

## Original Article

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# The Pediatric Serious Illness Conversation Program: Understanding challenges and experiences for clinicians after advance care planning training

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**Abstract**

**Objectives.** To explore experiences of pediatric clinicians participating in a serious illness communication program (SICP) for advance care planning (ACP), examining how the SICP supports clinicians to improve their communication and the challenges of implementing new communication tools into clinical practice.

**Methods.** A qualitative description study using individual interviews with a diverse group of pediatric clinicians who participated in 2.5-hour SICP training workshops at pediatric tertiary hospitals. Discussions were transcribed, coded, and arranged into overarching themes. Thematic analysis was conducted using interpretive description methodology.

**Results.** Fourteen clinicians from 2 Canadian pediatric tertiary hospital settings were interviewed, including nurses (36%), physicians (36%), and social workers (29%), from the fields of neonatology (36%), palliative care (29%), oncology (21%), and other pediatric specialties (14%). Key themes included specific benefits of SICP, with subthemes of connecting with families, increased confidence in ACP discussions, providing tools to improve communication, and enhanced self-awareness and self-reflection. A second theme of perceived challenges emerged, which included subthemes of not having the conversation guide readily accessible, divergent team communication practices, and particular features of the clinical environment which limited the possibility of engaging in ACP discussions with parents.

**Significance of results.** A structured program to enhance serious illness communication supports clinicians to develop skills and tools to increase their confidence and comfort in conducting conversations about end-of-life issues. Addressing challenges of adopting the newly learned communication practices, by providing access to digital SICP tools and conducting SICP training for clinical teams may further support clinicians to engage in ACP.

**Introduction**

There are an increasing number of children and youth with potentially life-threatening and life-limiting conditions where premature death may be expected, and advance care planning (ACP) is an important component of their health care. ACP is a process for discerning and documenting a person's values and preferences to guide future health-care decisions (Lotz et al. 2013). ACP has been identified as a key component of high-quality end-of-life (EOL) care for individuals with serious illnesses including cancer and HIV/AIDS (Curtin et al. 2017; Gaines et al. 2019; Lotz et al. 2017; Thompkins et al. 2021). Serious illness was referred to "a condition that carries a high risk of mortality, negatively impacts quality of life and daily function, and/or is burdensome in symptoms, treatments or caregiver stress" (Kelley 2014). When caregivers participate in ACP prior to their child's death, they benefit from improved preparation for their child's EOL, improvements in the child's quality of life at EOL, and palliative care in the child's preferred location of death (DeCoursey et al. 2019). Through ACP, parents are able to explore their goals for their family, which leads to them to feel that their child suffered less and they experience less decisional regret (DeCoursey et al. 2019). Serious illness conversations is used to describe a broader range of discussions with patients and their caregivers and loved ones about their goals and values, which can include ACP discussions.

Despite becoming increasingly more formalized, barriers to discussions about patients' goals and values across health-care settings still exist (Houben et al. 2014). Perceived barriers to this

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type of communication include lack of necessary skills and confidence among staff, concern that bringing up EOL issues will upset patients, lack of knowledge of patient and family goals, time constraints, uncertainty regarding who is the appropriate person to initiate ACP discussions, and absence of systematic process for initiating ACP discussions (Basu *et al.* 2021; Bernacki and Block 2014; Houben *et al.* 2014). Pediatric clinicians face additional challenges such as caring for patients too young to express their wishes, family dynamics, working with parents as surrogate decision-makers, and treating rare diseases for which prognostication is particularly difficult (Basu *et al.* 2021; DeCoursey *et al.* 2021; Katz *et al.* 2020; Lotz *et al.* 2015).

Despite these barriers, parents are highly interested to participate in serious illness conversations, and have identified that this need is often inadequately addressed by clinicians (DeCoursey *et al.* 2021, 2019; Lotz *et al.* 2013; Orkin *et al.* 2020). For parents of children with serious illnesses, those that are considered life-threatening and life-limiting, conversations with both pediatric subspecialists and their primary health-care teams are important (DeCoursey *et al.* 2019; Orkin *et al.* 2020). Delays in initiating conversations can lead to a loss of time for families to explore their wishes, goals, and values and a loss of opportunity for care which matches their goals and wishes (Durall *et al.* 2012).

