Toward an Understanding of Advance Care Planning in Children With Medical Complexity

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abstract

BACKGROUND AND OBJECTIVES: Children with medical complexity (CMC) often have multiple life-limiting conditions with no unifying diagnosis and an unclear prognosis and are at high risk for morbidity and mortality. Advance care planning (ACP) conversations need to be uniquely tailored to this population. Our primary objective for this study was to develop an in-depth understanding of the ACP experiences from the perspectives of both parents and health care providers (HCPs) of CMC.

METHODS: We conducted 25 semistructured interviews with parents of CMC and HCPs of various disciplines from a tertiary pediatric hospital. Interview guide questions were focused on ACP, including understanding of the definition, positive and negative experiences, and suggestions for improvement. Interviews were conducted until thematic saturation was reached. Interviews were audio recorded, transcribed verbatim, coded, and analyzed using content analysis.

RESULTS: Fourteen mothers and 11 HCPs participated in individual interviews. Interviews revealed 4 major themes and several associated subthemes (in parentheses): (1) holistic mind-set, (2) discussion content (beliefs and values, hopes and goals, and quality of life), (3) communication enhancers (partnerships in shared decision-making, supportive setting, early and ongoing conversations, consistent language and practice, family readiness, provider expertise in ACP discussions, and provider comfort in ACP discussions), and (4) the ACP definition.

CONCLUSIONS: Family and HCP perspectives revealed a need for family-centered ACP for CMC and their families. Our results aided the development of a family-centered framework to enhance the delivery of ACP through a holistic mind-set, thoughtful discussion content, and promoting of conversation enhancers.

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WHAT'S KNOWN ON THIS SUBJECT: Advance care planning has not been well established as a standard of practice for children with medical complexity, and there is limited research on how and when these discussions should be undertaken with this population.

WHAT THIS STUDY ADDS: In this study, we provide an advance care planning framework for families and care providers of children with medical complexity. Practitioners should consider broader domains of health alongside planning for end of life.

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ARTICLE

Medical advances have resulted in a growing cohort of children with medical complexity (CMC), many of whom would not have survived previously.[1,2] CMC have heterogenous diagnoses, high health care use, reliance on medical technology,[3-6] and substantial risk of morbidity and mortality.[5-7]

Advance care planning (ACP) has been defined as "the process of discussing life-sustaining treatments and establishing long-term care goals."[8] In pediatrics, the literature regarding ACP has primarily been focused on the intensive care setting and the oncology population.[9,10] In these populations, ACP discussions are often prompted by the anticipation of impending death, a need for clarification regarding do not resuscitate (DNR) orders, and/or when curative therapies fail and palliative care becomes the focus.[8] In CMC, because of the chronicity, fragility of illness, and uncertain trajectory, ACP discussions have been recommended early in the care pathway to ensure that quality of life is balanced with quantity and prolongation of life.[8] However, more than two-thirds of parents of children with chronic conditions have never heard of ACP.[11]

Despite parents wishing to be informed of all options, including those that involve forgoing potentially life-sustaining interventions,[12-15] many barriers to ACP conversations exist. These barriers include perceived parental readiness, unrealistic expectations, and differences between parent and clinician understanding of the prognosis.[16-18] Clinicians have reported discomfort with ACP because of fear of taking away hope, uncertainty of the prognosis, and not knowing the right time to address these issues.[11,16,17] Presently, there is a disconnect between the perceived benefits of early ACP discussions described in the literature[8] and the family and health care provider (HCP)

experience. Therefore, our study aim was to develop an in-depth understanding of the ACP experience from the perspectives of parents and HCPs of CMC.

METHODS

Study Design

We conducted a qualitative content-analysis study comprising interviews of parents of CMC and their HCPs. Data were collected between May 2016 and October 2016. Institutional research ethics approval was obtained. Parents were eligible for study inclusion if they (1) had a CMC managed in the complex care or long-term ventilation clinics, (2) could read and write English, and (3) were known to have participated in at least 1 previous ACP discussion as identified by their HCP. All CMC met at least 1 criterion from each of the following conditions: (1) technology dependent and/or users of high-intensity care, (2) fragility, (3) chronicity, and (4) complexity.[19] The purposive sampling strategy was used to ensure representation from parents of CMC of various ages by using a broad range of medical technology as well as interdisciplinary HCPs (physicians, nurses, and social workers). Written voluntary consent was provided before study enrollment.

