Reviewer's report

Title: Evolution of the model of palliative care in the perinatal setting: a review of the clinical literature

Version: 2 Date: 2 September 2011

Reviewer: Steven Leuthner

Reviewer's report:

In this section the quoted areas are from the text, and the non quotes are my comments/questions.

"Our aim was to systematically review the literature on this topic, summarize the evolution of the model of care and, based on the available data, suggest a current standard for this type of care."

Interestingly it is not clear there is one model as wording suggests.

Background paragraph very general and far reaching – could be shortened.

Page 3:
"The objectives of this study were: firstly, to systematically review the clinical literature on Neonatal Palliative Care (NPC) and Perinatal Palliative Care (PPC) to determine the best model of care" [maybe say to determine if there is a best practice model]; "secondly, to summarize the evolution of this model of care" [can this really be done?]; "and lastly, to suggest what the present standard of care could be" [if there is one?], "given the scarce data currently available."

Page 4:
"We excluded studies that focused only on a very specific aspect of the model of care, such as treatment of pain or ethical decision-making." Why? Couldn’t these be helpful to determine an evolution?

Page 5:
"a data extraction form to record the following data from each classified article: lead author and country; year; type of article or design; main topic; direct subjects and number if appropriate; indirect subjects and number if appropriate; and job or position of the authors." Not clear what this “data” means?

Pag 6:
"No quantitative empirical research studies were found"

But there are some case series with quantitative numbers? True no RCT or case cohort – although Pierrucci is sort of one and not included in this that I can tell because not true neonate. Later on the same page the authors say there were 8 clinical studies with 4 having quantitative series.
"Qualitative analysis of the content of the articles showed that the concept of PC has developed gradually. Although the development is not perfectly defined—" 

What do the authors mean by the concept develops? Is there a progression? Did early articles start with one thing and others added, and so on? Not clear I understand what they mean by this?

Page 7:
"The field of neonatal and perinatal medicine has also been affected by the general clinical interest shown in PC."

Does this mean the concepts of PC have now entered into the world of neonatal and Perinatal medicine?

"However, it should be pointed out that there are very few clinical studies that can provide empirical data on this issue."

On what issue? "Therapeutic obstination"? Sloppy writing? Maybe say 'we found very few clinical studies on…

"In contrast, three other qualitative studies by Swanson-Kauffman that focused on the experience of miscarriage and the caring needs of women who miscarry were not included in the classification."

Why not include these? Do they guide us in development of a model??

"this distribution (table III) may reflect a publishing bias that is influenced by the databases consulted and the lack of clinical literature from some parts of the world, such as Africa."

Maybe this is because clinical practice is different, or sociologic differences exist – such as no one in Africa or Europe would consider demanding what Americans want – so we offer PC as another option, when in those other countries it is the only options so a big deal is not made of it??

"However, it should be borne in mind that, as has happened in more developed subject areas, the awareness of the need for PC will increase gradually and during this process other, more pressing issues will be prioritised."

What does this exactly mean? Maybe they already prioritise and accept death and don’t need all this PC talk?? Not sure.

"This study has certain limitations, the greatest of which is a lack of evidence-based empirical studies to identify the best model for perinatal PC."

So in other words you can’t take what is written as a meta analysis? So you can’t describe a model? Or describe the “evolution?” Or can you. The weakness in the field may be lack of RCT, but that may be because ethically difficult to do?? That is why studies on specific areas may be more helpful in the development or evolution of a model??
"summarise the temporal evolution of the model of perinatal PC, we had to follow a method of consensus"

How is a model of consensus temporal?

Page 8:
"The qualitative evaluation of these articles seems to show an evolution over time that is very similar to that of the concept of care in the Neonatal Intensive Care Unit (NICU),"

Is this describing an evolution of PPC similar to PC in NICU, or overall PPC and PC in neonates is similar to all NICU care provided? Confusing.

"Although PC emerged in close combination with the NICUs, [24] to encourage integration of the process in the family environment, the possibility of PC taking place in the home (at least on a temporary basis) was considered.[27, 28] This option, however, would depend heavily on the professional support that could be provided and the changing circumstances of the patient and the family.[20]"

I'm sorry but what are you actually trying to say here? And just before this – are you saying kangaroo care and NIDCAP effected PC??

Page 10:
"One of the possible arguments in favour of this option, besides the quality of clinical care given to the foetus/neonate, is that it means that parents will not have to cope with the consequences of voluntarily terminating the pregnancy,[14, 38] and that parents and relatives will be able to cope better with bereavement because they can prepare for the death of the neonate and, even accompany the baby to his/her natural end.[39, 36]"

While this may be true, there is no data as you suggest, so you are only being speculative as much as these articles are.

"The current literature suggests that if PC programmes in perinatal medicine are to conform to the standard of excellence, they should a) be comprehensive; and b) be initiated early and be integrative (see figure 3)"

So are you now suddenly moving into a recommended model? Yet all along you said there is little data? I agree but needs to be transitioned into with better rational.

The figure with the rising arrow – how did you come up with this? Was it by these areas discussed in articles over time?? Not sure what this means.

The PPC figure with “comprehensive” in it – what does this add to the literature? Not sure all the tables are needed??

**Level of interest:** An article whose findings are important to those with closely
related research interests

**Quality of written English:** Acceptable

**Statistical review:** No, the manuscript does not need to be seen by a statistician.

**Declaration of competing interests:**

I declare I have no competing interests.