Palliative Care in the Pediatric Emergency Department: Findings From a Qualitative Study

Anne-Josée Côté, MDCM, MSc*; Antoine Payot, MD, PhD; Nathalie Gaucher, MD, PhD

*Corresponding Author. E-mail: coteannejosee@gmail.com.

Study objective: Children with medical complexity represent a fragile population and account for the majority of patients followed in pediatric palliative care. Little is known in regard to the role of the emergency department (ED) in caring for the families of children with medical complexity.

Methods: Semistructured focus groups were held with health care professionals from pediatric emergency medicine, palliative care, complex care, and intensive care to explore their perspective on pediatric palliative care in the ED. Data were transcribed and analyzed with NVivo software, and thematic analysis and theoretic sampling were performed.

Results: From January to October 2016, 58 participants were interviewed. Difficulties providing pediatric palliative care in the ED are related on the one hand to characteristics specific to the ED, such as its culture and its health care professionals' strong emotional responses when caring for children with medical complexity, and on the other hand to factors extrinsic to the ED; mainly, lack of continuity of care. For critically ill children with unknown goals of care and potential for end of life, professionals in the ED should evaluate the clinical situation, contact known health care teams, remain open to families' preferences, alleviate distressing symptoms, and create a caring environment. Communication between teams is targeted by health care professionals to facilitate and improve patient flow and care.

Conclusion: Although perspectives differ in regard to how to provide care for pediatric palliative care patients in the ED, several barriers to providing high-quality emergency pediatric palliative care can be overcome. [Ann Emerg Med. 2019;74:481-490.]

Please see page 482 for the Editor's Capsule Summary of this article.

Readers: click on the link to go directly to a survey in which you can provide **feedback** to *Annals* on this particular article.
A **podcast** for this article is available at www.annemergmed.com.

0196-0644/$-see front matter

https://doi.org/10.1016/j.annemergmed.2019.03.008

INTRODUCTION

Definitions of pediatric palliative care include children with life-threatening medical conditions and focus on caring for the patient and his or her family as a whole.[1,2] Although several models of pediatric palliative care units exist, they often consist of an interdisciplinary team including physicians, nurses, social workers, pharmacists, and volunteers, among others, working in close contact with families.[3,4] Many pediatric patients requiring pediatric palliative care are children with medical complexity, and they represent a population susceptible to visiting the emergency department (ED) recurrently.[5,6] Medical complexity is defined as children in need of special services from their ongoing multisystem illnesses, functional impairment, and dependency on technology for daily living.[7-10] They represent a vulnerable pediatric population at risk of fragmented care from suboptimal communication, care coordination, care integration, and case management.[6,11,12] These aspects of care are all related to continuity of care and have been shown to be associated with improved quality of care and health outcomes.[13] In Canada, guidelines recommend discussing goals of care for these children as early as possible to anticipate critical life decisions,[14] but this is rarely done when patients are well and stable.[15-19] Moreover, pediatric health care professionals report uneven training in pediatric palliative care and discomfort while communicating with families of children with medical complexity about palliative care.[20,21]

Since 2006, the American Board of Medical Subspecialties has recognized palliative care as a subspecialty of emergency medicine.[22] Several barriers to providing high-quality palliative care in the ED have been identified and include improper settings, lack of preexisting relationships with patients, fast-paced environments, and a culture of intense resuscitations.[1,23-27] Nurses in the ED also believe patients with anticipated death should receive uninterrupted devoted care with compassion and extra time, which the ED seemingly cannot provide.[24,28] Many

Editor's Capsule Summary

What is already known on this topic

Emergency providers may be uncomfortable caring for children receiving end-of-life pediatric palliative care, yet little has been studied about their role.

What question this study addressed

Using semistructured focus groups of health care professionals from multiple specialties, the authors examine the barriers, roles, and solutions for providing pediatric palliative care in the emergency department (ED).

What this study adds to our knowledge

Emergency physicians can help create a caring environment for the child and family in need of palliative care by eliciting and listening to their wishes, contacting their health care teams, and eliminating distressing symptoms.

How this is relevant to clinical practice

Communication, coordination of care, and compassion are critical in caring for children in need of palliative care in the ED.

health care professionals receive inadequate training in palliative care in emergency medicine curricula, which contributes to their discomfort in caring for such patients and their uncertainty about their role in this aspect of care.[29-31] Indeed, surveys from emergency medicine residency program directors have demonstrated the overall discomfort of their senior residents with managing a dying child despite recognizing it as being a major skill to acquire in palliative care.[32]

In pediatrics, little is known about pediatric palliative care in the ED. Recently, a study conducted in our center found that one third of pediatric palliative care patients visited the ED in a 5-year period, for a total of 219 visits.[33] One small qualitative study identified some challenges to pediatric palliative care in the ED, such as unknown patients and lack of time. This study also suggested that ED professionals believe that establishing early goals of care may improve quality of care for these patients by decreasing critical interventions in the ED.[21]

Pediatric palliative care in the ED for children with medical complexity is a multifaceted organizational problem and needs to be better understood to facilitate coordination and quality care during a patient's acute changes in health status. The objective of this study was to explore the challenges of providing pediatric palliative care in the ED and to describe potential roles for the ED in pediatric palliative care as perceived by the main services involved in the care of children with medical complexity. This study also aimed to propose concrete solutions to better implement pediatric palliative care in the ED.