Data Collection

Data collection included demographic surveys and individual semistructured interviews. Interview guides were developed iteratively by the research team after a review of relevant literature and consultation with content experts. After the first 2 parent and HCP interviews, transcripts were reviewed, and the guides were revised accordingly (see the Supplemental Information for final interview guides). These first interviews were included in the data analysis. Each interview began with the Canadian Paediatric Society's

definition of ACP[8] to ensure that all interviewees had a clear understanding regarding the discussion topic. Interviews lasted between 45 and 60 minutes and were conducted by a research coordinator (N.W.) at a location of the participant's choice.

Data Analysis

Interviews were recorded, transcribed verbatim, and de-identified by a professional transcriptionist. Qualitative data analysis software (NVivo 10)[20] was used for data and coding management. Content analysis was used to analyze the transcripts.[21-25] The inductive, 4-step content-analysis process[26] was conducted to identify, code, and categorize predominant themes from the text. After an immersive reading of the transcripts by 4 study investigators (J.O., R.A., N.W., and L.B.), initial patterns and recurring categories were identified. Next, similarities and differences between participant accounts were identified. Finally, codes were created by 4 study investigators (J.O., R.A., C.M., and L.B.). A codebook was created and iteratively modified. Content analysis helped to create relationships between concepts or variables that had a bearing on the expectations and experiences of ACP discussions.[27,28] Methodologic rigor was established through prolonged engagement and peer debriefing, and following the Consolidated Criteria for Reporting Qualitative studies.[29] After 25 interviews, recruitment was considered closed because thematic saturation had been achieved.[27]

RESULTS

The research team contacted 14 families; the mother was the parent who agreed to participate for all families. Eleven HCPs were contacted, and all those approached agreed to be interviewed. See Tables 1 and 2 for demographic characteristics of participants. None of the CMC were

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TABLE 1 Parent Demographic Characteristics

	n (%)
Sex	
Female	14 (100)
Relationship to child	
Mother	14 (100)
Age range, y	
26–35	2 (14)
36–40	6 (43)
41–50	3 (21)
Not specified	3 (21)
Marital status	
Married or living with partner	9 (64)
Divorced	1 (7)
Separated	1 (7)
Not specified	3 (21)
Education	
Diploma or certificate from community college or nursing school	2 (14)
Diploma or certificate from trade, technical, vocational, or business college	1 (7)
Some university experience	1 (7)
Bachelor's or undergraduate degree or teacher's college	4 (29)
Master's degree	3 (21)
Not specified	3 (21)
Household income range, $	
15 000–19 999	1 (7)
40 000–49 999	1 (7)
60 000–79 999	4 (29)
≥80 000	5 (36)
Not specified	3 (21)
Lived in Canada since birth	
Yes	8 (57)
No	3 (21)
Not specified	3 (21)
Ethnicity	
White	6 (43)
Mixed race	1 (7)
Jewish	1 (7)
Filipino	2 (14)
South Asian	1 (7)
Not specified	3 (21)
Other children with medical condition	
Yes	4 (29)
No	4 (29)
Missing data	3 (21)
Documented ACP discussion	
Yes	14 (100)

verbally or cognitively able to participate in the ACP conversations.

Framework of an ACP Discussion

Three themes were identified that provide a framework for ACP discussions: (1) holistic mind-set, (2) discussion content, and (3) communication enhancers. This framework (Fig 1) suggests that the patient and family should be the main consideration when leading ACP discussions, highlighting the importance of initially discussing topics such as quality of life, beliefs and values, and hopes and goals. One HCP clearly described this approach to ACP discussions:

> Think about the big picture and what are the goals, ensure the family understands the prognosis, and what they want for their child. Some of the secondary issues around life-sustaining and interventions come after that. But the first issue is what do the parents want, what are their expectations, what are their hopes and what are we trying to achieve.
>
> HCP 7

Holistic Mind-set

HCPs and parents expressed that the patient and family should be at the center of ACP discussions. HCPs noted the importance of taking time to recognize, understand, and support diversity and individuality between families. Parents also explained that the best ACP conversations were ones in which they felt involved, respected, and accepted (Table 3).

