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Title	A cross-sectional descriptive study of pediatric palliative care in Canada, 2012
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Reviewer 1	Dr. Donna L. Johnston
Institution	Children's Hospital of Eastern Ontario, Pediatric Hematology/Oncology, Ottawa, Ont.
General comments (author response in bold)	<p>This is a well written manuscript describing the usage of palliative care in paediatric patients in Canada and the change since 2002. There are a few suggestions to improve/clarify the manuscript.</p> <p>1. The authors state that 92% whose condition due to external cause were alive but list homicide and sudden infant death syndrome as an external cause. By definition these are conditions resulting in death so it is not clear what the authors mean by this definition.  <b>We removed sudden infant death in the list of examples and changed homicide to attempted homicide.</b></p> <p>2. On page 7 the authors state that in 2002 5% of deceased children received specialized PPC - is this 5% of all deceased children or excluding those who died of external causes?  <b>This statement was removed given the restructuring of the paper to move 2002 data to the interpretation section.</b></p> <p>3. On page 8 in the first paragraph of interpretation the authors state that 80% of children who might benefit still do not receive services. This is an assumption that no palliative care is being received other than at the centres with a palliative care team which is not really valid. There may be adult palliative care teams providing this service where none for paediatrics exists so the conclusion I don't think is able to be definitively made. This should be discussed.  <b>As noted in the background section, there is some evidence that specialized pediatric palliative care programs provide improved quality of care for children and families. In the setting section we have provided some information about other models of care and care providers. However we stand by our assertion that providers who have taken time to complete training both in pediatrics and in palliative care (as we defined in our inclusion criteria) and have designated resources to provide care, are able to provide a different level of care than someone who has an interest in the area and provides care as a generalist rather than as a specialist.</b></p> <p>4. Similarly the conclusion about timing of referrals may not be valid the way it is stated - the authors should instead look at time of diagnosis and time of referral as opposed to time of referral and death. If a child is diagnosed within 30 days of death and palliative care referral made then that is a timely referral.  <b>Although this is a valid comment, at times it is difficult to determine which diagnosis is being referred to, for example some children with neurologic problems may be identified early in their life but it may not be identified that their disease is progressive or life limiting until much later. In addition, children with cancer may be initially be considered low risk but may relapse, in which case which date is used (initial diagnosis vs first relapse or progression vs subsequent relapse). While not perfect, in palliative care research time from referral to death is a common metric used to assess quality.</b></p> <p>5. Again similarly on page 9 the conclusion about meeting PC team within week of death in critical care needs to see what the length of time in critical care or since diagnosis and death and compare that with PC referral.  <b>As above, there are challenges with determining a date of the life threatening diagnosis. Our point in examining the subgroup that died in critical care was to point out that most had an underlying progressive life limiting illnesses where the likelihood of death was likely evident more than 30 days prior to death.</b></p> <p>6. On page 10 the authors state that antenatal consults and number of infants receiving PPC fits with demographics of childhood death. This does not make sense. The number of deaths has not changed so why would this number change? This needs to be clarified.  <b>The number of deaths has not changed but in 2002 the PPC team provided care to very few infants less than 1 year of age. The number has increased in 2012 meaning that the proportion of children who received care in the various age ranges now more closely mirrors the proportion of children across Canada who die in each age range. We have rephrased to clarify our point.</b></p> <p>7. Figures - it is challenging to determine what variables the authors consider significant based on their description in the legend. It would be better if they presented which arms touch and which don't and are considered significant.</p>

	<p><b>The figures have been removed based on the editorial request above.</b></p> <p>8. Tables - in table 2 is the p value comparing the different rows or columns? I assume rows, and if so is this for the total? This should be clarified.</p> <p><b>As noted in the title of the table we are comparing the children who received care in a program affiliated with a hospice versus those who received care in one of the other programs.</b></p>
<b>Reviewer 2</b>	Dr. Wynne Morrison
Institution	The Children's Hospital of Philadelphia, Division of Critical Care, Philadelphia, Penn.
General comments (author response in bold)	<p>The submitted manuscript is a comparison of national pediatric palliative care services available (&amp; patients served) in Canada in 2002 vs 2012, using surveys of existing pediatric programs and some information from vital statistics data. Their main findings were that the number of children seen by pediatric palliative care specialists is increasing, but is still only the minority of children who might benefit from such services. There were also some shifts in demographics over time, with more children under 1 year of age being seen in the recent cohort, more children with congenital diseases, and more children who died in the ICU.</p> <p>The study is a very interesting and useful addition to the literature. Some of the discussion is speculative, as it must be, but the authors appropriately state their limitations and their ideas regarding explanations for the changes they have seen make sense. They had difficulty with not having access to the raw data from the 2002 cohort, but I believe they handled this problem appropriately &amp; also acknowledged it as a limitation.</p> <p>I have only a few questions:</p> <p>1. Your thoughts about why more children met by the teams died in the ICU are interesting. It is difficult to know if these are really "late" consults. I suspect it is likely that many of these children are children who never met palliative care teams in the past – for whom dying had been primarily managed by the intensivists. As the supportive services (social work, bereavement support) of palliative care teams have grown over time, the ICUs may be more likely to consult for patients who will never really have an opportunity to go home with hospice. In the past, when services were more limited, they likely only called about those who they wanted to try to get home. At first I wondered if some of that change was because consults were being called earlier, before goals were clear, but some of your other data clearly argues against that. As more clinicians train in systems that have access to palliative care teams, I suspect that consults to the teams will increase, which could cause exactly this shift in demographics. The above speculations are not exactly a question, but potentially fodder for an additional sentence or two in the discussion.</p> <p><b>It is difficult to speculate about reasons behind some of the findings from our study and the reasons for the increase in deaths in critical care is particularly puzzling and garnered much discussion amongst our research team. We did not record where the child was at the time of the referral, but presumably for the children who received care for less than a week, the child was already in critical care. For the others, referrals may have come from the general pediatric team rather prior to admission to critical care and again may reflect better integration of palliative care as appropriate along side attempts a life-sustaining therapy. We have added a sentence to reflect this possibility.</b></p> <p>2. In Table 2, I was concerned about the "time from referral to death or end of study" being presented in the same category. I realize that you would have to exclude or censor some of the patients, but presenting the time to death data (for those for whom you have it) independently would be useful. For analyzing this variable, would it be possible to use something like Kaplan-Meier statistics or hazard ratios that can take account of censored data?</p> <p><b>We have separated out the group that died in 2012 from the group that was still alive at the end of the study period and calculated the length of time each has received care. We reviewed the possibility of hazard ratios with out statistician who felt our approach of separating the two would likely be clearer for readers.</b></p> <p>3. The comments about how hospice is structured differently in Canada &amp; U.S. will be very useful for those in the U.S.</p> <p><b>Thank you! We have kept these statements but moved them to the setting section of the paper.</b></p>