Article details: 2019-0037	
Title	Gaps in public preparedness to be a substitute decision maker and the acceptability of high school education on resuscitation and end-of-life care: a mixed-methods study
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Reviewer 1	Dr. Ivy ShuShan Cheng
Institution	Emergency Department, Sunnybrook Hospital, Toronto, Ont.
General comments (author response in bold)	**We thank Dr. Cheng for insightful comments that improve our paper. She used a checklist and noted when we met checklist items as well as areas needing clarification. For clarity, I have removed her positive comments and listed only the requested changes / comments / checklist deficiencies below.** 1. 1. It is noted that the authors used the STROBE checklist. Given that qualitative methods were also used, the COREQ could be applied. **Please see attached COREQ checklist** 2. For the multivariate logistic regression model, how were outliers dealt with? Was the ratio of covariates to the dependent variable at least 10:1? Assumptions not violated? How was the best model found? **Model outcomes and covariates were all categorical or ordinal variables with no small cells in any of the bins. There were no outliers.** **The risk of model overfitting was low as the outcomes were common. For the preparedness model, the number of events to dependent variable ratio was 303 (number of participants who felt prepared to be SDM) to 18 predictor variables. For the model regarding whether SDM skills should be taught, there were 300 events to 19 covariates.** **Logistic regression assumptions were not violated:** **i) Binary outcome structure: both model outcomes were binary variables (Likert scale responses were grouped to create binary variables)** **ii) Independent observations: observations were independent due to systematic sampling technique** **iii) Absence of multicollinearity: correlation matrix was used to check for collinearity between covariates.** **iv) Linearity of independent variables and log odds: there are no linear continuous independent variables.** **v) Large sample: addressed above with regards to the 10:1 rule** **There was only one model per outcome as the covariates a priori based on potentially clinically/socially relevant predictors.** **The second paragraph of the Analysis section now reads, "Multivariate logistic regression was conducted with covariates selected a priori by consensus. […]. Assumptions for our model were confirmed to be apt, including absence of collinearity for the independent variables and an appropriate number of covariates for our sample size."** 3. How did you determine the covariates? Was there a literature source? Consensus?

As per our response to point #12 by the editors above,
They were selected a priori through consensus from the experts in palliative care, emergency medicine, and education represented in our author group. This is now mentioned in second paragraph of the Analysis section under Methods.

4.   Perhaps use the COREQ?
Please see the new COREQ checklist

5.   p. 7 (lines 39-56) Minor Revision: It is noted that the studied group was young and predominantly female. It would have been interesting to repeat this study with older participants, as their views may be different. Could the pedestrian areas been biased (i.e. it would exclude older or frail participants – and includes mainly urban dwellers? Does this bias to the young urban professional who could be different from the working class population? It is noted that there is a high proportion with university-college education. As well, are females more likely to participate in surveys than men? Younger more than older?). How does the survey population compare to the provincial demographic (>16yo)?
We revised the "Limitations" section to address the reviewer's concern. It now reads, "Our study population had higher proportions of young, female, and post-secondary educated participants than would be expected for Ottawa or Ontario. Among others, this underrepresents rural, elderly, impoverished, and disabled individuals."

6.   Consider confounders (i.e. location of survey that could have biased the survey population).
The "Limitations" section has been revised to recognize the potential bias of location. In addition, the list of locations has been added to Appendix A for the readers.

7.   p. 7 Lines 39-56: Unsure if there was missing data?
8.   Minor Revision: Consider stating the missing data (sounds like there were skipped questions?) in the results section (was found in Table 1).
Rates of missing data for each question is now presented as an independent table in Appendix B; no question had missing data greater than 3.5% of the 430 responses. We have removed the orphaned number in Table 1 of the rate of missing data for province.

9.   Figure 2 (p.24) – Minor Revision: Headings are not aligned over the columns
We have adjusted this, but also suspect this may be exacerbated by artifact from the submission software conversion to PDF. We have provided the original Excel file to CMAJ Open which will hopefully work well for the team to do publication formatting.
Please let us know if any change in file format or other changes are helpful here.