Discussion Content

Both HCPs and parents provided important topics they felt should be included in ACP discussions, notably (1) quality of life, (2) beliefs and values, and (3) hopes and goals (Table 4). 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. Discussing beliefs and values was explored by HCPs and supported by parents. HCPs noted that understanding a family's values and belief system is a foundational aspect of ACP discussions, allowing them to better tailor care to each individual family. Several parents reinforced the importance of discussing beliefs and values as they spoke to how their belief system and values guided their decision-making. HCPs expressed that understanding a family's hopes and goals in the context of the child's illness is an essential aspect of ACP discussions. Parents also indicated that ACP discussions that included conversation surrounding their hopes and goals for their child were beneficial to their child's life because they provided opportunities to collaboratively work toward and/or reframe hopes and goals.

Communication Enhancers

Parents and HCPs provided many insights into areas that would support the enhancement of ACP discussions.

TABLE 2 HCP Demographic Characteristics

	n (%)
Sex	
Female	5 (45)
Male	6 (55)
Age range, y	
36–40	1 (9)
41–50	6 (55)
50+	4 (36)
Discipline	
Physician	8 (73)
Nursing	2 (18)
Social work	1 (9)
Specialty	
Complex care	2 (18)
Pediatric medicine	3 (27)
Respiratory medicine	2 (18)
Pediatric haematology and oncology	1 (9)
Critical care	1 (9)
Neonatal intensive care	1 (9)
Palliative care	1 (9)
Years of medical practice range, y	
5–10	2 (18)
10+	9 (82)
Formal palliative care training	
Yes	2 (18)
No	9 (82)

Seven enhancers emerged from the data: (1) partnerships in shared decision-making (SDM), (2) a supportive setting, (3) early and ongoing conversations, (4) consistent language and practice, (5) family readiness, (6) provider expertise in ACP discussions, and (7) provider comfort in ACP discussions (Table 5).

The first enhancer, partnerships in SDM, was described by both parents and HCPs. HCPs agreed that decisions should be made in partnership with families, respecting their unique decision-making preferences. HCPs had varied perspectives regarding family-HCP partnerships for SDM. Some felt that parents are given too much responsibility in ACP discussions, whereas others felt the decision-making process should be more collaborative. There was also a large amount of variability between parents in how they preferred ACP decisions to be made. Some parents wanted to always be seen as the expert, some parents wanted the HCP to make the decisions, and others wanted the HCP to provide them with all the options and guidance regarding what they think is right but allow the parent to make the final decision.

Parents and HCPs provided many examples for how ACP discussions could be more supportive for the family, thus enhancing the ACP experience. Many of these suggestions covered topics such as ensuring a comfortable and appropriate location, budgeting enough time, providing the opportunity for all key team and family members to be present, and ensuring that the family feels supported. Participants emphasized that ACP conversations should start at the time of diagnosis, occur before a medical crisis, and be an ongoing and dynamic part of the child's care. This affords families with adequate time to make decisions they are confident in as well as enough time to understand and come to terms with the reality of their situation.

Another enhancer was for HCPs to use consistent and unambiguous language. HCPs were cognizant of this and advocated for better communication through the use of clear, nonmedicalized language. In addition, HCPs mentioned the importance of delivering a consistent message between different HCPs and health care teams. Parents cited examples of situations in which the language used by the medical team was not explained or was too vague.

Some HCPs spoke about the need to gauge family readiness for ACP discussions and to follow the family's lead, whereas others felt that families might never feel ready to engage in ACP. Parents elaborated on this topic by stating that HCPs should respect their feelings and not push for conversations if family members make it clear that they are not ready to engage. Thus, initiating ACP discussions when the family is ready can be seen as an enhancer.

HCPs expressed mixed feelings regarding provider expertise in ACP discussions. Some HCPs and parents stated that specific training and capacity building would be beneficial, whereas some HCPs noted that the best way to gain expertise is through experience. All participants agreed, however, that provider expertise can enhance ACP conversations. Closely related to expertise, HCP comfort was also noted to be of importance. Many HCPs think that provider discomfort is a prominent barrier to ACP discussions. Therefore, an additional enhancer for ACP discussions is provider comfort.