MATERIALS AND METHODS

This research used social constructivism as the interpretative framework and was not based on a tested assumption.[34-36] A qualitative study using a strategy of triangulation was designed to include different health care professionals from acute care units and long-term care units who were involved in the problem being studied. This study does not simply report the subjective experiences of the participants but rather uses a critical approach and a reflexive attitude to generate an understanding of the reality.[37] Methods from grounded theory were used to produce reliable and valid data, including open coding and in vivo codes, theoretic sampling, and constant comparative method.

A.-J.C. is a master's student in clinical ethics and a pediatric resident from another university. N.G. is part of the pediatric emergency medicine staff at the study hospital and is a researcher with experience in qualitative research, clinical ethics, and palliative care. A.P. is the director of the clinical ethics unit at the study hospital, is also part of the palliative care team, and has experience in qualitative research. He participated in one of the focus groups; however, he did not help prepare the questions that were asked during that focus group, and to avoid influencing his answers as a participant, nor was he made aware of the data collected up to that point. He was presented with the full data as a researcher after his participation in the pediatric palliative care focus group.

Setting

The research was conducted in the CHU Sainte-Justine, a specialized pediatric tertiary care university-affiliated center in Montreal. Its pediatric ED receives approximately 85,000 visits per year. The interdisciplinary pediatric palliative care team provides consultations to all health care teams and is available during regular working hours.

Selection of Participants

This study sought to obtain perspectives from as many providers as possible and not to reach saturation. Given its single-center nature and the limited number of participants a priori, whether data saturation would be attainable was uncertain. Enrollment was limited by the number of potential participants, which was how the number of focus groups was determined. Almost all the members of the naturally occurring pediatric palliative care and complex care groups participated in the study, therefore limiting the number of focus groups to one for each. The authors' goal for the recruitment of the ED providers was to include most of the emergency physicians, which prompted the decision to perform 3 focus groups in the ED, with 5 physicians per focus group. At the study, the ED team included 16 eligible board-certified pediatric emergency physicians. Sampling was deemed acceptable when most of the emergency physicians had participated in the study; 10 emergency physicians were involved in it, representing 62.5% of the group sample.

All providers from pediatric palliative care, complex care, pediatric intensive care, and pediatric emergency medicine were invited to participate in the study in person. The authors believed almost all participants would have an interest in pediatric palliative care, given the voluntary basis of the focus groups. A.-J.C. presented the project in each of these units after an e-mail was sent to the chief of each of these divisions. The chief then served as the intermediary between their group and the researchers and a date was set to conduct each focus group with a maximum of providers. Posters were also put in the ED a few days before the focus group meetings to encourage all health care providers to participate.

This project obtained approval from the CHU Sainte-Justine Ethics Review Board in August 2015. Participants provided written informed consent to participate in this study and were asked to keep all focus group discussions confidential.

Data Collection and Processing

Six semistructured group interviews of 1 hour each were conducted with naturally occurring groups in the ED (n=3), in pediatric palliative care (n=1), in the children care service (n=1), and in the pediatric ICU (n=1). Groups were not mixed between the different units being studied because there existed previously established trusting group dynamics in each unit that likely maximized participation within each focus group and favored honest and open conversations. It was believed by the authors that mixing interdepartmental groups would have created dominant members and likely would have prevented the emergence of new themes.[38] Baseline demographic data were collected. Each focus group included on average 9 participants (ranging from 8 to 10 participants) and was intended to be a representative sample of health care professionals from each service. Interviews were guided by A.-J.C. and N.G.

The focus groups were held during 12 months and were conducted in the following order: ED, children care service, ED, pediatric palliative care, pediatric ICU, and ED. The goal was to conduct the first and last focus group with the ED to first uncover the main themes and to finally validate all the themes discussed with the previous groups. In between, the order was conducted according to availability. All participants were first asked to explain their beliefs and perceptions about pediatric palliative care to have a shared understanding of its definition. Commonly used definitions of pediatric palliative care were then reviewed with participants during the group discussion. Next, ED participants were asked about experiences with palliative care in the ED. Pediatric palliative care, children care service, and pediatric ICU professionals were asked to elaborate on experiences with pediatric palliative care in their practice and with patients who visited the ED. The interviews included questions aiming at understanding cases in which the ED staff were confronted to initiating discussion about goals of care. Further questions aimed at identifying difficulties and limitations of pediatric palliative care in the ED. Some questions were modified from one group to the other according to emerging themes. The last ED group was asked to comment on ways to approach a family of children with medical complexity in the ED and how to validate goals of care with them. They were also asked to discuss concrete areas of focus to provide satisfactory pediatric palliative care. The pediatric palliative care group was asked to describe what palliative care in the ED means for them because its definition was believed to be well acquired.

