Trends in Pediatric Palliative Care Research (TPPCR) 2019; Issue #9: Commentary on *Janvier et al.*

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Abstract:

This TPPCR commentary discusses the 2019 paper by Janvier et al., “Building trust and improving communication with parents of children with Trisomy 13 and 18: A mixed-methods study” published in Palliative Medicine.

This commentary is a part of the Trends in Pediatric Palliative Care Research commentary series. To learn more or to sign up for our monthly newsletter visit: <https://pediatricpalliative.com/research-blog/>

If there is one thing fascinating about medicine, it is the dynamic evolution of knowledge. So many notions and facts that I learned as a medical student have since been challenged, modified, advanced or sometimes proven completely wrong. New research designs have also been developed, allowing researchers to answer old questions with new methodology.

The article by Janvier et al.¹ represents all those changes; it challenges knowledge I learned twenty years ago, it forces me to re-examine my practice and even the vocabulary I use, and gives me information I wished I had years ago.

So many times during my training, and well into my career, did I cringe when I heard the expression “non-compatible with life”. How can one’s life not be compatible with life while being alive at the same time? Back in my residency days, no guidelines or recommendations were available on how to support families whose child had just been diagnosed with T13 or T18. Data on prognostic was either lacking, was dated or anecdotal.

It took a while, but parents are now recognized for their expertise in parenting a child with medical challenges. Parents are often the best teachers a medical student or resident can have; they can teach what is helpful, what is useless and what is harmful when interacting with them. This study shows how building trust is crucial in establishing supportive and respectful communication between all members of the care team, including the most important members, the parents (and the patient, when able to participate).

Parents are also involved in research, not only as participants, but in planning the design, and making sure the most meaningful and relevant questions are being asked. After all, for research to be clinically relevant, it has to create knowledge that can be applicable to clinical practice and improve care in its global meaning.

The biggest strength of this article is in its concrete suggestions, in all the examples provided, on how to be supportive in our interventions with families. Many of those suggestions can guide health care providers supporting families facing situations with a high level of uncertainty. Table 1 to 4 provide rich educating tools ideas: OSCE stations, role play during workshops, bioethic class reflexion, etc. Of course, positive role models and mentors putting these examples of supportive interaction into practice are invaluable.

The parental recommendations listed in Figure 1 should be shared with everyone caring for children living with a life-limiting condition. It essentially summarizes the pediatric palliative care approach in half a page. These recommendations can be implemented in one's clinical practice at any point in a career and improve communication with families.

Finally, this paper underlines the uniqueness of each family we are privileged to meet. If all parents want to be involved in the care of their child, not all families are comfortable leading the care team for their child. Some want more guidance than others and developing a relationship based on trust will allow parents to share their preferences without being afraid of being judged or pressured.

For more information about the experience of parenting a child with T13 or T18, see Janvier et al. (2016).²

References

1. Janvier, A., Farlow, B., Barrington, K. J., Bourque, C. J., Brazg, T., & Wilfond, B. (2019). Building trust and improving communication with parents of children with Trisomy 13 and 18: A mixed-methods study. *Palliative Medicine*. <https://doi.org/10.1177/0269216319860662>.
2. Janvier, A., Farlow, B., & Barrington, K. J. (2016). Parental hopes, interventions, and survival of neonates with trisomy 13 and trisomy 18. *American Journal of Medical Genetics. Part C, Seminars in Medical Genetics*, 172(3), 279–287. <https://doi.org/10.1002/ajmg.c.31526>