ACP Definition

Through our interviews, many caregivers noted that they had never heard of the term ACP. Understanding surrounding these conversations varied greatly from caregiver to caregiver. Some parents viewed ACP as negative and as preparing for the worst, whereas others noted that in the past, they had positive ACP experiences and that ACP meant planning for the future. HCPs also held varied perspectives regarding
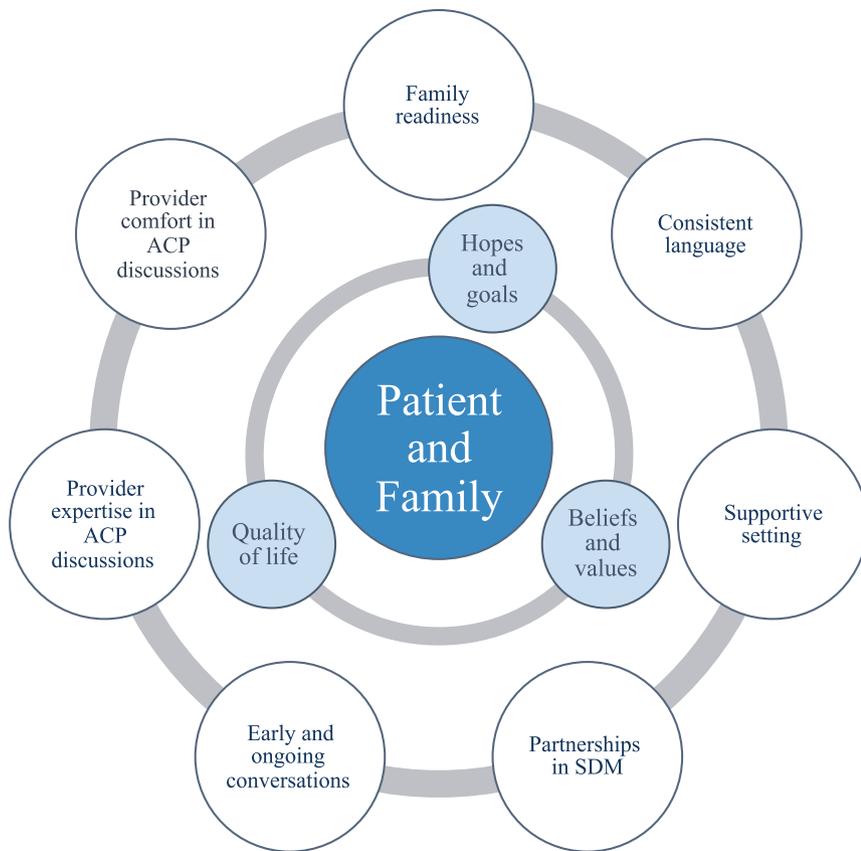
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FIGURE 1
A conceptual model of the framework for a family-centered ACP discussion.

DISCUSSION

This is the first qualitative study to explore how ACP is experienced by the definition of ACP. Some felt it was geared toward end of life specifically, whereas others had a more general definition, such as understanding the family and their goals. A comprehensive table of participant's comments regarding their familiarity with and definition of ACP can be found in Supplemental Table 7.

This is the first qualitative study to explore how ACP is experienced by parents of CMC and their HCPs. Previous research into pediatric ACP has been focused largely on children with cancer; however, CMC differ greatly from this population. In oncology, patients often experience stark changes in their quality of life after a cancer diagnosis. HCPs are usually able to provide a clear prognosis, and treatment is usually oriented to cure. ACP discussions often occur solely when no further treatment is possible.[8,30] In CMC, disease-related changes in quality of life are hard to discern, outcomes are uncertain and it is often difficult to provide a prognosis, and there is often no cure. These circumstances inevitably impact the frequency and characteristics of ACP discussions. Ultimately, this study highlighted the need for and aided in the development of a patient- and family-centered framework for ACP discussions for CMC (Fig 1).

In this study, many parents had never heard of the term ACP, and understanding surrounding these conversations varied greatly. The large amount of variability in the definition of ACP has been described in previous research in which clinicians provided differing responses when asked what ACP meant to them.[31] This lack of consensus highlights our first recommendation from this article: parents and HCPs should discuss the definition and goals of ACP before partaking in an ACP conversation (Table 6).