Overall, participation in the different focus groups was excellent for all participants. Indeed, because participants were also naturally occurring care teams and knew one another well, trust was already established, as well as respectful relationships. Nonetheless, to ensure all voices would be heard and to improve everybody's comfort from the outset, at the beginning of each focus group, each participant was asked to give his or her own perception of pediatric palliative care. On only 3 occasions did one of the authors (N.G) redirect the discussion when it was being dominated by 1 participant. Consensus was not a goal because the problematic was being explored for the first time. Discussions included some disagreements, and this was encouraged to enrich discussions and ensure every professional was comfortable expressing his or her thoughts. Participants remained anonymous and were identified by a code referring to their provider type and work environment to facilitate the analysis. Interviews were recorded with a microphone and the application ShurePlus MOTIV (Shure Inc, Niles, IL).

Interviews were transcribed verbatim by A.-J.C. and reviewed by N.G. Transcriptions were entered in full into

NVivo (QSR International Inc, Doncaster, Victoria, Australia). Recordings were kept in a secured locker in the CHU Sainte-Justine ED. Demographic data were entered into an Excel database (Microsoft, Richmond, WA).

Primary Data Analysis

Transcribed interviews were coded by thematic analysis after each focus group by 2 of the researchers separately (A.-J.C. and N.G.). Codes were used to generate nodes and ultimately major themes. The codification process was facilitated by using the constant comparative method to understand the relationships of the codes and their relevance in generating knowledge about how the experiences of the participants were connected to the reality.[36] The process was further validated by the comparison of each author's open coding analysis; each focus group code was reviewed and compared. Discussions between the authors helped maximize the codification process and provide a reliable understanding of the participants' meaning. In some instances, new codes and categories were identified and other codes were removed because they were judged irrelevant to the research objectives. Theoretic sampling was then conducted whereby hypotheses generated in the first focus groups were tested in the subsequent ones to validate or nuance emerging nodes and enrich the analysis.[36] After data collection was completed, a specialist in qualitative data analysis was met to review the codification process and theme generation.

Triangulation was used in this research and refers to obtaining various perspectives to examine a complex phenomenon and validate, oppose, or nuance points of view. It is a means to ensure validity and integrity of emerging data between different sources.[36] In this project, different professionals from acute care units and long-term care units were interviewed to triangulate perspectives and data, and to generate a more comprehensive overview of the research question.

RESULTS

From January to October 2016, 58 participants were included in the 6 focus groups (Table 1). The participants were asked to describe their medical practice as "never, occasionally, or mostly" working in the ED and to mention whether they had a personal interest in pediatric palliative care. Forty-eight respondents (48%) practiced "mostly in the ED," representing 28 ED health care professionals who provided their perspectives, and including 62.5% of all full-time pediatric emergency physicians. Data analysis led to 3 main themes; namely, barriers to providing pediatric palliative care in the ED, roles of the ED in pediatric palliative care, and comprehensive approach of pediatric palliative care in the ED.

Table 1. Participants' demographic characteristics (n=58).

Characteristics	No. (%)
Sex	
Men	11 (19)
Women	47 (81)
Age, y	
21–30	12 (21)
31–40	16 (28)
41–50	16 (28)
51–60	14 (24)
Ethnicity	
White	55 (95)
Other	3 (5)
Profession	
Physician	19 (33)
Nurse	18 (31)
Social worker	5 (9)
Physician fellow	4 (7)
Respiratory therapist	4 (7)
Patient attendant	2 (3)
Psychologist	2 (3)
Nutritionist	1 (2)
Physiotherapist	1 (2)
Clerk	1 (2)
Spiritual care provider	1 (2)
Practice	
Mostly in the ED	28 (48)
Interest for PPC	54 (93)
>3 formal training sessions in PPC	19 (33)

PPC, Pediatric palliative care.

Health care professionals from the ED mentioned many struggles in providing pediatric palliative care, mainly related to their own culture of care and emotions when interacting with children with medical complexity. Other health care professionals from pediatric palliative care, the pediatric ICU, and the children care service suggested that problems extrinsic to the ED contribute to the difficulty in integrating palliative care in the ED. These intrinsic and extrinsic barriers are summarized in Table 2.

Each group suggested important dimensions of pediatric palliative care that could be integrated in the ED. Major themes discussed in each focus group reflected the perceptions, experiences, and values of each team. Some of the roles proposed by long-term care

Table 2. Barriers to the provision of PPC in the ED.