10.   For Table 2 (p.16), all 430 participants answered the questions? 1.4% missing data? Minor Revision: Consider mentioning this by placing a N in the Table 2
Rates of missing data is now presented as an independent table in Appendix

	B; no question had missing data greater than 3.5% of the 430 responses. We have removed the reference in Table 1 of the rate of missing data for province, and apologize for the lack of clarity. **For the two models, missing data on either the independent or dependent variable resulted in that participant being excluded. This is now stated in paragraph 2 of "Analysis."** 11. Key Results: Summarizes the results with reference to SDM preparedness only, but not with the other objective (Population Level Education) Minor Revision: Consider summarizing the result with reference to for Population Level Education **A line was added to the last paragraph of the discussion to highlight the main result for education, it reads, "71.9% of all respondents, and 95.5% of 16-17 year old respondents, supported high school education around substitute decision making."** 12. p. 10 (line 10) Minor Revision: Probably do not have to repeat the odds ratio with the confidence interval in the discussion. **This was removed per your suggestion.** 13. Minor Revision: Consider summarizing the result with reference to for Population Level Education **A line was added to the last paragraph of the discussion to highlight the main result for education, it reads, "71.9% of all respondents, and 95.5% of 16-17 year old respondents, supported high school education around substitute decision making."** 14. (p. 11, lines 35-46) Minor revision: As mentioned above – the surveyed population seems different from the Ontario population. Urban will likely be different from rural. Consider commenting. Generalisability: As outlined in the limitations above. Would recommend doing this study in different settings. **We revised the "Limitations" section to address the reviewer's concern. It now reads, "Our study population had higher proportions of young, female, and post-secondary educated participants than would be expected for Ottawa or Ontario. Among others, this underrepresents rural, elderly, impoverished, and disabled individuals."**
Reviewer 2	Ms. Damanpreet K. Kandola
Institution	Health Sciences, University of Northern British Columbia, Prince George, BC
General comments (author response in bold)	1. While it is true that there is limited literature in this area, especially for a Canadian context, I would like to highlight additional pertinent literature I think was missed. This includes Heyland & CARENET Investigators 2013, McLennan et al. 2015/Banner et al. 2018 (Community Perspectives on EOL/ACP), and work by Teixeria et al. 2015 (CDN perspectives on ACP) which I think has strong relevance to this conversation and lends support to some of your findings. There is also some grey literature from BC on cross-cultural considerations for a Canadian society which you may find helpful. I think better integrating the literature and highlighting where this current study fits within this context will strengthen this piece. **We considered a longer discussion of the Heyland and Teixeira citations in our drafts but had originally removed those paragraphs for word count. We have reintroduced the Heyland (citation 7) and Teixeira (citation 19) papers**

in our intro (paragraph 2) and discussion (paragraph 1), mindful of the word count.
Could the reviewer clarify if the Banner 2018 reference is the poster in BMJ Supp & Pall Care entitled "Including people with learning disabilities in end of life care"? Assuming we have found the same citations Ms. Kandola is referencing, we note that the McLennan and Banner studies hail from Australia and the UK, and are thus less relevant to the Canadian social setting. To maintain this focus, we have chosen not to include them.

2.   Design: I would disagree that this is truly a mixed methods study, multi-methods yes but both pieces (qual and quant) appear to be able to be standalone.
There are differing definitions of "mixed methods" cited in the literature, but we agree with the reviewer that at the core of a mixed methods study is a need to integrate qualitative and quantitative results. Admittedly, our results are not as deeply integrated as some mixed-methods studies, but we feel that our qualitative discussion of enablers and barriers for both the main research questions does help explain why reported preparedness and support for high school education are quantitatively high.
It may be confusing to the reader to use the term "multi-method," which includes pure qualitative or pure quantitative studies that utilize multiple methods.
We have thus not changed the term in our manuscript at present, but are happy to oblige a final decision by the editorial team.

3.   pg 6 results section: unclear what exclusion because of activity means. One can infer group size exclusion means that +1 individuals walking together were not approached. Is this correct?
This has been clarified in paragraph 2 of the section entitled "Participants and Sampling" in the methods.
We felt that it would be inappropriate to interrupt individuals at work (e.g. mall employees), exercising (e.g. joggers or those running for buses), or in groups of 3 or greater. Groups of 2 were approached and if they were willing to stop, only one was interviewed. This guideline was established a priori to beginning data collection.

4.   Authors discuss public preparedness of being an SDM, also think the converse question should have been asked on whether interviewee would be comfortable/has an SDM. This would have provided a more comprehensive picture of public preparedness.
Whether participants had participated in advance care planning in the past was question #2 on the survey (see Appendix A). This includes designating a decision maker and communicating to them values, wishes, and beliefs in a verbal or written fashion (i.e. writing a living will).
To clarify, someone can designate a specific SDM, but all individuals have a default SDM, including those without a pre-existing advance care plan. In Ontario and most other provinces, a hierarchy of "next-of-kin" substitute decision makers is enshrined in law. We have added a sentence in paragraph 1 of the paper to emphasize this point.