Family-centered care (FCC) is an established standard of pediatric care that centers on the parent and HCP partnership, respectfully honoring patient and family care preferences.[32,33] In our study, parents and HCPs emphasized the importance of the patient and family being at the center of ACP discussions and described the need for a holistic mind-set and discussion surrounding quality of life, beliefs and values, and hopes and goals. Discussing these topics will allow HCPs to gain broader understanding and respect of the patient, their family, and their care preferences, ultimately allowing for true FCC. Partnering with families by

TABLE 3 Example Quotations From Parents and HCPs Regarding a Holistic Mind-set

Parent	HCP
"I'm happy with the team because they give me what I need, and if I tell them something, they accept me, they're just not ignoring me as a mother. They're not insisting on what they want." (ACP 11)	"We need to do some more to understand who they are, how they like information and how the information should flow and who is involved with decision-making." (HCP 4)
"I think the best conversations I've had have started with 'How are things going right now?' you know, 'How do you feel your child is doing?' and, you know, 'What are your plans right now?' and, kind of, like, focus on, like, what is important to you guys right now." (ACP 2)	"We like the team to be aware that this family may have restrictions, whether it's financial, language, lack of family support et cetera. They need a well-rounded picture of the family dynamics." (HCP 10)

TABLE 4 Example Quotations From Parents and HCPs Regarding Discussion Content

Discussion Content	Parent	HCP
Quality of life	"Their automatic assumptions…this is all the things she has wrong with her, oh, her life at home is horrible, she has a painful life, she probably lays in bed all day, she does nothing. And we're like, what, that doesn't describe our daughter at all." (ACP 2) "I think when we have advanced care planning discussions, people don't focus enough on those realities of everyday life; they focus on this stigma or this stereotype." (ACP 1)	"I almost feel like we should throw out quality of life because I do think the family probably has a better sense of whether the child is happy or not and whether the pros and cons of whatever intervention makes sense for this person." (HCP 5) "The bottom line for health care providers is, 'Do we put a breathing tube in and pound on the chest or not?' It's about the things that we're not going to do, whereas the family is far more interested in hearing about the things that we will continue to do, all the ways we will continue to provide care and comfort to keep their child alive and having a good quality of life." (HCP 11)
	"They can tell us, 'We found out that your child is special needs and we are going to do everything in our way to make sure that the child is comfortable and we will try our best to do everything we can to help them.' Instead of 'Hey, your child is special needs, and they're never going to be normal like you and me and they're going to have a short life span and you need to get prepared for it and if they get sick, maybe it's time to let them go.'" (ACP 7)	"I think one has to be realistic about what the real opportunities or potential for a particular child would be. I've seen people give overly negative sort of pronouncements based on testing, without really observing the child themselves, or the family." (HCP 9)
Beliefs and values	"In our faith, I would say it's kind of like we definitely deal with the death with the grief, with the sorrow, but it's something we have to accept it because it's something has happened from God. It's something we couldn't have intervened." (ACP 10)	"They told us about their beliefs, in terms of what's right for families and when, in their culture, when God intervenes. The bottom line was they were quite comfortable." (HCP 2)
	"We were very open with our goals, and we're religious, it's like ending her life is not even an option that we would be able to make ourselves with them." (ACP 9)	"Some parents are very well developed in terms of their preferences around what they want and what they don't want and how that is aligned with the bigger picture. So some family's bigger picture might be aligned by religion, other family members, their own experiences from the same child going through things." (HCP 7)
Hopes and goals	"Our team has been amazing 'cause they understood the goals that I had for her and how badly I want to make her life normal and fun and positive." (ACP 9)	"It's about understanding what's important to the family and what their goals are, but also what things are important to them, so making memories or having experiences with their family, thinking about what things would I hate to have missed the chance to do, and then looking back and not having regrets about that." (HCP 4)
	"That conversation shaped the way we do things in our family. Trips that we think we'll put off for five years, it's more like…if my child is doing well, maybe we should look at doing that sooner than later." (ACP 2)	"I think that it's important to talk about hopes, but it's also important to talk about fears as well, to round it out. So I think all of those things go into it. I think the timing, the pace, reading the rules of the game, understanding goals and hopes, but also fears and worries." (HCP 4)

first understanding their goals and perceptions can help to frame the ACP 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. Furthermore, parents who believe that the HCP understands their child's needs are confident in the HCP's ability to partner during times of crisis.[15] Therefore, we suggest that a holistic approach to ACP is essential in building a strong, trusting partnership between HCPs and families of CMC, which will lead to improved conversations and communication.

