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Instructional Module 8

Question:

In the pediatric population with medical complexity, how does early advanced care planning compare to a lack of advanced planning affect the patient's overall well-being towards the end of life?

Summary:

In the pediatric population, it is tricky for healthcare workers to push the idea of wanting to tell guardians to begin planning for advanced care for their children. Many times physicians and nurses are unsure of how to start the conversation and when it's deemed appropriate to begin speaking about sensitive topics like palliative care. However, contrary to popular belief, having open and honest conversations about advanced care planning offers a "greater sense of empowerment in patients, improves their quality of life, and potentially decreases their worries about the future" (Johnson, K. A. 2021). Having these critical conversations throughout the patient's disease process not only allows the patient to have a sense of empowerment but also permits the family to have a sense of family-centered care which aids in reducing stress and conflict, and improves communication with the healthcare team. "Partnering with families by first understanding their goals and perceptions can help to frame the advanced care planning conversation. This partnership is at the core of ACP discussions, and the resulting outcome of the discussion is truly secondary to the partnership that was formed" (Orkin, J., et al. 2020). The earlier the healthcare team decides to have these crucial conversations, the more beneficial they become for the patient and family, in the article *Early Initiation of Pediatric Palliative Care* (Neuburg, L., 2021) states that "early integration of pediatric palliative care enhances the quality of life and reduces suffering in these children, but many clinicians fail to initiate advanced care planning, establish goals of care, and refer to specialists." Unfortunately, many providers and nurses miss the chance to engage their patients and their families in advanced care planning due to these common issues, "lack of structured approach to these discussions, concern for the emotions the discussions will stir in the patient and families, the emotional toll on clinicians, and prognostic uncertainty about treatment options and care management strategies" (Johnson, K. A. 2021). Although the initiation of these conversations may be difficult for the family, patient, nurse, and healthcare provider there are several ways to enhance the discussion about advanced

care planning, in the article *Toward an Understanding of Advance Care Planning in Children with Medical Complexity*, it is stated that these seven enhancers aid in advanced care planning discussions,

1. Partnerships in shared decision-making
2. A supportive setting
3. Early and ongoing conversations
4. Consistent language and practice
5. Family readiness
6. Provider expertise in ACP discussions
7. Provider comfort in ACP discussions

(Orkin, J., et al. 2020)

Conclusion:

In conclusion, after reading these three articles about advanced care planning, it is clear that the most difficult conversations are the most necessary to have in order to assure the patient has a high quality of life. Though many of us believe that we are taking away hope from the family and patient when we speak about non-resuscitative measures or palliative care, it is actually beneficial for everyone to discuss what the patient wants. As stated in the *Official Journal Of The American Academy Of Pediatrics* (Orkin, J., et al. 2020), “Advanced care plans should be a holistic and ongoing process that includes discussions surrounding hopes and goals, beliefs and values, and quality of life. As we engage in these difficult conversations, we justly uphold our oath to strive for beneficence and avoid maleficence.” Overall, being able to have conversations about advanced care planning will give everyone a sense of comfort and knowledge on what’s to come in the unknown. Giving everyone the ability to be heard and understood during a strenuous and exigent time in the patient and family's life.

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Work Cited:

Primary Article

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Secondary Article

Johnson, K. A., MD, FAAP (2021). Advance Care Planning in Pediatric Serious Illness: Centering in the Family Experience. *Hospital/Palliative Medicine*, *Volume 147* (Issue 6) https://doi.org/10.1542/peds.2020-048660

Tertiary Article

Neuburg, L., MSN, RN (2021). Early Initiation of Pediatric Palliative Care. *Journal of Pediatric Health Care*, *Volume 35* (Issue 1). https://doi.org/10.1016/j.pedhc.2020.05.006