

Adapting the Serious Illness Conversation Guide for Use in Pediatrics

Camara van Breemen, MN, NP (F)

To the Editor:

In British Columbia (BC), the Centre for Palliative Care and provincial health authorities promote the use of the Serious Illness Conversation Guide (SICG) developed by Ariadne Labs. Staff at Canuck Place Children's Hospice (CPCH), Vancouver, BC, recognized that the SICG could be helpful for improving communication with parents and their children with serious illness. However, the guide lacks family-centered language and does not consider a child's developmental stage or address issues related to difficult prognostication in children with rare illnesses.

In July 2017, CPCH began the process outlined by Ariadne Labs to adapt the SICG for pediatrics.¹ An experienced palliative medicine nurse practitioner convened a group of 10 clinicians and an SICG Master Trainer provided a three-hour training session. The guide questions were reviewed and adapted by the group. The initial draft was then trialed with various families at times when a clinician-specific serious illness conversation was appropriate. The parents verbally consented to the conversation and their feedback was solicited. Some of the clinicians used the questions and process verbatim while others made changes. All clinicians documented their observations of the flow, language used, and outcome of the meeting and relayed them to the nurse practitioner, who made further adjustments to the language.

The adapted SIGC (SIGC-peds) was then presented to the Family Advisory Committee of CPCH and to professional groups with a focus on palliative care. Further feedback was incorporated (see Supplementary Data; Supplementary Data are available online at www.liebertpub.com/jpm). Once the final version was approved by the clinician group, a Master SICG trainer and the nurse practitioner adapted the Train the Trainer component of the Ariadne program. The four-hour Train the Trainer session was then offered to the clinical expert group.

Results

To date, >25 clinician:family SIGC-peds encounters have occurred. Clinicians have commented that it is not more time consuming than their prior communication practices and it allows for a sensitive and thorough conversation even when the clinician is fatigued. In addition, through using the guide, learners (medical residents, nurses, or allied health providers) can easily identify essential components of permission, re-

spect, and the essential aspects of sharing prognosis. Parents of seriously ill children have identified that shared decision making, a gradual and sensitive approach, touching on home and nonmedical issues, and involving the child are essential in advance care planning for children.

Emerging data suggest that integrating pediatric palliative care early in a child's illness leads to more effective communication, shorter hospitalization, fewer emergency department visits, and less intensive treatment at the end of life.²⁻⁴ Having a specific guide for initiating the difficult conversation about advance care planning in children can enhance clinicians' confidence, maintain a consistent message from clinician to clinician, and ensure all potential concerns of the family are addressed.

By including relevant clinicians, families who had or have a seriously ill child, and groups with a professional interest in palliative care in the adaptation process, a range of perspectives was captured. Education sessions have been scheduled and pre- and postassessments will be conducted.

References

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Address correspondence to:
Camara van Breemen, MN, NP (F)
Canuck Place Children's Hospice
1690 Matthews Avenue
Vancouver, British Columbia V6J 2T2
Canada

E-mail: cvanbreemen@canuckplace.org