Characteristics	Barriers	Participants' Verbatim Response
Specific to the ED	ED reality (multitasking, sporadic health care professionals)	"You can't provide proper support to a family in palliative care that really requires your presence because you have other patients, you are busy, [and] you are always being interrupted." (ED professional)
	Health care professionals' emotions (powerlessness, fear of hurting families)	"It's because we do nothing in terms of treatments. I will give his morphine, his scopolamine, clear his secretions; but I can't do anything else." (ED professional)
	Ambiguous/unstable situations	"And then he presents to the ED and he seizes. And this happens in the resuscitation room. And you are constantly asking yourself, "What if he crashes," constantly wondering about his level of care." (ED professional)
	Inadequate physical environment	"There is no confidentiality. There is a glass window separating us. It forces us to speak louder. The parent has to speak louder. There are lots of other parents sitting there, lots of people screaming." (ED professional)
	Rare cases/lack of expertise	"I think the malaise comes from the fact that we don't know these patients. They precisely don't come often; it is their last resort. So we are not used to treating these patients." (ED professional)
Extrinsic to the ED	Lack of continuity of care	"I get the impression that when palliative care is involved in the case, everything is organized except when they come to the ED. Everything is set; we do this and this…. But then in the ED, nothing is set and we start from scratch." (ED professional)
	Families' reactions	"Palliative care suffers from its label. As soon as you pronounce the term, parents think you are abandoning their child." (pediatric ICU professional)
	PPC stigmatization	"When a palliative patient is transferred from one medical team to another, the first thing we say is that he is in palliative care. This colors the situation…. I think there is still a lot of work to do for both families and medical teams on what palliative care is." (children care service professional)
	Hospital organization	"It is certain that without learning, without seeing death, without continuing to see death,… if patients all go up to the wards, the emergency physicians don't see it anymore and then it becomes harder." (PPC professional)

teams included elements of a reflective practice with increasing sensibility toward palliative care and adopting a nonjudgmental attitude toward families' preferences. Other elements suggested by all groups were mostly related to continuity with primary care teams, relationships with patients, and clinical duties. Figure 1 presents a summary of each discipline's main perspectives on the potential roles of the ED in pediatric palliative care.

Improving communication between teams was targeted as an important theme throughout all focus groups to better organize pediatric palliative care in the ED, whether it serves to support the ED in managing a known patient or to ensure continuity of care management by transmitting information about families' preferences. Particularly, many participants were interested in the idea that parents could be prepared beforehand in case they needed to consult the ED. Following this line of thought, pediatric palliative care, pediatric ICU, and ED groups insisted on the importance of strengthening primary care and community physicians' ability to discuss goals of care early in the illness trajectory. However, children care service and pediatric palliative care groups highlighted that there exists a paradox in regard to discussions about goals of care: it is difficult to find a right moment to initiate critical discussions with families because they progress along different paths at different speeds throughout the illness of their child. Children care service and pediatric palliative care groups therefore suggested that health care professionals in acute care settings develop an awareness and empathy toward the reality of families caring for children with medical complexity. Some experts from the pediatric palliative care group suggested ideas and cues for health care professionals to open up discussions with families during acute deteriorations. The vocabulary used in these cases needs to be delicate, precise, and open (Figure 2, yellow box).

All groups suggested an understanding of the key dimensions required in the ED to provide palliative care. Figure 2 offers a comprehensive approach integrating these different points of view on the role of pediatric palliative care in the ED setting (see above). This

ED	Pediatric ICU
• Anticipation of arrival "When we are forewarned, I really have the impression that everything is better prepared. We anticipate the situation, we put him in the right room." (ED professional) • Rapid clinical evaluation • Caring approach "Our role is really to listen when [parents] have something to tell us, not necessarily to validate them but to listen to parents and children and provide reassurance." (ED professional) • Disposition planning "Our role will be…to bring them up to the wards as fast as possible. There are rooms adapted for this [in the hospital]. We don't have to leave them in resuscitation rooms." (ED professional)	• Redirecting goals of care "I think that many people have to repeat the message and it can help when it has been done in the past, when an idea has been shown in the ED, so that after, management continues in the same direction." (pediatric ICU professional) • Ownership and devotion to palliative care patients "This patient requires as much attention from an [emergency] physician as the patient you are currently resuscitating." (pediatric ICU professional)
Children Care Service	**PPC**
• Continuity of care management "I am not sure discussions [about goals of care] lead to anything, except maybe disrupting the relationship with the emergency physician from the start.… Maybe contact a treating physician when possible to verify if they've already had discussions…?" (children care service professional) • Nonjudgmental attitude "In acute care, all you see is a child who is very handicapped on paper, with a poor prognosis, and you would probably judge that this child has no quality of life. But there is a quality of life for the parents that is nonnegligible." (children care service professional) • Individualized care • Decision support "[The mother] was really anxious; she was scared he would die that night. She wanted the doctor's reassurance. She didn't want to change her mind: she had put him in palliative care. But it did not stop her from being very anxious." (children care service professional)	• Sensibility and responsibility toward PPC "It is a slightly different approach which is not necessarily focused on survival but on accompanying. And to be able to experience death in the ED." (PPC professional) • Identification of patient known to PPC "Parents don't have the reflex to mention it, so we should ask them, 'Is there someone meaningful we should call to help you get through this?'" (PPC professional) • Alleviation of symptoms • Transparency to families "It is about having someone who is open and who says "Have you ever discussed this before?" And then someone else says, 'I am worried; it might be the end at this time.' This is what parents want." (PPC professional)