Patients expect that clinicians will initiate important conversations at the appropriate time and thus do not raise questions about ACP or goals and values (Bernacki *et al.* 2015). However, outside of pediatric palliative care, few pediatric clinicians have received specialized communication training and many report discomfort and inexperience in initiating conversations about EOL issues (Durall *et al.* 2012; Heckford and Beringer 2014; Lotz *et al.* 2017). The Serious Illness Conversation Program (SICP) was initially developed to aid adult clinicians in conducting conversations about values and goals (Bernacki *et al.* 2015). In 2018, the SICP was adapted to pediatrics through a collaborative process involving clinicians and families of seriously ill children (van Breemen 2018). The Pediatric SICP includes a validated conversation guide (Fig. 1), training workshops with individual coaching and supplemental resources. SICP training follows the training and coaching program described by Bernacki *et al.*, including didactic teaching, role play with debriefing and discussion (Bernacki *et al.* 2015). The Pediatric SICP has been successfully implemented at several tertiary hospitals in Canada (van Breemen 2018).

This study aims to describe the experiences of pediatric clinicians who participated in a SICP at 2 tertiary hospitals in Canada, specifically the processes by which SICP supports clinicians to improve their communication, exploring perceived changes in communication skills and confidence in conversations about goals and values, and the challenges of implementing the new communication tools into clinical practice.

This will lead to enhanced understanding of how clinicians' communication can be improved through the SICP and how to improve the SICP training and its implementation to support clinicians.

## Methods

### *Serious Illness Conversation Program structure*

In 2017, led by the palliative care team from Canuck Place Children's Hospice, the existing adult SICP was adapted to pediatrics using the process outlined by Ariadne Labs, which include consultations and feedback from pediatric clinicians, patients and

families and other key stakeholders. Further details of the adaptation of the serious illness conversation guide (SICG) to pediatrics have been described in our previous publications (Ariadne Labs 2019; van Breemen 2018).

The SICP includes a 2.5-hour in-person workshop led by master trainers and facilitators. Prior to the workshop, participants are provided with written copies of the SICG, didactic presentations, role play scenarios, and a clinician guide (Supplement 1). The clinician guide is a 21-page manual which provides more detailed information about common challenges and pitfalls of ACP, including suggested language to use with parents.

Each workshop consists of an interactive presentation about ACP and key communication practices from the SICG, followed by a demonstration of a serious illness conversation (between a clinician and parent) using a role play scenario which follows the structure shown in the SICG. After this demonstration, learners are lead through a debriefing of the role play, which allows them to reflect on the performance they observed and identify key practices.

Learners work in small groups (of 2 to 3), paired with facilitator where each participant practices leading a serious illness conversation using the guide with another participant playing the role of a parent. A role play script, which includes wording for clinicians and parents, is provided to participants. When leading the serious illness conversation, participants are encouraged to follow the script to ensure adherence to key components of the SICG process. Facilitators observe the role play, answer questions, and support participants' reflections and feedback.

There is a final opportunity for reflections from all participants at the end of the workshop where participants are encouraged to share their reflections about how the SICG could be used in their clinical practice in the future and what are the potential barriers to its implementation. After the workshop, clinicians are encouraged to contact facilitators for further advice and support and are encouraged to attend the SICG training for a refresher or to participate in the SICP Train the Trainer (TOT) program. The SICP TOT program is a structured 2.5-hour workshop for clinicians who have completed the SICP training workshop. The TOT workshop includes training on how to teach the SICP, including best practices for teaching communication training to clinicians. TOT participants also practice facilitating role play scenarios and engage in debriefing of role plays and their role as a facilitator. The Pediatric SICP was implemented at 2 academic tertiary pediatric hospitals: the Children's Hospital of Eastern Ontario (Ottawa) and British Columbia Children's Hospital (Vancouver) in Canada in 2018.

