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Abstract:

This TPPCR commentary discusses the 2021 paper by Thompkins et al, "Pediatric Advance Care Planning and Families' Positive Caregiving Appraisals: An RCT" published Pediatrics.

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The article by Thompkins et al.¹ addresses the important area of pediatric advance care planning (ACP) in the context of cancer in adolescents and young adults. Clinicians may be hesitant to initiate conversations about ACP due to concerns that these conversations may add to the distress of already burdened families. However, delaying these conversations may result in some adolescents and young adults being no longer able to express their views and preferences due to disease and symptom progression.

Thompkins et al.¹ have described a randomized controlled trial in which they evaluate the Family-Centered Pediatric Advance Care Planning Intervention for Teens with Cancer (FACE-TC), relative to a standard care control condition in four tertiary children's hospitals in the United States. The intervention incorporated the use of various ACP resources, including the Advance Care Planning Survey, Next Steps: Respecting Choices, and Five Wishes. The authors reported an interim analysis, documenting family caregiver perspectives. A planned 18-month post-intervention evaluation will be reported in due course.

When family caregiver satisfaction was assessed after the third study visit, those who received the FACE-TC were significantly more satisfied with their study participation than those in the standard care condition. Families in the treatment condition were more likely to report that the experience was worthwhile, useful and something they needed to do, compared to those in the standard care condition. Moreover, three months after the study intervention, families who received the FACE-TC intervention did not differ significantly in their reported levels of distress or strain relative to families receiving standard care. Family caregivers in the treatment group did appraise their own caregiving significantly more positively than caregivers in the standard care condition. The authors suggest that caregiver perceptions of being a "good parent" to their seriously ill adolescent place importance on engaging in complex medical decision-making, which ACP conversations and resources may help support. Taken together, these results should help allay the concerns of clinicians about the potential of heightening distress in families by engaging them in conversations about ACP.

Clinicians often wonder when is the best time to commence pediatric ACP conversations (for a discussion of this issue see DeCoursey et al.²). Although the study reported by Thompkins et al.¹ does not directly examine this question, they have adopted the approach of engaging in the ACP intervention at any time from cancer diagnosis, irrespective of prognosis. Data from this study suggest that family caregivers found this an acceptable approach. It seems possible that patients still receiving active treatment, and hopeful of a full recovery, may not engage in ACP conversations in the same way. However, the intervention described in this manuscript was not intended as the “end-point” of ACP. Rather, the intervention described is likely to be a starting point, and that as circumstances and symptoms evolve, clinicians and families can continue these conversations.

It has been reported elsewhere, using the same sample of adolescent-family dyads receiving the intervention as analysed in the Thompkins et al.¹ manuscript, that adolescents with cancer who were willing to enrol in a study about ACP, preferred to talk about end-of-life and ACP when they were first diagnosed or throughout the disease process, rather than when they were hospitalized or dying.³ Similar findings were reported in their earlier pilot study with 17 adolescents.⁴ These findings contrast to the views of family caregivers, who reported believing that their child would prefer to delay ACP conversations.³

The study protocol described by Thompkins et al.¹ required careful training for the health professionals who facilitated the FACE-TC intervention to ensure both quality of delivery and appropriate standardization of methodology. Notably, the facilitators were not necessarily a clinician with whom the patient and family were familiar. On the one hand, it may be easier for clinicians who already have a good rapport with a patient/family to engage them in challenging ACP conversations. On the other hand, there may sometimes be advantages in a ‘neutral’ person, who does not necessarily know all about the patient’s illness ‘journey’, but is well trained and comfortable in ACP, to initiate these discussions, ideally setting up the context for patients and families to have subsequent conversations with their treating teams. The results outlined by Thompkins et al.¹ indicate that the latter scenario is also acceptable to families.

In summary, the study described by Thompkins et al.¹ is notable for its scientific rigour, typified by careful standardization allowing for replicability; use of a standard care control condition; randomization to conditions; a large sample size; and recruitment from a wide spectrum of socioeconomic backgrounds and ethnicities. Consequently, the study offers much needed, high-level evidence in this field and will hopefully encourage other teams to embark on other similarly ambitious, well-designed comparative studies, which are currently too few in the field of pediatric ACP. Future research is also warranted to evaluate the use of the FACE-TC intervention with pediatric patients with serious medical conditions other than cancer.

References

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