Author's response to reviews

Title: Interventions to Support Children's Engagement in Health-Related Decisions: A Systematic Review

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Version: 2 Date: 23 March 2014

Author's response to reviews: see over
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Title: Interventions to Support Children’s Engagement in Health-Related Decisions: A Systematic Review

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Date: March 22, 2014
March 22, 2014

Dear Dr. O'Donovan,

MS: 1602731755113642 Interventions to Support Children’s Engagement in Health-Related Decisions: A Systematic Review. Bryan Feenstra, Laura Boland, Margaret L. Lawson, Denise Harrison, Jennifer Kryworuchko, Michelle Leblanc, & Dawn Stacey

Thank you for the feedback on our manuscript. We have carefully reviewed the feedback and incorporated it to strengthen the manuscript. Our response is indicated in the table below. Please let us know if you require anything further from us for this paper.

Sincerely,

Laura Boland, MSc, SLP-C, PhD student, University of Ottawa Scientist, Institute of Population Health

Dawn Stacey RN, PhD, Associate Professor, University of Ottawa

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<th>Reviewer feedback</th>
<th>Our response to the feedback</th>
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<td>Reviewer 1: Paul Brand</td>
<td>We agree and when the data were available, we have added it to the paper. However, effect size was only reported in 1 of the original papers. This additional information was added (pages 10-11).</td>
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We agree and when the data were available, we have added it to the paper. However, effect size was only reported in 1 of the original papers. This additional information was added (pages 10-11).

“For decision quality outcomes, 1 study [27] reported improved values congruence between parent and child for 1 of the 3 scenarios tested. Specifically, there were no statistically significant differences for the low survival and functional impact scenario as it related to HIV end of life decisions; however, improved parent-child congruence was found for the cognitive impairment scenario (69%; CI 0.45-0.90 vs. 11%; CI 0.05-0.25, congruence).

“In one study, an educational workshop with weekly assignments increased decision-making quality in one of three scenarios presented. Compared to the control group, the intervention decision-making quality scores improved in the cognitive impairment scenario at 1 (mean difference of 0.34 vs. 1.62, \( P=0.02 \), respectively) and 12 months (-0.38 vs. 1.79, \( P=0.001 \)), but not 6 months post-intervention (mean difference of 0.23 vs. 1.05, \( P=0.10 \)). [30] Note that higher scores indicate better decision quality.
On pg. 11, we clarified the lack of statistics at our disposal by adding the following sentence:

“Original reports on the decision-making process outcomes did not include descriptive statistics of outcome measure scores.”

Unfortunately, we were unable to comment on clinical significance because either: (1) effect sizes or any data from which effect sizes could be calculated were not reported in the original articles, or (2) the measurement tool used does not have psychometric properties on which we could evaluate the clinical significance. To clarify, the following sentence was added to the discussion on pg. 12:

“We could not comment on the clinical significance of the findings because either the scale used to measure the outcome lacked psychometric properties or the effect size of significant results were not provided in the original article.”

| 2. When a SR ends with the conclusion that we need more studies, it would be extremely useful if the authors could suggest an ideal (or preferred) study design. Please add this to the discussion | We agree and have added (page 14):

“Despite increasing interest in supporting children’s participation in health decision-making, this systematic review affirms the need for further research examining targeted interventions to support the involvement of children in SDM. Future studies evaluating interventions to support children’s decision-making should use rigorous designs such as randomized control trials or cluster randomized control trials, using outcome measures with evaluated psychometric properties, and clear and detailed reporting of decision support interventions and results.” |
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<td>3. Figure 1 was missing in the material that I could download</td>
<td>We will re-upload Figure 1</td>
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| 4. In the background and discussion, the authors highlight the importance of involving children in healthcare decisions. | We have added the following sentence:

“Children’s ability to make health decisions is influenced by multiple factors such as developmental stage, experience with the disease, and parental and |
Although no one will question this, it is highly age dependent: newborns and infants can not be expected to contribute to decisions regarding their own health. This issue should be explored a little bit: from what age onwards can children be expected to engage in decisions regarding their own health? health professional attitudes about the child’s capacity.[9, 10] For example, in a recent study involving children with Type I diabetes making decisions with their parent and healthcare team, children as young as 8 years old were successfully recruited.[11] Therefore, the extent that children can participate in health decisions should depend on their ability and not their chronological age. As such, children's competence should be assessed on an individual basis and in relation to the decision being made. Nonetheless, lack of competence should not be a reason to restrict children's right to participate in decisions about their health.[9]"

5. Page 3, study selection: please give a web page or reference to the web-based tool used for screening of selected studies

We added the following paragraph to explain our study selection web application (pages 5-6):

“After removing duplicates, retrieved article citations were uploaded onto a web-based screening application designed by our research team’s information technologist. This program allows independent reviewers to evaluate study eligibility through a multi-stage screening process: titles, abstracts, and full-text. First, references identified by the search are loaded into the title screening application and randomly assigned to reviewers for initial screening. Excluded titles are assigned to the second reviewer for screening. Reviewers do not know if they are screening first or second. All included citations then move to the second (abstracts) screening stage, using the same process.” “Full-text versions were reviewed manually for final inclusion by BF and LB”.

6. Page 4, data collection: in the listing of information extracted from each study, the item with the letter d) is missing

The missing d) has been added and now reads:

“The following information was extracted from each study (as per the data extraction sheet): a) characteristics of child participants (location, age, gender, ethnicity, diagnosis, and stage of illness), b) study methods (aims, design, allocation, recruitment, inclusion/exclusion criteria, informed consent, ethical approval, funding, and statistical methods), c) intervention(s) and control intervention(s) (enrollment and attrition of participants, type(s), co-interventions, content, mode of delivery, timing, frequency, duration, provider, training, and elements of decision support), d) outcomes (primary and secondary measures, definition(s), methods of follow-up, timing, validity of instruments used and adverse events), e)
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<td>7. Same paragraph: were the limitations and conclusions extracted from retrieved studies those of the Original authors, or those of the investigators of the SR?</td>
<td>7. Same paragraph: were the limitations and conclusions extracted from retrieved studies those of the Original authors, or those of the investigators of the SR? We have clarified this item, as follows: &quot;f) limitations and conclusions indicated by the original authors”</td>
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<td>8. The text on &quot;decision support interventions&quot; and &quot;outcome measures&quot; (pages 9-10) is relatively long and contains a number of duplications with the info in the tables. Please review and condense where possible</td>
<td>8.1 To condense the Decision Support Interventions section, we have deleted the following paragraph as Table 4 contains all the information: “Interventions were administered either by the child (e.g. self-use of computer program or workbook), by a health care provider (e.g. nurse practitioner), or by a non-clinician trained as a facilitator (e.g. research assistant). Four studies used interventions that were delivered in stages, ranging from 1 week to 3 months apart [26-28, 30, 31] and 1 study used an intervention delivered at a single encounter. [29] Total duration for main interventions in 4 studies ranged from a single minute session to 3 sessions totaling 180 to 270 minutes, and a full day camp workshop. Co-interventions (e.g. computer programs, workbook exercises, information packages) ranged from 30 to 90 minutes. Two of the 3 attention placebos were comparable in duration to the main experimental intervention; however, length of time was not specified for the other control groups. [27, 28, 31]” 8.2 To condense the outcome measures section we have revised Table 6 to be more succinct.</td>
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| 10. Please provide some clarification on what kind of intervention the "coaching" is, e.g. by giving an example | To provide clarification, we have added the following sentences: “In the Lyon study, [27] decision coaching consisted of trained facilitators who elicited and stimulated
conversation about patients’ views and opinions about their disease. In the Adelman study, decision coaches encouraged children to participate, and facilitated a discussion about participation strategies. Then the decision coach and child rehearsed participation strategies. [29]"

Reviewer 2: Veronica Lambert

This manuscript presents a clear outline of the screening and evaluation process undertaken in this systematic review on interventions to support children’s engagement in health-related decisions. As evidenced in the paper, the review calls for high quality studies and interventions to support children’s engagement in health-related decisions. The limitations of the review are noted.

We thank this reviewer for the positive feedback.