Figure 1. Individual groups' suggested roles for the ED in pediatric palliative care.

approach implies an active participation of the physicians, nurses, respiratory therapists, social workers, and patient attendants in the ED caring for children with medical complexity who visit the ED. Roles varied slightly, depending on 2 complex clinical situations well identified by the ED focus groups: the critical deterioration of a patient with medical complexity, and a child with medical complexity who is not imminently unstable. This approach seeks to offer support for health care professionals in the ED and improve care for families. For all patients who require a palliative care approach in the ED, professionals should seek to offer quality time to families. For instance, time without interruption was reported by acute health care professionals as being meaningful and appreciated during difficult interactions with families: just a few minutes without being disrupted was reported as being an important starting point to provide high-quality care to families.

LIMITATIONS

This study has some limitations. First, it did not address parents' experiences with pediatric palliative care in the ED. However, this has been a known and acceptable limitation from the beginning of this study because the goal was to explore professionals' perspectives before engaging with parents. Because little was known about the topic from previous studies, it was believed to be ethically responsible to first explore professionals' opinions and better situate the

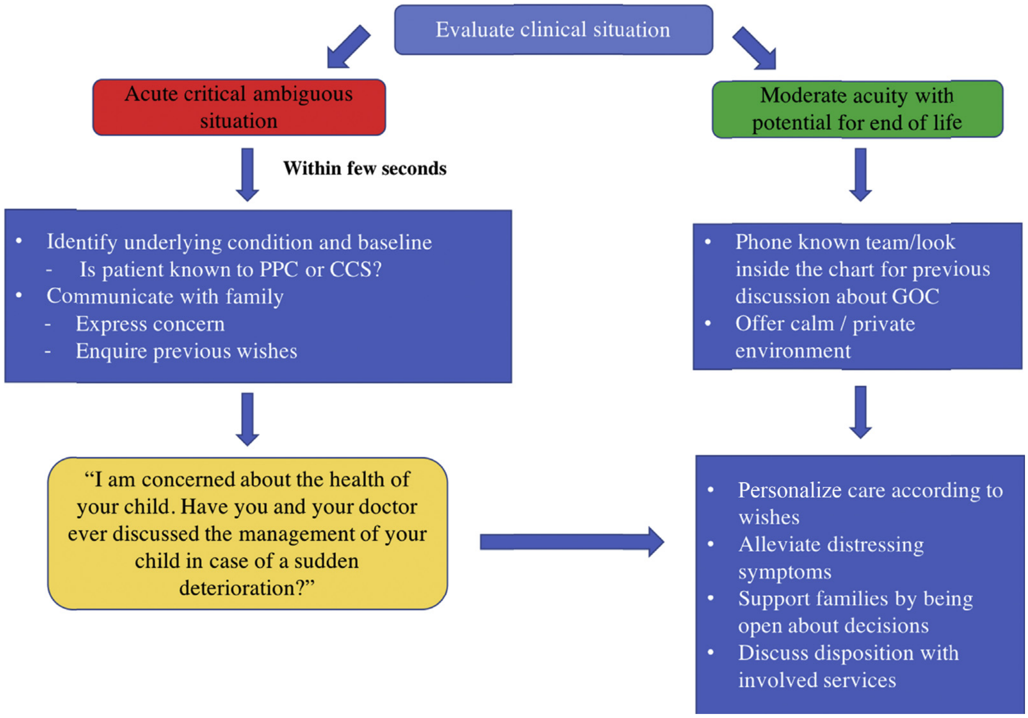

Figure 2. Approach to pediatric palliative care in the ED. *GOC*, Goals of care.

problem before interviewing patients in pediatric palliative care, parents of children in pediatric palliative care, or bereaved parents. Further studies should aim to explore the experiences of families of children with medical complexity during their ED visits and their beliefs about the role of the ED in pediatric palliative care to assess the quality of such a comprehensive approach to palliative care.

Second, this study was performed in 1 tertiary care center and its findings are not generalizable to all settings for 2 important reasons. First, given that the participants in our focus groups all worked in ultraspecialized pediatric teams, our findings cannot be generalized to less specialized institutions. It is expected that variation in management exists between community hospitals and specialized centers, and we recognized the difficulty of integrating all aspects of the suggested approach to pediatric palliative care in a general ED, given the small number of cases encountered. However, Level II centers and community primary care providers are involved in the continuity of care of children with medical complexity and benefit from understanding the pathways of their patients in a specialized tertiary care center. Second, pediatric palliative care is a highly value-laden clinical field and practice: institutional culture, as well as local and professional culture, likely modulates our findings.

Third, the majority of the participants in our study mentioned having an interest in pediatric palliative care, and although this may have induced a form of bias in our results, given the qualitative nature of the study, it was helpful that most participants had some basic knowledge about the research question because this led to high-quality discussions, reflections, and team brainstorming.