### *Study population and setting*

Clinicians who participated in SICP workshops in 2018 and 2019 were invited by email to participate in individual interviews exploring their perspectives and learning experiences with the SICP. All participants who had completed SICP training were eligible for this study, which included a total of 235 potential participants who completed SICP training during the study time frame. Demographic and professional practice characteristics were collected. Interviews occurred between 3 and 12 months after workshop participation.

### *Sampling strategy*

Purposeful sampling was used to incorporate a broad range of participants focusing on recruiting participants from a variety of

professional backgrounds and specialties for maximum variation within the dataset (stratified purposeful sampling) and maximum variation sampling, sampling from a wide range of perspectives (Given 2008; Maxwell 2012). All 14 participants who were invited consented and subsequently participated in this study.

**Data collection**

Initial interviews were conducted in person (6 interviews, all at Site 2). After the advent of the COVID-19 pandemic, the remainder of interviews were conducted using internet-based videoconferencing (Zoom). Two study team members conducted interviews (MF, female physician; NL, female nurse). Interviewers were trained in qualitative interviewing and received ongoing mentorship and support from experienced team members and additional staff at local research institutes. Interviews were conducted one-on-one, with the choice of interviewer being based on the participant’s location. Interviews were audio recorded and interviewers also took field notes. Data were collected from all study participants who were able to participate, based on availability.

One interviewer (NL) was known to some study participants, from her involvement as an SICP facilitator, while the second interviewer (MF) was not known to participants. The participants were introduced to the facilitator at the beginning of the interview and

were provided with information about the goals of the research, which was also outlined in the study invitation documents. The researcher team consisted of experienced pediatric palliative care clinicians (CB, MD, and NL) and trainees (PG and MF), and included SICP master trainers who were involved in developing Pediatric SICP (CB and MD).

An interview guide was developed by the research team, after a review of literature related to ACP training and implementation among clinicians, and incorporated experiences with implementing the SICP from research team members (Supplementary Materials, S2). The interview questions were designed to be open-ended, and the interview used probes to encourage participants to explore interview topics thoroughly (Ritchie et al. 2013). Interviews were audio-recorded and transcribed verbatim.

Interview data were analyzed using interpretive description, which is widely used in health professionals’ education, as it was developed specifically to provides a formal qualitative methodology to address health-related research questions which apply to clinical practice (Thompson Burdine et al. 2021). The initial coding scheme was developed and refined as the analysis proceeded, and the team members became more familiar with the data using the steps described by Braun and Clarke (2012). The key components of learning from the SICP, challenges of implementing SICP practices, and workshop experiences were used to


