**Trends in Pediatric Palliative Care Research (TPPCR) 2019; Issue #4: Commentary on
*Ekberg et al.***

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Abstract:

This TPPCR commentary discusses the 2020 paper by Ekberg et al., “Finding a way with words: Delphi study to develop a discussion prompt list for paediatric palliative care” published in Palliative Medicine.

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I have chosen to highlight the paper by Ekberg et al.¹ this month as it provides clinicians working in paediatric palliative care (PPC) a tool that is aimed at empowering our parents and carers through communication. The emphasis in research is often to support professionals with their communication, however an aid for carers resonated with me and some of the issues we face during challenging discussions.

When palliative care is introduced to a family it is often after a series of bad news and loss. Although we can recognise the importance of PPC involvement, families may be feeling vulnerable facing a clinical deterioration or progression of their child's health status. In practice, the medical teams lead the conversation and may only, in hindsight, know how much the family have understood. The flow of the conversation should be responsive but remains in the control of the person steering the discussion. The concept of a prompt guide as a self-management tool flips the information acquisition encounter on its head by carers seeking important information regarding the service and how it can affect their lives. Not all carers have the confidence to question professionals in real time but the document also infers permission to seek relevant information and focuses the conversation on the carer and child. It also allows for the carer to pace set discussions into digestible chunks of information if an extensive discussion feels overwhelming. The prompt list can also work as a helpful adjunct to anticipatory care planning documents rather than reinventing a new version of existing paperwork.

Families may also prefer to discuss palliative needs of their child with the clinical team that knows them best as opposed to introducing a new one. Although well placed to do this, the lead professionals may not feel they have the experience to have these discussions and a parent voice taking a lead has the potential to create a mutually beneficial framework to support a conversation. The research team sought responses from a wide network of professionals; those with no PPC training as well as experienced and PPC trained professionals who worked in both community and tertiary hospital settings. The breadth of feedback expands the applicability of the guidance generated. Even with a variable response rate within cycles, Ekberg et al.¹ have created a robust document that the team have made freely available.

The document was created using the Delphi technique to garner professional consensus on successive document iterations. A real key to their process has been the involvement of 6 families within the latter stages to inform the document from their perspective. Although it is completely logical that a document aimed at parents should have their feedback, this step is often missed in the process. In doing so they have facilitated a qualitative understanding of the parents lived experience. This resulted in the introduction of a 2 stage document that can allow the pacing of discussions and introduction of end of life issues at a later date if felt appropriate. Patient and parent participation in this type of research is vital to keep the output relevant and informed.

I have broken down the key features that I feel emphasise why this piece of work can support our clinical practice and empower parents and carers. Conflict, communication breakdown, silent dissatisfaction and feeling not heard. We have all experienced some, if not all of these in our practice. The reasons for these are often complex and I don't mean to imply that a single document will prevent this from occurring. However, I do feel that the importance of supporting the parental voice and how they retain a sense of control cannot be underestimated. Ekberg et al.¹ have made an attempt at addressing this by proposing a prompt discussion document and giving us access to it.

References

1. Ekberg S, Herbert A, Johns K, et al. Finding a way with words: Delphi study to develop a discussion prompt list for paediatric palliative care. *Palliative Medicine*. 2020;34(3):291-299. <https://doi.org/10.1177/0269216319888988>