DISCUSSION

This was a qualitative study with interprofessional focus groups, reporting the experiences and beliefs of health care professionals involved in the care of children with medical complexity regarding their ED care. To our knowledge, this was the first study to explore the organization of pediatric palliative care in the ED by using a triangulation strategy and to develop an understanding of this complex problem by combining multiple points of view.

In this study, many barriers to providing pediatric palliative care were described; these contribute to professionals' malaise when caring for children with medical complexity. Similar difficulties have been described in previous adult studies of ED palliative care, including inappropriate settings, differences in culture, lack of continuity of care, pressure to be efficient, and lack of expertise.[23,24,26-28,30,31,38,39] Most of the barriers identified in the study have therefore already been described in adult studies, and many lessons can likely be learned from this literature. However, in pediatrics, the complexity of surrogate decisionmaking for children remains specific and particular to pediatric palliative care. In our study, by interviewing teams of professionals involved in palliative care all along the continuum of palliative patient care, we identified several new barriers both intrinsic and extrinsic to the ED environment. Such a research strategy allowed a more comprehensive understanding of the sources of professionals' discomfort and allowed targeting of areas of improvement consistent with the realities of the involved practitioners.

Discussions about goals of care were an important theme for all participants in this study. Overall, from a health care professional's perspective, there seems to never exist a "good moment" in a pediatric patient's life to discuss goals of care. However, participants also believed that goals of care are likely not addressed enough throughout the continuum of care (ie, before, during, and after acute deteriorations). Addressing this topic in the ED therefore remains inevitable and is needed to validate previous wishes when there is an imminent concern about end of life, especially because it is well recognized that an acute event can precipitate a change in the families' preferences.[40] Moreover, earlier studies have demonstrated families' desires to be involved in discussions about the care of their children and to be told of specific medical information.[41-43] Parents also appreciate being involved in the care of their child during the dying process because it helps them with bereavement.[19,44] In our study, experts in palliative care suggested prompts for ED professionals to open the door to these conversations and involve meaningful teams to facilitate collaboration and continuity in care management.

Our study also showed that professionals from various backgrounds involved in the care of children with medical complexity emphasized different dimensions required for a good practice of pediatric palliative care in the ED. Some participants were single providers from their profession and brought a new element to the discussion, given their unique contact and proximity with families. For instance, the nutritionist and physiotherapist were able to engage with families by asking about their home schedules and watching parents perform care tasks. Overall, these dimensions should be integrated when one considers the role of the ED in pediatric palliative care to reflect the heterogeneity of families' experiences with illness and provide the best possible holistic care for families.

Finally, most ED groups in our study expressed the necessity of preparing children with medical complexity and their families for an ED visit and strengthening the relationship between primary care providers and the ED. A recent article by Hoffman and Larson[45] offered different tools to primary care providers to better prepare families for a successful encounter when ED visits are unavoidable. Tools presented in the article include providing telephone triage with on-call service and preparing an emergency care plan with a contact person to assist in decisionmaking. Emergency information forms have been shown in simulations to decrease the time of case completion and reduce the amount of complications.[46] These findings support the suggested roles of the ED in our study, which include rapidly identifying the children known to children care service or pediatric palliative care and contacting the right person to better support the family in their decision process. Such a partnership between a specialized tertiary care center and community providers calls for a will to share responsibility in providing pediatric palliative care and creating a successful ED visit for children with medical complexity. Because acute episodes in the health of children with medical complexity will continue to happen, health care professionals from different specialties should develop a reflective practice to become aware of their own role in pediatric palliative care, with families and with other services involved. This reflection should further include a sensibility toward the main difficulties of providing pediatric palliative care in the ED and the acknowledgment of the complementary roles of other professionals. This would likely reduce malaise and moral distress for all professionals involved by improving their satisfaction with the provision of high-quality pediatric palliative care.[1]

The main strength of this study lies in its interprofessional data collection to provide a comprehensive overview of the problem of pediatric palliative care in the ED and offer potential systemwide solutions. Addressing the role of the ED within the continuum of care that is palliative care can suggest many novel solutions to previous problems. Many of our findings suggest a need for a transversal approach to pediatric palliative care in which all professionals commit to supporting families through their journey and engage with primary care physicians to respect families' previous wishes. This is desired for consistent, competent, and compassionate palliative care within teams and it is an important and generalizable message.

To conclude, clinical judgment is always required from health care professionals in the ED when approaching a child with medical complexity who might be eligible for palliative care. In acute critical situations, ED professionals have an individual role of assessing a family's preferences and offering them compassion. Most important, this research emphasizes the need for an organizational approach in the hospital to be better prepared internally at anticipating the management of children with medical complexity who present with acute deterioration. This process is eased by continuity of care management with primary care teams, who follow families and their child throughout the illness trajectory and can be very supportive in their decisionmaking process in critical moments. To better inform practice, future research should aim to understand the experiences of patients and families of children with medical complexity before, during, and after their ED visits.