 <b>Serious Illness Conversation Guide —PEDI</b>	
<p><b>1. Set up the Conversation</b></p> <ul style="list-style-type: none"> <li>• Introduce the idea and benefits</li> <li>• Prepare for future decisions</li> <li>• Ask permission</li> </ul>	<p>"With your permission I'm hoping we can talk about where things are with your child's (insert child's name) illness and where things might be going — is that ok?"</p> <p>OR</p> <p>"Talking today will help us get to know you and your child better and help us prepare and plan for the future. Is this okay?"</p>
<p><b>2. Assess Illness Understanding and Information Preferences of Parent</b></p>	<p>"What is your understanding now of where your child is at with his/her illness?"</p> <p>"How much information about what is likely to be ahead with your child's illness would you like from me?"</p>
<p><b>3. Share Prognosis</b></p> <ul style="list-style-type: none"> <li>• Frame as "I wish ... worry, and/or I hope ... wonder ..." statement</li> <li>• Allow silence, explore emotion</li> </ul> <p>Clinicians have a responsibility to provide parents with ongoing support and guidance as symptoms of dying become present.</p>	<p>"My understanding of where things may be at with your child's illness is ..."</p> <p><b>Uncertainty:</b> "It can be difficult to predict what will happen and when. I hope he or she will continue to live well for a long time, but I worry given what we know (insert information about illness/condition) ... he or she could get sick quickly ..."</p> <p><b>Function:</b> "I see the following (fragility, instability, assessment of function) and I am worried that this represents ..."</p> <p><b>Time:</b> "It is very difficult to predict time. Like you, I also want your child to ... But I am worried that time may be shorter than we hope." *If using time in prognosis, it MUST be paired with a statement of uncertainty and with function information.</p>
<p><b>4. Explore Key Topics</b></p> <ul style="list-style-type: none"> <li>• Goals</li> <li>• Fears and worries</li> <li>• Sources of strength</li> </ul> <p>Optional points to explore</p> <ul style="list-style-type: none"> <li>• Critical abilities</li> <li>• Trade-offs (balance of interventions)</li> <li>• Involvement of child and/or siblings</li> </ul>	<p>"What are your most important goals/hopes if your child's health worsens?"</p> <p>"What are your biggest fears and worries about the future with your child's health?"</p> <p>"What gives you strength as you think about the future with your child's illness?"</p> <p>"What abilities are so critical to your child's life that you can't imagine him/her living without them?"</p> <p>"If your child becomes sicker, how much medical intervention are you willing to go through for the possibility of gaining more time?"</p> <p>(see reverse)</p> <p>If involvement of child / sibling is appropriate / necessary, arrange for another meeting to explore (see reverse)</p>
<p><b>5. Closing the Conversation</b></p> <ul style="list-style-type: none"> <li>• Summarize</li> <li>• Make a recommendation</li> <li>• Check-in with parents</li> <li>• Plan follow-up</li> </ul>	<p>"I've heard you say (insert goals/hopes).... is very important to your family and that you also worry about ..."</p> <p>"Keeping this in mind and what we know about your child's illness, I recommend that ... (e.g.; change the care plan, create ACP, watch and wait)."</p> <p>"How does this plan seem to you?"</p> <p>"We will schedule/check-in again in (time frame — days/weeks/month) to ensure ongoing support."</p>
<p><b>6. Document your Conversation</b></p> <p><b>7. Provide Documents to Parents</b></p> <p><b>8. Communicate with Key Clinicians</b></p>	

Figure 1. Serious illness conversation guide (SICG) pediatric adaptation.



### Assessing with Parents their Child(ren)'s Understanding/ Involvement

Questions to be considered if child (or sibling) is able to participate in the conversation:

- "What do you believe your child understands about his/her illness?"
- "How much information do you think your child is ready for? And from whom?"

Consider exploring the child's (and/or siblings) biggest:

**HOPE** "What goals or hopes do you think your child(ren) have?"

**FEARS AND WORRIES** "What worries or fears do(es) your child(ren) have?"

**STRENGTH** "What are your child(ren)'s strengths?"

**CRITICAL ABILITIES** "Have you spoken with your child or other children about your priorities and wishes? Do you know what theirs are?"

If you are sharing or supporting the parents to share the prognosis with the child or siblings, consider stage of development, temperament, and available supports (e.g. parent, counsellor).

### Reciprocal/Attuned Responses

#### NON-VERBAL

- Use of silence, pauses
- Physical space/body positioning

#### VERBAL

- Inquiry
- Advice (given when asked)
- Reflection (paraphrase words, meaning or circumstance)
- Responding safely to emotion
- Normalizing/acknowledging experience

