limitations to this study. It was conducted at a single academic cancer centre, and the respondents, on average, were relatively young or, in the case of oncology residents, had relatively little experience in subspecialty oncology settings.”
Minor comments

Comment #4

I am a little concerned about the differences in age in the three cases. For example, in case B where the patient was younger, the participants may have been more willing to engage in GoC discussions, which might have introduced a bias.

Response

The vignettes were created based on consultation with clinical experts in the respective fields of hematology-oncology, medical oncology, and radiation oncology, and pilot-testing with end-users, so that the vignettes would reflect common scenarios encountered in clinical practice. We agree with the reviewer that the difference in age of the 3 hypothetical patient cases used in the vignettes could have introduced some bias into our study. However, our sample size is not sufficiently large to conduct an analysis to determine whether there were important and independent differences in the rating of the importance of barriers to goals-of-care discussions depending on the age of the patient in the vignette. Furthermore, as discussed above, our findings were remarkably consistent with the findings from our earlier, larger, multi-center survey of hospital-based medical practitioners that used a different clinical vignette (i.e., a 70 year old patient with advanced COPD).

Comment #5

The authors indicated that previous studies had not quantified barriers experienced by physicians such as personal discomfort with death and dying and had been limited by small sample sizes. However, some larger studies have actually quantified them (e.g., Mori M, Shimizu C, Ogawa A, et al. Oncologist 2015;20:1304-11).

Response

We thank the reviewer for alerting us to this important and relevant study and have cited it in our revised manuscript on page 4 (reference 20 in our revised manuscript). Also, we have removed the corresponding phrase on page 4 “…but have not quantified them and were limited by small studies” from the sentence in the Introduction discussing previous studies in this area.
Comment #6

How were the GoC discussions defined in the questionnaire?

Response

Below is the definition of goals-of-care discussions that was included in the preamble to the study questionnaire and that is based on our published multi-disciplinary consensus work to establish a conceptual framework of end-of-life communication and decision making (Sinuff T et al. reference 11):

“Goals of Care

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).”

We have included this definition in the Methods section on page 6 of our revised manuscript.

Reviewer 2

Comment #1

This is well written paper with an important relevant study question which has been justified clearly by the authors in the introduction. The response rate of 37% is consistent with most survey-based studies.

Response

We thank the reviewer for the positive comments about our manuscript. See our response to Reviewer #1, Comment #2 with respect to the response rate.
Comment #2

I am interested as to why the return for oncology nurses was lower. Could this have biased the results?

Response

The reviewer raises an interesting question but, unfortunately, we are not able to determine the reasons for non-response in our study and can only speculate about the root causes. Perhaps nurses do not feel as engaged or included in the process of discussing goals of care, or did not feel that sharing their opinions would have an impact on changing future care. At any rate, to the extent that non-responders were systematically different from responders in ways that are associated with our outcome of interest (importance of different barriers to goals-of-care discussions), this may have introduced a risk of bias into our study. However, despite this potential limitation, our findings were very consistent with an earlier, larger, multi-center study of hospital-based medical practitioners that achieved a response rate of 78%, suggesting that our findings are indeed generalizable (see response to Reviewer #1, Comment #1 above).

Comment #3

The conclusion is that "oncology practitioners perceive patients and family factors as the most limiting barriers to GoC discussions". While this has been demonstrated in the literature in other settings (e.g. heart failure, seriously ill hospitalised patients), there is also literature to suggest that physician factors play a role as well. While not the most limiting barrier that is perceived by the survey respondents in this study, the authors referenced some relevant papers #26, #27, #30, #31 that suggest physician factors are important to consider; and if I could suggest a paper by Trice et al: Communication in end-stage cancer: review of the literature and future research (J Health Commun. 2009;14 Suppl 1:95-108) as well. Thus I think a more in-depth discussion about practitioner factors inc lack of training, lack of communication skills, discomfort with difficult conversations etc could be provided. Here are some additional references:


Response

We agree entirely with the reviewer that a nuanced interpretation of our findings is important and that physician-level factors are still likely to be important barriers to goals-of-care discussions. We are very grateful to the reviewer for suggesting these relevant publications. The expanded paragraph dealing with these issues in our revised manuscript (pages 9-10) now reads as follows and includes citations to the additional references suggested by the reviewer:

“While GoC discussions improve the dying experience for patients [24], this study adds to the literature demonstrating that patient and family factors are the biggest barriers to effective GoC discussions as perceived by clinicians [21]. Although study participants rated practitioner factors as less important barriers to GoC, this has several interpretations and implications. First, it reflects that patients who have advanced cancer and their families may often find it difficult to confront a poor prognosis. As a result, oncology clinicians should anticipate that patients and families may find GoC conversations difficult or emotionally laden and be prepared to guide patients and families through these discussions. However patients who have cancer report that physicians are particularly inadequate in discussing emotional symptoms, life support preferences and hospice care, regardless of the patient’s age or disease stage [25]. Indeed, other studies have found that oncology practitioners often lack communication skills training and have discomfort with difficult discussions that include mortality acknowledgement and the introduction of a palliative approach to care [26-29]. This suggests that oncology clinicians may benefit from further training and continuing professional development to enhance their communication skills in order to best support patients and their families in GoC conversations [30]. Patients facing serious illnesses prefer to actively participate in EOL care planning [31-34]. While patient factors are often rated as the most significant barriers to communication, with formal training, oncology clinicians can master communication skills that will empower them to guide patients with advanced cancer through frank discussions about their prognosis and preferences for care at the end of life, preferably early in the course of disease [35, 36]. Formal training would also give clinicians an opportunity to learn and use validated tools for initiating these discussions [37] and develop an approach that recognizes the benefits of these conversations, while helping patients to discuss their values and preferences [19].”