Supervising editor: Kathy N. Shaw, MD, MSCE. Specific detailed information about possible conflict of interest for individual editors is available at https://www.annemergmed.com/editors.

Author affiliations: From the Department of Pediatrics, Montreal Children's Hospital, Montreal, Quebec, Canada (Côté); the Service of Neonatology (Payot) and Department of Emergency Medicine (Gaucher), Department of Pediatrics, CHU Sainte-Justine, University of Montreal, Montreal, Quebec, Canada; and the Clinical Ethics Unit and Palliative Care Unit, CHU Sainte-Justine, and the CHU Sainte-Justine Research Center, Montreal, Quebec, Canada (Payot).

Author contributions: All authors conceived the study, designed the research protocol, applied for funding, and participated in data analysis. A-JC and NG were responsible for participant recruitment and data collection and contributed to dissemination of knowledge in different meetings. AP supervised participant recruitment. A-JC drafted the article and all authors contributed substantially to its revision. A-JC takes responsibility for the paper as a whole.

All authors attest to meeting the four ICMJE.org authorship criteria: (1) Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND (2) Drafting the work or revising it critically for important intellectual content; AND (3) Final approval of the version to be published; AND (4) Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Funding and support: By *Annals* policy, all authors are required to disclose any and all commercial, financial, and other relationships in any way related to the subject of this article as per ICMJE conflict of interest guidelines (see www.icmje.org). The authors have stated that no such relationships exist. This work was supported by a grant from the Hubert Doucet Scholarship.

Publication dates: Received for publication October 15, 2018. Revision received January 12, 2019. Accepted for publication March 6, 2019.

Presented at the CAEP Conference, June 2017, Whistler; the Canadian Pediatric Society annual conference, June 2017, Vancouver, Canada; the Pediatric Academic Societies meeting, May 2017, San Francisco, CA; the 8th Annual Canadian Bioethics Society Conference, May 2017, Montreal, Canada; the 7th Annual Joint Pediatrics Resident and Fellow Research Day, March 2017; the 21st International Congress on Palliative Care, October 2017; and the 7th International Congress in Pediatric Palliative Care, September 2017.

REFERENCES

1. Chan GK. End-of-life models and emergency department care. *Acad Emerg Med*. 2004;11:79-86.
2. Wolfe SLDPJ. Paediatric palliative care: challenges and emerging ideas. *Lancet*. 2008;371:852-864.
3. Mierendorf SM, Gidvani V. Palliative care in the emergency department. *Perm J*. 2014;18:77-85.
4. Canadian Hospital Palliative Care Association. *Pediatric Hospice Palliative Care: Guiding Principles and Norms of Practice*. Ottawa, Canada: CHPCA Standards Committee; 2006.
5. Liberman DB, Song E, Radbill LM, et al. Early introduction of palliative care and advanced care planning for children with complex chronic medical conditions: a pilot study. *Child Care Health Dev*. 2016;42:439-449.
6. Schwantes S, O'Brien HW. Pediatric palliative care for children with complex chronic medical conditions. *Pediatr Clin North Am*. 2014;61:797-821.
7. Cohen E, Kuo DZ, Agrawal R, et al. Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics*. 2011;127:529-538.
8. Msall ME, Tremont MR. Measuring functional outcomes after prematurity: developmental impact of very low birth weight and extremely low birth weight status on childhood disability. *Ment Retard Dev Disabil Res Rev*. 2002;8:258-272.
9. Tennant PW, Pearce MS, Bythell M, et al. 20-Year survival of children born with congenital anomalies: a population-based study. *Lancet*. 2010;375:649-656.
10. Wong LY, Paulozzi LJ. Survival of infants with spina bifida: a population study, 1979-94. *Paediatr Perinat Epidemiol*. 2001;15:374-378.
11. Bogetz JF, Schroeder AR, Bergman DA, et al. Palliative care is critical to the changing face of child mortality and morbidity in the United States. *Clin Pediatr (Phila)*. 2014;53:1030-1031.
12. Le Conte P, Riochet D, Batard E, et al. Death in emergency departments: a multicenter cross-sectional survey with analysis of withholding and withdrawing life support. *Intensive Care Med*. 2010;36:765-772.
13. Stange KC, Ferrer RL. The paradox of primary care. *Ann Fam Med*. 2009;7:293-299.
14. Tsai E. Advance care planning for pediatrics patients. *Pediatr Child Health*. 2008;13:791-796.
15. Heckford E, Beringer AJ. Advance care planning: challenges and approaches for pediatricians. *J Palliat Med*. 2014;17:1049-1053.
16. Keele L, Keenan HT, Sheetz J, et al. Differences in characteristics of dying children who receive and do not receive palliative care. *Pediatrics*. 2013;132:72-78.
17. Noyes J, Hastings RP, Lewis M, et al. Planning ahead with children with life-limiting conditions and their families: development, implementation and evaluation of "My Choices.". *BMC Palliat Care*. 2013;12:5.
18. Levetown M, Pollack MM, Cuerdon TT, et al. Limitations and withdrawals of medical intervention in pediatric critical care. *JAMA*. 1994;272:1271-1275.