### Assessing Clinical Status to Help with Prognosis Wording

**FRAGILITY:** degree of risk of a significant deterioration

**ROBUST** **FRAGILE**

**CNS:** seizures, increased ICP, hemorrhage

**CVS:** heart function, arrhythmia, hemodynamics

**RESPIRATORY:** central +/- pulmonary

**GI:** nutritional status, obstruction

**IMMUNE SYSTEM:** sepsis

**INSTABILITY:** rate of change in child's wellbeing

**STABLE** **UNSTABLE**

**SYMPTOM BURDEN:** pain, nausea, feeding intolerance, dyspnea etc.

**CARE NEED CHANGE:** feeding, respiratory, transfusion support

**FUNCTIONAL CHANGE:** eating, ambulation, interaction/engagement

**DEVELOPMENTAL CHANGE:** loss of or failing to meet milestones

### Wish/Worry Framework

#### RATIONALE

- "I wish" allows for alignment with the parent's & child's hopes.
- "I worry" allows for being truthful while sensitive.
- "I wonder" is a subtle way to make a recommendation.
- "I will" is a direct way of expressing your commitment to ongoing support and care.

#### Examples:

- "I wish we could slow down or stop your child's cancer/disease and I will continue to look for options that could work for him/her."
- "But I worry that you, your child, and your family won't be prepared if things don't go as we hope."
- "I wonder if we can discuss a plan if symptoms continue to get worse."
- "I will continue to connect with you daily so we can ensure this plan is working."

### Goals of Care

SUSTAIN LIVING

SUSTAIN LIVING + COMFORT CONSIDERATIONS

COMFORT-FOCUSED

### Optional Questions to Explore

#### CRITICAL ABILITIES

Explore if parents have indicated that they are weighing development and abilities in treatment decisions. Listen for subtle inquiries about what is 'ok' to do or not do.

With infants or critically ill children, ask about 'future' abilities and hopes and fears related to those.

With non-verbal children with disabilities, listen for the abilities the parent's value and explore potential losses of those.

#### TRADE-OFFS — BALANCE OF INTERVENTIONS

Examples of trade-offs are time in hospital vs time at home, increasing respiratory support (bipap, intubation), treatment for potentially reversible causes, or care planning directed at comfort treatments. Provide recommendations about what may or may not be of benefit instead of offering a 'choice' or a menu of options.

#### INVOLVEMENT OF CHILD/SIBLINGS

(See Assessing with Parents their Child(ren)'s Understanding/ Involvement)

### Self-Awareness — Consider your Tendency to...

- Fix, placate or falsely reassure
- Overly identify
- Feel responsible (role or relationship)
- Be triggered by strong emotion
- Avoid difficult feelings or difficult comments from parents
- Be attached to own agenda

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Figure 1. (Continued.)

inform the development and organization of codes. The coding scheme was finalized and then the transcripts were manually coded by researcher (PG) and independently verified by a second team (MD) to ensure consistency and accuracy. Discrepancies in coding were discussed among team members and resolved by consensus. Data analysis was done using NVivo-12 (QSR International Inc., Cambridge, MA).

## Results

### Participant characteristics

Fourteen clinicians participated in SICP interviews, including 6 in Vancouver and 8 in Ottawa. Participants practiced in variety of pediatric disciplines including neonatology ( $n = 5$ , 36%), palliative care ( $n = 4$ , 29%), and complex care ( $n = 3$ , 21%). Further details of participant characteristics are shown in Table 1. Interviews were 25–50 minutes in duration.

There were 2 main themes and 6 subthemes identified from analysis of interview transcripts (Table 2).

### Theme: benefits of the SICG and workshop

All participants described various benefits of the SICG and the training workshop. These were classified into 4 subthemes:

connecting with families, increased confidence in ACP discussions, providing tools to improve communication, and enhanced self-awareness and self-reflection.

### Connecting with families

After participating in the workshop, participants noticed they were better able to understand and connect with families' emotions. Participants noted that they had started to realize that there is not a universal set of emotions to expect from families during serious illness conversations. Participants reported being able to better identify parental reactions including anxiety, anger, disbelief, or no reaction at all. One participant (P9) noted,

"By first exploring the parents' understanding and needs, the team is able to direct their efforts and speed of information towards best supporting the family where they are at with the child's illness....it's excellent that it's in the guidelines saying allow silence and explore emotion, allow it to happen. Let them get angry if they're getting angry and try to remind yourself, this isn't personal."