SDM is the basis for FCC[34] and occurs when parents and HCPs work together to reach agreement surrounding a treatment plan.[34,35] Thus, SDM enables families of CMC to have decision-making opportunities that embody their care goals for their children. Parents in our study had contrasting decision-making preferences. This is consistent with Beecham et al,[36] who found that parents' approaches to decision-making are dependent on the type of decision being made, may change over time, and reflect opportunities to keep options open. Thus, when providing ACP to families of CMC, HCPs should practice SDM by attempting to understand and support parents' varied preferences for making decisions at each step in their child's care trajectory.

This requires HCPs to be flexible and adaptable when dealing with individual families and patients.[37]

Parents and HCPs believed ACP should extend beyond medical goals of care, begin early in the child's disease trajectory, and continue across the child's life span. The need for early conversations has been emphasized in the literature[38,39]; notably, initiating conversations with family members before the patient is in critical condition is helpful in maintaining hope and preparing for the patient's death.[40] Revisiting and continuing ACP discussions across the life span has proven beneficial because it allows opportunity for goals to

TABLE 5 Example Quotations From Parents and HCPs Regarding Ways to Enhance Communication in ACP Discussions

Communication Enhancers	Parent	HCP
Partnerships in SDM	"The doctor assumes they know more than you do…but they need to see you as the expert, and I mean that with a family with a special-needs child, the family is the expert." (ACP 5)	"Part of the problem is the health care providers, usually they leave the decisions completely 100% to the parents. They do not give their recommendation from the beginning, which makes it more difficult to make decisions. And as a parent, sometimes you cannot decide about advanced care for your child and you feel internally forced to do everything for your kid. Even if it's not the best for quality of life and care for the kid." (HCP 3)
	"She said we have two options, option A and option B. I heard the 2 options, and then I said, 'But I can't be the one to make this decision, please take it back to my doctor, and I want him to decide or at least tell me what he thinks we should be doing, and then we can make the final decision.' I feel like I should have the last word, but most of the time, I want them to at least weigh in and tell me what they think." (ACP 9)	"I find that in the end, it's just basically talking to the parents and making sure that they're really thinking their decisions through and they understand what the consequences are and the kid is involved as can be and you, as a group, come together with a plan for the child." (HCP 5)
Supportive setting	"My husband wasn't there at that time, so you know, you're there alone, the kid is so sick in the ICU, to have this conversation hit you like a load of bricks is the most awful feeling. So it has to be better planned, like, you want to make a suggestion, like, that, you have to have both parents with the social worker, somebody to give support, and then explain clearly what you mean. Instead of like giving these vague types of ideas that are not helpful at all, 'cause it's not like I want to make the decision then anyways, by myself." (ACP 9)	"Patient rooms belong to the hospital, they don't belong to the patient. The number of times you're in a discussion with a family and somebody just opens the door. There are rooms that can be used to have private meetings with family, and they get used a lot because they're multiple-patient rooms, but families will say, 'Oh this is the bad news room.'" (HCP 11)
	"I mean we're dealing with life and death and it's your child, it's a lot to deal with and to take in. So how do you go about addressing that with the person but also making sure you have people in place that can kind of read the individual to see if are they coping with it okay." (ACP 6)	"I do not force the discussion to be in detail because my clinic, my program, my settings, and my clinical area doesn't allow me to have an expanded discussion. It needs a separate meeting and multidisciplinary teams, including either social worker or the advanced care or the palliative care team, as well as the primary care providers for those patients." (HCP 3)
	"I think doctors are always pressed for time, so…having a conversation at the end of the hallway, to a parent, can be very challenging. It feels rushed. And the doctor is being interrupted and there's people walking by and it doesn't feel very private. And you might feel yourself getting emotional and that sort of thing. And you want to feel like, as a parent, that you have time to ask your questions." (ACP 2)	
Early and ongoing conversations	"There needs to be continuous follow-up. Because they have to remember that you're going to grieve even if the child hasn't died yet. Just knowing that that's going to happen because that's what you're preparing for." (ACP 2)	"I think that they should be spread out and it should be just part of regular conversation and we should always be reassessing it. I think that whenever you can do it out of crisis they're going to be much, much more rich and then they're going to have time for the parents and the family will have time to think about things, how they want to be treated." (HCP 4)
	"I think kids who have a condition that's likely terminal, I think, having these discussions early and having them very much laid out is an important piece. Because it's very hard for parents to make those kinds of decisions in a crisis." (ACP 3)	
Consistent language and practice	"They kind of assume that you understand everything a lot of the time, but as parents, you don't. A lot of us don't have the medical background, so you have to dumb it down a bit and you have to really explain things." (ACP 6)	"In the actual conversation, I think you have to use language that is understandable. So people often use lots of medical lingo but being very simple in terms around what we're talking about, what we're expecting and then making it concrete as to what we're trying to achieve by the conversation." (HCP 7)
	"He said, 'Oh, well, you know, with kids at your daughter's stage, this is what we would expect,' and my husband and I were like, 'What do you mean her stage? I don't under…' like, 'What?' and they're like, 'Oh, yeah, well, at this stage of the dying process,' and we're like, 'Who? What? What are you talking about? I don't understand what you're saying,' like, 'We're not trying to be difficult, but no one has talked to us about this.'" (ACP 2)	"The next issue is language. The medical profession in all of its different parameters retreats into a language that they feel comfortable with…unfortunately, that's the language that families do not understand, so you need to try to gauge how you address the issue, what kind of words you use with each family, and it's going to vary significantly. The other very important thing is to be very clear as you speak, not use words that may be ambiguous. If you're going to talk about death and dead, speak about death and dead, don't talk about passing or something else, because that means different things to different people." (HCP 6)

