Reviewer’s report

Title: Barriers and Facilitators to the Implementation of a Paediatric Palliative Care Team

Version: 0 Date: 22 Mar 2017

Reviewer: Joel E Frader

Reviewer’s report:

General: While the authors have attempted an important assessment of issues involved with the establishment of a pediatric palliative care program in their institution, the manuscript has two substantial problems: 1) the information in the manuscript does not add a great deal to the existing literature, especially as there are problems with the survey (see below) and 2) in many places in the manuscript the meaning of the statements is just not clear. The later problem might or might not have to do with the authors not having English as their primary language.

With regard to the survey, most social scientists would say that one needs a response rate of 40% or more to have confidence in the accuracy of the findings. Second, the survey only included health care professionals, whereas those for whom pediatric palliative care has the most importance, i.e., patients and families, have no voice. While the focus of the survey was on institutional factors that hinder or help establishment of a program, the absence of patient/family voices leaves a large void in understanding the process.

Specific comments:

Abstract: The authors imply that a value of the PPCT includes a role in improving and ensuring "continuity, coordination...of PPC." Why aren't continuity and coordination of care the responsibility of the primary subspecialty team caring for the patient (oncology, cardiology, neurology, etc.)? While PPCTs might have the capacity to do this, the authors should explain and justify the claim that these essential elements of good care do not belong in the realm of those with long-standing relationships with patients and families.

In the abstract and in the body of manuscript the authors refer to the lack of formal agreements with other services for the provision of PPC. This seems puzzling, at least to a U.S. reviewer. Our team has no formal agreement to see all cardiac failure/heart transplant patients, but we do. We have no documents regarding our regular provision of services to stem cell transplantation patients, etc., but the lack of a bureaucratic relationship does not stand in the way of our providing consultation and service for the patients. Do oncologists in the authors' institution have formal arrangements for infectious disease subspecialists or cardiologists to see the cancer patients? Are such formalities common in the authors' institution or in the Netherlands?

Page 3, line 60: do the authors mean that HCPs have difficulty providing primary palliative care (however defined) and if so, why? Does this have to do with lack of training, with attitudes, with lack of time, or something else?
Line 68 (and elsewhere): the authors use the phrase "three year during pilot...." Do they mean pilot program with a three year duration?

Line 78: when the authors write "the user" do they refer to HCPs or patients and families, or both?

Page 4, line 81: It is not clear that the generic comment about the difficulties of implementing organizational change, of the sort in reference 28, have much relevance for the development of PPCTs.

Line 94: I do not understand "and to position the team into regular PPC."

Page 5, line 131: to whom does the team provide coaching? Do they mean home care HCPs or the patients and their families, or both?

Page 6, Data Collection section: the authors should provide an explanation for the decision to survey only HCPs.

Page 7, line 179-180. The authors should indicate the percentages for the non-participants (what percent of doctors did/did not participate, etc.)

Page 8, line 193: factually correct knowledge about what? E.g., prognosis, opioid dosing, family decision making preferences. The authors should also say more about the population of patients referred to in the survey--where in the illness trajectory, etc.

Lines 196-197: How are "care is better attuned to the needs of the child" and "helps to improve the quality of care" similar or different?

Line 212: explain the phrase: "kept active direction while giving them enough space for their own initiatives." Again, does this refer to "space and initiatives" of HCPs or of patients and families? While the context suggests the authors means HCPs, the actual writing is ambiguous.

Page 9. The authors, in the discussion, should clarify any distinctions they see as important (at least in their setting) between PPC and the use of PPCTs. Who should provide PPC and when should the expertise of the PPCT come into play.

Paragraph beginning line 236: The authors seem to say that what counts most in the establishment of a team is the demonstration by PPCT members of what they add to patient care for HCPs. If so, they should say it more simply and directly; if not I do not understand their point.

Page 10, line 249: while the authors infer that the "PPCT is not only important for parents..." the survey does not actually demonstrate that and this should be rephrased.

Line 257: do the authors mean "helps with the formation of (an early) plan of care?"
Page 11, lines 278-281: I do not understand what the authors are saying here. This needs to be rewritten.

Tables: it is not clear to me that Table 2 adds much --it could be included in supplementary materials, rather than the main body of the manuscript.

**Are the methods appropriate and well described?**
If not, please specify what is required in your comments to the authors.

No

**Does the work include the necessary controls?**
If not, please specify which controls are required in your comments to the authors.

Unable to assess

**Are the conclusions drawn adequately supported by the data shown?**
If not, please explain in your comments to the authors.

Yes

**Are you able to assess any statistics in the manuscript or would you recommend an additional statistical review?**
If an additional statistical review is recommended, please specify what aspects require further assessment in your comments to the editors.

Not relevant to this manuscript

**Quality of written English**
Please indicate the quality of language in the manuscript:

Not suitable for publication unless extensively edited

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