The workshop taught clinicians the importance of focusing on parents' goals, worries, and values. Participants found that the SICP training provided them with tools for inquiring about and then listening to parents' emotions and this helped clinicians to connect more deeply with families. Participant 11 noted,

**Table 1.** Participant characteristics

	Site 1 (n = 8)	Site 2 (n = 6)	Total	%
<b>Gender</b>				
Female	7	5	12	85.7
Male	1	1	2	14.3
<b>Health Profession</b>				
Nurse (includes nurse practitioner)	3	2	5	35.7
Staff physician	1	3	4	28.6
Social worker	3	1	4	28.6
Resident physician	1	0	1	7.1
<b>Primary Practice Setting</b>				
Academic tertiary children's hospital	6	6	12	85.7
Pediatric hospice	2	0	2	14.3
<b>Primary Area of Practice</b>				
Neonatology	2	3	5	35.7
Pediatric palliative care	2	2	4	28.6
Pediatric oncology	2	1	3	21.4
Pediatric complex care	1	0	1	7.1
Pediatric rehabilitation	1	0	1	7.1

**Table 2.** Major themes and subthemes

Theme	Benefits of the SICP and workshop	Challenges to implementing the SICP
Subthemes	Connecting with families	Guide accessibility
	Increased confidence in ACP discussions	Divergent communication practices within the team
	Providing tools to improve communication	Clinical environment
	Enhancing self-awareness and self-reflection	

"By discussing some of those more emotional aspects and seeing that mom responded to certain questions in a certain way that allowed us to then delve a little bit deeper in that part of the conversation, then as we step back into the decision making, she was able to identify that yes, this is how I feel, these are my fears and my worries and my wishes and my hopes."

Participants noted that role play scenarios during the training workshops also enhanced their understanding of parents' perspectives, with 1 participant describing "having the [role play scenarios] ... as a family member gives you that perspective but also observing the communication between the two really helps" (P1).

### *Increased confidence in ACP discussions*

Participants felt more confident having serious illness conversations, with 1 participant (P10) noting "I had more confidence in just having those conversations whether or not I was leading them." During the training, participants were exposed to a

variety of clinical scenarios where they were able to role play the serious illness conversation, participants noted that this practice increased their confidence, noting that the role play "really helps to consolidate the knowledge and to practice" (P4).

### *Providing tools to improve communication*

Many participants felt the SICG and workshop provided communication tools which helped them structure their communication with parents more effectively. One participant (P6) described how the SICG "gave structure" and "allowed me to feel like I was staying on track." Another participant (P14) noted that the SICG was helpful as it provided a way to include "parent participation in a non-directive way, allowing for open-ended answers and interpretation of the situation that their son or daughter is currently in." Participants identified that the workshop role play was particularly important in allowing them to practice using the communication tools they had learned from the workshop.

Clinicians identified that the workshop helped them know how to initiate serious illness conversations, identifying that this had previously been a barrier in ACP communication. Participants identified challenging events in their clinical practice when the SICP had been particularly helpful, describing how specific phrases from the SICG guide helped them to respond to parents' questions or during difficult moments in the conversations.

Participants felt the training improved their active listening skills which gave families more opportunities to share their feelings. Participants also identified how listening helped them to identify non-verbal cues which suggested that parents were not ready to have a detailed ACP discussion.

### *Enhancing self-awareness and self-reflection*

Participants noted how the guide became a tool for personal reflective practice. Clinicians noted how they developed insights into their own communication practices and the limitations in their personal communication skills, which led them to develop techniques to improve their own communication. One participant (P9) described personal awareness about needing to talk less, "I definitely learned ... not to talk all the time, but to talk – which I'm very good at doing, but to talk and then listen." Participants developed personal cues, to initiate new practices such as sitting on their own hands or placing a hand subtly over their mouth to remind themselves to allow silence for parents to speak.

Additionally, participants noted that observing the role plays also provided an opportunity for self-reflection, "watching somebody else [which] gave you ideas of things that might of rub the simulated parent the wrong way or opening that went well" (P8).

