Trends in Pediatric Palliative Care Research (TPPCR) 2021; Issue #9: Commentary on *Rapoport & Gupta*

Katherine Ketchum

University College Dublin Medical Student

Email: Katherine.ketchum@ucdconnect.ie

Abstract:

This TPPCR commentary discusses the 2021 paper by Rapoport & Gupta, “Children and adolescents with hematologic cancers deserve better end-of-life care” published in Cancer.

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There still exists a large gap in knowledge among the general population when it comes to understanding palliative care. A stigma still surrounds the word “palliative”, with many seeing it as synonymous with “giving up”. The issues highlighted in this article by Rapoport and Gupta are a possible consequence of this misunderstanding. The team found that vast differences in end-of-life (EOL) care exist between adults and children with hematological malignancies. EOL benchmarks for adults with hematological malignancies are that fewer than 10% of patients receive aggressive care (chemotherapy, visits to intensive care, etc.) in the last 14 days of life, and fewer than 17% die in the acute care setting. Contrast this with studies that have looked at children with hematological malignancies at the end-of-life: up to 57% of children receive aggressive therapy in the last 14 days of life, and around 80% die in the acute care setting.¹

The authors presented possible reasons for this discrepancy, which I agree with. Treatment-related complications of hematological malignancies may lead to aggressive therapy at the end of life. Complications such as neutropenic infections are difficult to reconcile as the cause of death in children with cancer. It is unimaginably difficult to ask parents to understand that that which was supposed to save their child may be what contributed to their child’s decline, and this inadvertent denial may lead parents and doctors to pursue aggressive treatment right up until the end of the child’s life, rather than acknowledging the need for palliative care.

The other hypothesis presented was that high rates of remission among pediatric hematological malignancies (somewhere around 80%)² may motivate parents and doctors to pursue every last medical intervention, fuelled by skepticism that that particular child could be one of the minority that does not survive his or her illness.

Getting back to the role of pediatric palliative care in all this, I believe that another contributing factor to poor EOL care for children with hematological malignancy is that palliative care is more likely to be hesitantly discussed, or not discussed in the most effective of ways with the families in the pediatric

population. Studies have shown that early implementation of palliative care in the pediatric setting has beneficial effects on the patient and the patient's family in the long-term.³ Thinking must change to support the idea that early induction of palliative care in children does not equate to the child's death being imminent or that the physicians have exhausted all avenues of care, but that whatever does happen, the child will be comfortable throughout and the parents and siblings will be better off in the end, no matter the outcome.

This way of thinking could decrease the amount of possibly unnecessary aggressive therapy given to these children at the end of life, as it would give parents hope that should the unthinkable happen, their child will be comfortable and relieved of pain at the end of life. Having this in their minds would allow parents to make a clearer decision on what interventions to include in their child's care, especially when the child's health is deteriorating. Timely palliative care could provide children with the dignity, comfort and peace that is given to palliative adult patients at the end of life.

I found this paper to be enlightening in its analysis of a little-known healthcare problem and compelling in arguing the need for change. Children deserve to be given the same access to quality EOL care as adults, and should not have to endure highly aggressive treatment at the end-of-life when it is not warranted. The importance of early palliative care introduction cannot be overstated, as this can give parents and patients alike peace of mind near the end of life, and allows time for emotional processing of the situation and informed decision-making. It is natural for us as members of the medical community to want to save everyone, using whatever means possible, especially those we deem to be too young to be at the end of their lives. But aggressive and unpleasant interventions are not always warranted or beneficial at the end of a human's life.

References

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