TABLE 5 Continued

Communication Enhancers	Parent	HCP
		"It's really helpful if everybody sort of feels the same way in terms of what advice to give to the family. I think there's nothing, well, it's extremely difficult when different providers are giving different prognostic outlooks, and different levels of hope and messages, type of thing." (HCP 9)
Family readiness	"Be respectful that if it's too much for them and they want you to step away, to, you know, have the conversation but then respect the fact that they may not be ready to have those conversations at that time." (ACP 6)	"For most families, they need time around realizing what's going on and what life is going to be like and to digest what the health care team is saying and to actually believe it. So, you first have to gauge where they are along that continuum." (HCP 7)
		"I don't think that usually the parents will be ready ever. I think these discussions should be initiated as soon as the understanding of the disease has been made. But to be wait for them to be ready for the discussion is very difficult." (HCP 3)
Provider expertise in discussion	"Perhaps there might be eventually some kind of training for some of these doctors to be able to listen and want to try some of the things that we think might be an option or a possibility." (ACP 8)	"I've seen people do an outstanding job, and I've tried to model what I do based on those people. I've also seen conversations led by people who, I think, have done a terrible job, and I've tried to not fall into the same kind of pattern. So I think it's purely based on experience." (HCP 9)
		"I think formal training may give you a foundation, but not a lot more than that. I've watched people who have had formal training come in and they try and apply a model to an advance care planning discussion and unfortunately their model's not adaptable enough for the huge variability of conditions with which we deal. And that's where experience and exposure comes in." (HCP 6)
		"I think that it's not perfectly taught; I don't know that it can be perfectly taught. I do think that it can be better mentored, though." (HCP 4)
Provider comfort in discussion		"If there is a barrier, it's people's comfort level. It's people saying, 'I'm not really comfortable initiating this discussion,' and then feeling uneasy when the family is uneasy. Because it's not a nice thing to talk about generally and you can try and be friendly about it but talking about advanced, difficult scenarios. Not necessarily death, but stuff that you're trying to plan for, that may not be nice to think about. And so that would be the major barrier, comfort." (HCP 5)
		"It's probably dwarfed by health care readiness, and are we ready to have these conversations? I think part of it has to do with if we're having these conversations, it means that we have failed in some way. That's a perception in medicine, if we're having conversations about goals, it must be because things aren't going well and that's because I haven't managed things well, which is a total farce. That's not true at all." (HCP 4)

evolve as the patient's health changes.[31]

Also related to timing was the sentiment of parental readiness. Participants in both our study and the adult ACP literature felt that ACP should not be initiated when the family does not feel ready.[41,42] This can become challenging if a family never feels prepared to participate in these conversations, and it is possible that assessing readiness is a difficult task. However, the aim of these conversations is largely to align the patient and family's goals of care with the plan of care. Therefore, reframing these discussions as such can help to facilitate these conversations. Ultimately, we recommend that HCPs begin ACP discussions as early as possible and allow them to continue across the life span; reframing them as conversations to ensure that the goals of care align with the plans of care may result in families feeling less overwhelmed.

