Question: In children with medical complexity does advance care planning, compared to routine care, influence long term quality of life balanced with prolongation of life?

Summary: Advance care planning (ACP) has been defined as "the process of discussing life-sustaining treatments and establishing long-term care goals (Orkin et al., 2020). "ACP discussions are often prompted by the anticipation of impending death." However, "discussions have been recommended early in the care pathway to ensure that quality of life is balanced with quantity and prolongation of life" (Orkin et al., 2020). During this study regarding advance care planning, "some parents noted that their child's quality of life was often underestimated by HCPs, thus highlighting the importance of asking parents about their child's quality of life at baseline rather than making inferences on the basis of their clinical status when admitted to the hospital" (Orkin et al., 2020). "Attention to building a human connection is essential to supporting the family in decision-making. Before even beginning to have a conversation about a difficult decision, a human connection must be established" (Madrigal & Kelly, 2018). Prior studies have demonstrated that parents value ACP because of the potential for optimizing a child's quality of life and achieving better end-of-life outcomes (Lord et al., 2020).

Conclusion: Advance care planning is a useful tool to facilitate communication between families and health care providers of medically complex children. It requires the health care provider to first build a trusting human connection with the parents, to establish trust and effective communication. Once established ACP can greatly improve the child's quality of life during end-of-life care. Although, it must be noted that quality of life can not be assumed and must be discussed with each family individually since interpretation of quality is based on individual vales.

References:

Primary:

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Secondary:

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Tertiary:

Lord, S., Moore, C., Beatty, M., Cohen, E., Rapoport, A., Hellmann, J., Netten, K., Amin, R., & Orkin, J. (2020). Assessment of bereaved caregiver experiences of advance care planning for children with medical complexity. *JAMA Network Open*, *3*(7). https://doi.org/10.1001/jamanetworkopen.2020.10337