### *Theme: challenges to implementing the SICG*

Participants described several challenges to implementing their learning, which occurred under several subthemes: guide accessibility, divergent communication practices within the team, and clinical environment.

#### *Guide accessibility*

The SICG was distributed to participants during workshops, but participants did not always have a copy of the SICG with them during clinical duties and this limited their use of the guide at times when they felt that they could have used it. One participant (P8) noted "if I had it in my phone as something to have a quick look at from time to time would help."

### *Divergent communication practices within the team*

Participants identified that some team members who had not completed the SICG training had divergent approaches to ACP. A participant (P3) described this challenge, noting that

“if I’m working with a physician that doesn’t use the guide or is not familiar with it or something the conversations are not going to natural flow in that direction whereas if you work with someone that has, it really allows that back and forth and that predictability which is a great facilitator.”

Participants found that this limited their ability to implement the SICG in their clinical practice, particularly when they were not the team leader.

Participants felt that clinicians who had not participated in SICG training were unfamiliar with the importance of early initiation of ACP, leading to situations where ACP was delayed, despite participants identifying that an ACP conversation would have been beneficial for the patient and family. Conversely, participants who worked with team members familiar with the SICG noticed that there was improved conversation structure and overall ACP communication within their team.

### *Clinical environment*

Finding an appropriate setting of having an ACP conversation was a barrier commonly described by participants, and participants noted that the in-patient setting was particularly challenging due to the focus on acute issues and discharging the patient home as quickly as possible. Participants also describe feeling that they did not have adequate time in their clinical workflow to have a serious illness conversation. One participant (P1) noted, “I think [discussions about ACP] gets done mostly in the outpatient clinic when you’re doing your continuity clinic. I think on the inpatient unit there are a lot of patients who are very sick and things are very busy.”

### **Discussion**

Early and timely discussions with health professionals have been identified as important for children and their parents, by ensuring that care for seriously ill children is aligned with their goals and values (DeCoursey *et al.* 2021; Lotz *et al.* 2017). This study explores a stakeholder-driven serious illness communication program (SICP) for children and their caregivers, focussing on the perceptions and experiences of pediatric clinicians participating in this program which includes tools and training to support clinicians to talk to families about their goals, values, and future wishes for their child’s health care. The study describes the processes by which the SICP leads clinicians to adapt their communication, exploring the elements which are most relevant and beneficial and the challenges to changing their clinical practice. The study describes a training and communication program which addresses key barriers to ACP communication which have been identified in previous literature.

A lack of education has been consistently identified as a barrier to communication about goals and values by clinicians, yet despite this barrier, few education programs for pediatric clinicians have been reported in the literature (Basu *et al.* 2021; Carr *et al.* 2021). In a study of possible strategies to overcome these barriers, clinicians identified formal training in communication as a potential strategy (Basu *et al.* 2021). The present study describes a novel educational intervention which provides communication training for pediatric health-care clinicians. In the same study, clinicians also identified that a shared “ACP communication framework” could

reduce barriers to communication and additional studies have identified the need for prompts and conversation starter examples (Basu *et al.* 2021; Carr *et al.* 2021). Our study describes the use of a structured communication program, the SICP, which includes a step-by-step communication guide with patient tested phrases for use during serious illness conversations. Our study identifies that the SICP was acceptable to clinicians, and participants felt that the SICG provided them with a tool to structure their communication and enhance their connections to families. The use of structured communications tools in our study helped clinicians to feel more confident in discussions, as clinicians felt that they were staying “on track” and the guide provided predictability in the conversation flow. The benefits of using guides and checklists to decrease cognitive load have been well described in other areas of medicine, and the SICP brings this innovative approach to ACP and other forms of serious illness conversations (Clay-Williams and Colligan 2015; Conley *et al.* 2011; Daubman *et al.* 2020). Further studies should further explore the impact of a structured guide on clinical practice change in communication and explore changes in patient-level outcomes.

