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Acute and long-term healthcare professionals' perspectives on the role of the Emergency Department in Pediatric Palliative Care

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Résumé

Perspectives des professionnels de la santé d’équipes de soins aigues et de longue durée sur le rôle de l’urgence dans les soins palliatifs pédiatriques

Le rôle de l’urgence pédiatrique dans les soins palliatifs pédiatriques (SPP) est très peu connu. Cette recherche vise à explorer les perceptions de professionnels d’équipes de soins aigues et de longues durées quant aux soins palliatifs à offrir aux enfants atteints de maladies complexes se présentant en détérioration aigüe.

Des groups de discussions ont eu lieu avec des professionnels de la santé pédiatriques de l’urgence, des soins palliatifs, des soins complexes et des soins intensifs. Le logiciel NVivo© a servi à l’analyse thématique des données.

Au total, 58 professionnels de la santé ont été recrutés. Les soins palliatifs pédiatriques sont bien compris par les participants de différentes spécialités. Chaque groupe a démontré une culture différente, influençant son rôle dans les SPP et sa perception du rôle de chaque autre groupe. Les rôles de l’urgence dans les soins palliatifs pédiatriques proposés incluent évaluer la situation clinique, contacter l’équipe connue, assurer un environnement de bienveillance et soulager les souffrances. Des désaccords ont été soulevés par rapport aux circonstances entourant les discussions sur les objectifs de soins. Offrir des soins personnalisés, communiquer avec la famille et favoriser la continuité de soins sont des éléments clefs identifiés pour améliorer la qualité des soins et la satisfaction des professionnels.

Les perceptions sur les soins à offrir aux patients nécessitant des SPP à l’urgence sont hétérogènes malgré une vision homogène de la notion de SPP. Les solutions pour améliorer la qualité de soins visent à créer une collaboration interprofessionnelle basée sur l’approche mutuel d’apprentissage.

Mots-clés : Soins palliatifs pédiatriques ; médecine d’urgence pédiatrique ; éthique clinique ; continuité de soins ; soins critiques ; soins complexes

Abstract

Acute and long-term healthcare professionals' perspectives on the role of the Emergency Department in Pediatric Palliative Care

Little is known regarding the role of the pediatric Emergency Department (ED) in Pediatric Palliative Care (PPC). This research aims to explore acute and long-term care professionals' perspectives about PPC for children with medical complexity presenting with acute deterioration.

Semi-structured focus groups were held with professionals from pediatric emergency medicine, palliative care, complex care and intensive care. Data was analysed using NVivo© software and performing thematic analysis and theoretical sampling.

58 participants were interviewed. PPC is well recognized by healthcare professionals from different specialties. Each group demonstrated different culture that influence their role in palliative care and their perceptions on other groups' roles. Suggested roles for the ED in PPC include evaluating the clinical situation, contacting known teams, developing a caring environment and alleviating distressing symptoms. Disagreements regarding when and how to discuss goals of care were expressed. Personalized care, communication with families and continuity of care were key elements to improve quality of care and professionals' satisfaction.

Perspectives in caring for PPC patients in the ED are heterogeneous despite homogenous theoretical vision of PPC. Solutions to improve quality of PPC in the ED aim at creating an interprofessional collaboration to care using the mutual learning approach.

Keywords: Pediatric Palliative Care; Pediatric Emergency Medicine; Clinical ethics; continuity of care; Critical care; Complex care

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List of Acronyms

AAP: American Academy of Pediatrics
pACP: Pediatric Advanced Care Planning
CCS: Complex Care Service
CPS: Canadian Pediatric Society
CSHCN: Children with Special Healthcare Needs
ED: Emergency Department
EPEC-EM: Education in Palliative and End-of-life Care in Emergency Medicine
GOC: Goals of Care
PICU: Pediatric Intensive Care Unit
PPC: Pediatric Palliative Care
PT: Physiotherapist
RT: Respiratory therapist
SW: Social Worker

I wish to dedicate my Master to my father, Pierre Côté, who passed away from brain cancer in 2014. He has always showed me how every personal and professional initiatives in life is a matter of timing. He believed everything has a reason to happen at a certain point in time while meeting the right person and he had always trusted the path his life would go. He had been fighting for life against Type 1 diabetes and showed the medical world how he could beat all records by having a wonderful world philosophy, a powerful mind and a diligent physical health. Despite the very difficult and sudden diagnosis of brain cancer, he continued to care for his family, to make us laugh and love each other, to show us to embrace our surrounding world and its wonders and to teach us to live out our deepest dreams.

During his year of surgery, chemotherapy and radiotherapy, I decided to support my father along these steps and take rotations off Medical School, delaying my graduation. Further in the year, a family decision had been made to provide home palliative care and dedicate ourselves in offering him the best possible end-of-life. During my father's last month of life, I was struggling to complete an elective in Pediatric Emergency Medicine at CHU Sainte-Justine, as my father was strongly encouraging me to not give up on my rotation despite his critical condition. Being submerged by all those events and facing uncertainty about his prognosis, Dr. Gaucher showed me great support and addressed the idea of starting a Master's in clinical ethics the following year, as I wouldn't be entering a Residency program. This was not a priority for me at the moment, but the idea grew as the month progressed. After the passage of my father, I took time off to reflect on my future career choices and decided to embrace this project with only one topic in mind: palliative care in the Emergency Department.

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Major actors in this research were the healthcare professionals from different services in the hospital. It has been a pleasure to meet all them and to witness their openness in sharing emotions, thoughts and experiences. I want to thank everyone who devoted their personal time and volunteered in participating as the research would not have existed without their generous insights in the problematic. They are responsible for the scope of this project and for giving the study all its significance.