5.   Would be interesting to see future research on the acceptability of SDM's

by HCPs and the challenges HCPs encounter with SDMs in practice as pt mentioned challenges with navigating this care for their loved one

You et al. provided a description of the barriers that cardiology and internal medicine physicians and nurses perceive in discussing goals of care with patients and their families.(2,3) They found that there were two main categories of barriers – those based on SDM-factors, and health care factors. HCPs perceived that SDM factors were the more difficult barriers to overcome. We agree that there is an opportunity for such a study to be done with emergency and critical care teams who face similar discussions under great time pressures, though certainly cardiology and internal medicine teams are experienced in this area as well.

6.   No details provided on the ethnic backgrounds of respondents. Canada is generally a rich mix of cultures and people from various backgrounds. Having information on ethnicity would be useful to see whether this survey may truly reflect some of the opinions of a 'Canadian' society. In certain cultures, including some parts of Asia, speaking of ACP/death/dying is considered taboo, so it would be interesting to see if there was representation from these groups in the current sample. Was there a rationale for not including/collecting this information?

We agree that there are cultural differences that have very real clinical impacts at the bedside with regards to family discussions and goals of care discussions.
However, many Canadians self-identify as hailing from multiple cultures and it would be difficult to categorize an individual into a single culture. Furthermore, there are so many cultures that there could be hundreds of covariates. The difficulty in categorizing participants into a single culture and the sheer number of covariates would undermine a robust statistical analysis.
Unfortunately, we did not record self-reported ethnicity (to maximize anonymity), however we will look towards exploring this in a future survey.

7.   Another interesting point to consider may have been respondent readiness to participate in the proposed SDM program at the high school level - i.e would you/or would you have participated in this type of a program if it is/had it been available?

This is an interesting question that we did not include but may consider in a future national survey. We do report in the manuscript that 95.5% of the 16-17 year old respondents report willingness to undergo a curriculum.
We also separated whether participants felt 16 year olds can vs. should participate in a curriculum. In the end, answers to the two questions were highly collinear. One might extrapolate that if a participant felt 16 year olds should learn this topic, that it would include their own participation if they were still that age.

8.   I would add something on what this could mean for HCPs and their practice as well as policy and decision makers (as opposed to the general statement of the potential this work has to inform policy-be more specific)

Thanks for the suggestion to increase the immediate impact of our work – we have added a paragraph discussion accordingly (paragraph 4 and first sentence of paragraph 5). It reads,

"Our study also has direct clinical implications. The gap in perceived preparedness and actual conversations suggests that in facilitating goals of care discussions for an incapable patient, physicians must ensure SDMs understand their role and base their understanding of the patient's wishes, values, and beliefs on reasonably detailed conversations. That one theme was that it could be difficult to separate their own beliefs from the patient's underlines the risk that SDMs project their own beliefs when making decisions.

Before acute illness strikes, chronic care physicians should ideally meet with the patient and their SDM together, to ensure the SDM has a good understanding of their role and a full understanding of the patient's wishes should they become unable to communicate.[…]"

Works Cited

1.   Seale H, Heywood AE, McLaws ML, Ward KF, Lowbridge CP, Van D, et al. Why do I need it? I am not at risk! Public perceptions towards the pandemic (H1N1) 2009 vaccine. BMC Infect Dis [Internet]. 2010;10(September 2009):99. Available from: http://www.ncbi.nlm.nih.gov/pubmed/20403201

2.   You JJ, Downar J, Fowler RA, Lamontagne F, Ma IWY, Jayaraman D, et al. Barriers to goals of care discussions with seriously ill hospitalized patients and their families: A multicenter survey of clinicians. JAMA Intern Med. 2015;175(4):549–56.

3.   You JJ, Aleksova N, Ducharme A, MacIver J, Mielniczuk L, Fowler RA, et al. Barriers to Goals of Care Discussions With Patients Who Have Advanced Heart Failure: Results of a Multicenter Survey of Hospital-Based Cardiology Clinicians. J Card Fail [Internet]. 2017;23(11):786–93. Available from: https://doi.org/10.1016/j.cardfail.2017.06.003