The use of a structured guide for education is consistent with task-centered instructional design, where optimal learning occurs when learners are presented with a focused task and easy access to information to complete the task (Daubman *et al.* 2020; David Merrill 2007). In role play scenarios during the SICG workshops, participants were provided with a clearly defined clinical scenario for a serious illness conversation and a role play script which included exact phrasing matching the SICG. Participants were encouraged to closely adhere to this role play script which provided stepwise direction for how to complete the task. Our study identified that participants found the use of the structured role plays during training workshops was particularly helpful for improving their communication practices. The use of this learning process for Pediatric ACP has not previously been described and should be further explored in future studies.

The absence of systematic process for initiating discussions has been identified in previous studies as a barrier to conducting ACP discussions (Basu *et al.* 2021). This study identified that the structured conversation of the SICG provided clinicians with a tool which helped them to initiate these conversations. Participants identified the importance of SICP training for their whole team, they noted that team training facilitated the use of the SICG, by ensuring that team clinicians had a shared mental model about how and when to approach ACP communication, this finding is consistent with previous studies of ACP barriers which have identified that multi-disciplinary teamwork is important for implementing ACP. Previous studies have found that physician attitudes have a powerful impact on when and whether ACP discussions occur, with many physicians reporting that they would not initiate these conversations when the patient appears well, does not have significant symptoms, or has not exhausted all treatment options (Keating *et al.* 2010). Including physicians, who are typically key to decisions about when to initiate ACP conversations, in training programs, may address these common core beliefs and support the team to proceed with ACP conversations earlier in the illness trajectory. Our study found that after training, clinicians have a newfound awareness about the importance and benefits of early initiation of serious illness conversations; however, we identified that if lead physicians have not been included in the SICP, practice change does not occur. Further studies should explore the impact of clinician roles and team training on changes in communication practices, particularly related to ACP.

This is the first study to describe the experiences of variety of types of health-care clinicians with an SICIP for children and their caregivers, which may provide a degree of transferability of the study findings to other tertiary pediatric health-care facilities.

This study has several limitations. First, the small sample size may limit generalizability of the results, as non-participants may have different views about the SICIP and ACP communication. Second, the study uses a cross-sectional design, with clinicians participating 3 to 12 months after training, this duration does provide some insights into how the SICIP translates into personal clinical practice change, further studies are needed to explore how well these changes are sustained and lead to changes in patient care. Lastly, this study did not include patients or their caregivers, and did not collect data about their experiences. Exploring the impact of cultural background, language, and race may be important.

Future studies should explore the impacts of SICIP implementation on patient-level outcomes, including focusing on the experiences of caregivers participating in discussions with clinicians using the SICIP and the outcomes for children, including changes in use of high-intensity care in the terminal phase of a child's illness. Additional studies could explore the impacts of a longitudinal approach to communication training, in the context of an SICIP.

Clinicians participating in a structured program to enhance communication report enhanced awareness of best practices in communication and improvements in their ability to connect with families. A structured ACP communication program supports clinicians to initiate and conduct conversations about EOL issues using a structured approach. Addressing challenges but providing access to digital communication tools and ensuring that all team members participate in SICIP training together may support clinicians to conduct serious illness conversations with patients and families in pediatrics, which may lead to improved understanding among clinicians about what is most important to individual children and their families in these situations.

**Supplementary material.** The supplementary material for this article can be found at <https://doi.org/10.1017/S1478951523000500>.

**Data availability statement.** The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

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**Competing interests.** The authors declare that they have no competing interests.

**Ethical standards.** This study approved by Children's Hospital of Eastern Ontario's Research Ethics Board, approval number of 19/59X and the British Columbia Children's Hospital Research Ethics Board (Approval Number: H18-02611).

Written informed consent was obtained from all study participants. For participants contacted remotely, consent discussions occurred over videoconference with the investigators. Participants' signed consent forms were sent to the investigators electronically. Participants consented to interviews being audio recorded and transcribed and this information being published in such a manner that it would not be possible to identify any individual participants.

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