19. Liberman DB, Pham PK, Nager AL. Pediatric advance directives: parents' knowledge, experience, and preferences. *Pediatrics*. 2014;134:e436-e443.
20. Liben S, Papadatou D, Wolfe J. Paediatric palliative care: challenges and emerging ideas. *Lancet*. 2008;371:852-864.
21. Lotz JD, Jox RJ, Borasio GD, et al. Pediatric advance care planning from the perspective of health care professionals: a qualitative interview study. *Palliat Med*. 2015;29:212-222.
22. American Board of Medical Subspecialties Research and Education Foundation. *2002 Annual Report and Reference Handbook*. Evanston, IL: American Board of Subspecialties; 2002.
23. Decker K, Lee S, Morphet J. The experiences of emergency nurses in providing end-of-life care to patients in the emergency department. *Australas Emerg Nurs J*. 2015;18:68-74.
24. Gloss K. End of life care in emergency departments: a review of the literature. *Emerg Nurse*. 2017;25:29-38.
25. Granero-Molina J, Diaz-Cortes M del M, Hernandez-Padilla JM, et al. Loss of dignity in end-of-life care in the emergency department: a phenomenological study with health professionals. *J Emerg Nurs*. 2016;42:233-239.
26. Hogan KA, Fothergill-Bourbonnais F, Brajtman S, et al. When someone dies in the emergency department: perspectives of emergency nurses. *J Emerg Nurs*. 2016;42:207-212.
27. Smith AK, Fisher J, Schonberg MA, et al. Am I doing the right thing? provider perspectives on improving palliative care in the emergency department. *Ann Emerg Med*. 2009;54:86-93.e1.
28. Russ A, Mountain D, Rogers IR, et al. Staff perceptions of palliative care in a public Australian, metropolitan emergency department. *Emerg Med Australas*. 2015;27:287-294.
29. Bailey CJ, Murphy R, Porock D. Dying cases in emergency places: caring for the dying in emergency departments. *Soc Sci Med*. 2011;73:1371-1377.
30. Meo N, Hwang U, Morrison RS. Resident perceptions of palliative care training in the emergency department. *J Palliat Med*. 2011;14:548-555.
31. Shearer FM, Rogers IR, Monterosso L, et al. Understanding emergency department staff needs and perceptions in the provision of palliative care. *Emerg Med Australas*. 2014;26:249-255.
32. Kraus CK, Greenberg MR, Ray DE, et al. Palliative care education in emergency medicine residency training: a survey of program directors, associate program directors, and assistant program directors. *J Pain Symptom Manage*. 2016;51:898-906.
33. Gaucher N, Humbert N, Gauvin F. What do we know about pediatric palliative care patients consulting to the pediatric emergency department? *Pediatr Emerg Care*. 2018.
34. Creswell JW. *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. 3rd ed. Los Angeles, CA: SAGE; 2013.
35. Green J, Thorogood N. *Qualitative Methods for Health Research*. 3rd ed. Los Angeles, CA: SAGE; 2014.
36. Schwandt T. *The SAGE Dictionary of Qualitative Inquiry*. 4th ed. Los Angeles, CA: SAGE; 2015.
37. Green J, Thorogood N. *Qualitative Methods for Health Research*. 3rd ed. Los Angeles, CA: SAGE; 2014:xvii.
38. Grudzen CR, Richardson LD, Hopper SS, et al. Does palliative care have a future in the emergency department? discussions with attending emergency physicians. *J Pain Symptom Manage*. 2012;43:1-9.
39. Grudzen CR, Richardson LD, Major-Monfried H, et al. Hospital administrators' views on barriers and opportunities to delivering palliative care in the emergency department. *Ann Emerg Med*. 2013;61:654-660.
40. Feudtner C. Collaborative communication in pediatric palliative care: a foundation for problem-solving and decision-making. *Pediatr Clin North Am*. 2007;54(ix):583-607.
41. Lyon ME, Jacobs S, Briggs L, et al. Family-centered advance care planning for teens with cancer. *JAMA Pediatr*. 2013;167:460-467.
42. Wiener L, Zadeh S, Battles H, et al. Allowing adolescents and young adults to plan their end-of-life care. *Pediatrics*. 2012;130:897-905.
43. Xafis V, Wilkinson D, Sullivan J. What information do parents need when facing end-of-life decisions for their child? a meta-synthesis of parental feedback. *BMC Palliat Care*. 2015;14:19.
44. de Vos MA, Bos AP, Plotz FB, et al. Talking with parents about end-of-life decisions for their children. *Pediatrics*. 2015;135:e465-e476.
45. Hoffman A, Larson IA. Primary care preparation for children with medical complexity for emergency encounters in the community. *Pediatr Ann*. 2018;47:e102-e105.
46. Abraham G, Fehr J, Ahmad F, et al. Emergency information forms for children with medical complexity: a simulation study. *Pediatrics*. 2016;138.