Parents are more likely to have negative experiences with ACP when they do not have confidence in the physician's knowledge about their child's treatment wishes or in the way that potentially upsetting news is presented.[43,44] Parents in our study did not specifically relate negative experiences to lack of provider expertise; however, both parents and HCPs indicated that expertise was or would be helpful in enhancing ACP conversations. Previous literature

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TABLE 6 Recommendations for Family-Centered ACP Discussions

Recommendation	Corresponding Themes and Subthemes
Begin with an initial discussion regarding the definition of ACP. Provide a clear explanation of what ACP is and discuss parents' perceptions of ACP.	ACP definition
Approach ACP with a holistic mind-set. Ensure discussion around perception of the child's quality of life, the family's hopes and goals for their child, and the family's unique beliefs and values.	Holistic mind-set, discussion content: quality of life, hopes and goals, beliefs and values
Establish an HCP-parent-child partnership that is grounded in a holistic view of the child and his or her family and provides opportunities for SDM in which each person's unique levels of expertise and decision-making preferences are respected.	Communication enhancers: partnerships in SDM
Implement a standard ACP practice that is used to encourage consistent use of terminology, is relationship based, and is initiated early and continues throughout a child's life.	Communication enhancers: consistent language and practice, early and ongoing conversations
Advocate for organizational support that provides space, time, capacity building, mentorship, support, and recognition of the time required to provide family-centered ACP care.	Communication enhancers: provider expertise in discussion, provider comfort in discussion, family readiness

suggests that HCPs often feel unprepared for discussions surrounding end-of-life care,[45,46] and HCPs in our study spoke to the importance of provider confidence in ACP discussions. In a previous study, individualized communication training was felt to be helpful in improving physicians' confidence in end-of-life communication.[47] Therefore, capacity-building endeavors may be beneficial for HCPs who experience a lack of confidence in leading ACP discussions. HCPs must take it on themselves to advocate at the organizational level for support that provides capacity-building and mentorship opportunities that will allow them to provide family-centered ACP care.

This discussion of HCP comfort and expertise leads to the following question: Who is the best HCP to lead ACP discussions for CMC? Our results suggest that this person should be someone who has experience with ACP discussions and is comfortable with the topic of conversation but, most importantly, has a strong relationship with and thus, a comprehensive understanding of the family. Ultimately, this HCP will be different for each family, from a palliative care physician to a primary care provider.

Although our study led to several recommendations on the basis of our findings (summarized in Table 6), there are some limitations to our study. The research was conducted at a single tertiary care institution, and all parent participants were English-speaking women from predominantly well-educated, middle- to high-income families. Although in the sampling strategy, parents of children with various medical conditions and of various ethnicities and economic backgrounds were purposefully selected to reflect the diversity of families who live in Ontario, Canada, our study results may not reflect the experiences of fathers or of other socioeconomically or linguistically diverse families.

CONCLUSIONS

CMC differ greatly from other populations because of the uncertainty surrounding their incurable illnesses. Because of their children's unique medical status, parents of CMC have valuable insight regarding ACP discussions. For families of CMC, ACP is much more than advance directives and DNR orders. ACP should be a holistic and ongoing process that includes discussions surrounding hopes and goals, beliefs and values, and quality of life. Parents and HCPs of CMC in this study highlighted the need for and informed the development of a family-centered framework to approach ACP.

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ABBREVIATIONS

ACP: advance care planning
CMC: child/children with medical complexity
DNR: do not resuscitate
FCC: family-centered care
HCP: health care providers
SDM: shared decision-making

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Toward an Understanding of Advance Care Planning in Children With Medical Complexity

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