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Chapter 1: Introduction

Definitions of Pediatric Palliative Care (PPC) seek to include all patients with a chronic life-threatening illness, in order to improve focus on caring for the patient as a whole, to integrate the patient's medical care and to address the physical, psychological, social and spiritual components of every patient (1, 2). It has been shown that the majority of children requiring PPC follow up are Children with Medical Complexity (CMC) and that this population represents about one third of pediatric deaths annually in the USA (3, 4). In Canada, data does not yet exist but the Canadian Pediatric Society (CPS) encourages all provinces to have a child death review committee to better understand the causes and circumstances of death in the pediatric population (5). Nonetheless, guidelines in Canada recommend discussing advanced care planning for children with medical complexity, consisting of long-term and short-term goals of care with a focus on active measures that will be provided to the child. A detailed plan includes both active curative treatment and palliative care with an objective of improving communication between families and healthcare teams (6). Although the CPS recommends initiating discussions with patients and their families as early as possible to open reflection, this is rarely done when patients are well, stable and followed on an outpatient basis. In fact, discussions often occur in pediatric and neonatal intensive care units where critical decisions about life or death have to be made rapidly (7-12). Conversations about care planning and palliative care earlier in diagnosis are nonetheless desired by parents and families (13, 14), even though pediatric specialists acknowledge feeling uncomfortable having these discussions (14, 15). Also, it has been shown that even when premature death is expected, for instance in pediatric oncology, only half of the primary healthcare teams will initiate discussions about advance care planning as they assume families desire to exclusively pursue active treatment. This is even more rarely discussed when patients have multiple chronic illnesses with unknown prognoses, as teams are unsure how to address this prognosis and a potentially shortened life expectancy (6). Multiple studies have however shown that adequate palliative care early in the care of these children benefits patients and their families, particularly in anticipating critical life decisions (8, 9, 12, 16, 17).

CMC represent the most fragile pediatric population with the highest mortality and morbidity (18, 19). Furthermore, they represent a population highly susceptible of recurrent admissions and visits to the Emergency Department (ED) for distressing symptoms (3, 4). At a time when patients cannot contact their primary care physician, the ED is the door to the hospital and the first contact within the health care system (20, 21). The ED is also an important place where decisions regarding goals of care are taken because of an acute change in baseline medical conditions (22). However, ED physicians often lack continuity of care with these patients and find challenging to have discussions with patients who are unknown to them (20). Although it is very uncommon for children to die in the ED, they can present for any concern at any time in their disease's trajectory (19). Moreover, healthcare professionals from different backgrounds may understand PPC and patient goals of care differently, which adds to the complexity of PPC in the ED (23, 24). In fact, each profession is known to have its own values, defined as stable convictions and beliefs on what is desirable (25), experiences, practices, training and roles in the care of children and their families. These create unique groups of professionals who share a common and very specific culture (24). Exploring the understanding, experiences and roles of the healthcare professionals involved in the care of CMC about PPC is a first important step in improving continuity of care. Further, understanding the role of the pediatric ED in PPC from the perspectives of different healthcare professionals is crucial in order to improve communication between healthcare teams and patients and their families.

Most recent studies have focused on understanding the role of the ED in the end-of-life care of adult and geriatric populations, but very little is known regarding the provision of PPC in the pediatric ED. The research problematic therefore seeks to explore the role of the ED in providing palliative care for CMC. Given that these children often navigate in and out of acute and long-terms services as their clinical state evolves, our study aims to gather the experiences, perspectives and challenges in the provision of palliative care from diverse professionals in one healthcare setting. This research project was initiated as part of a Master's in clinical ethics. Themes intrinsic to this topic include children with medical complexity, pediatric palliative care, palliative care in the Emergency Department, goals of care discussions and continuity of care. The literature review will focus on these concepts, as they are the most relevant themes to achieve the main objectives of this study.

Chapter 2: Literature Review

Children with medical complexity

With the progression of research and technology in neonatology, oncology and advanced critical care in pediatrics, an increasing number of children are living with ongoing multisystem illnesses, congenital or neurological diseases and have functional impairment requiring technology for daily living (3, 19, 26-28). These children are in need of special services and healthcare support and they are usually followed by specialised interdisciplinary teams who accompany them and their families (29). They were broadly described by the Maternal and Child Health Bureau as children with special healthcare needs (CSHCN) in 1998 (30). Terms used in the literature to describe these children vary and include children with complex chronic medical conditions, medically complex children, children with complex health conditions, children with complex medical needs or complex chronic life-threatening illnesses (4, 31-35). In 2010, the American Academy of Pediatrics (AAP) used the term children with medical complexity to emphasize an approach primarily oriented toward the person with a focus on services required to optimize their outcomes (19). This term will be favored by the author throughout the project.

Research and advances in care have enabled new surgical and medical interventions for CMC to prolong their life by controlling underlying comorbidities (17). In addition to developing new physical interventions to improve outcomes, efforts have been made to develop care models and clinical initiatives to better address the needs of CMC and their families (19). Indeed, they are at risk of suffering from fragmented and suboptimal care from lack of coordination, communication and continuity from the different health care professionals involved (3, 17, 36). The AAP model encompasses 4 broad features that characterise areas of focus to optimize the quality of care for CMC. First, these families require family-centered care with accessible medical, psychosocial and community services in order to empower the family in management. Second, there should exist a sound continuum of care between the community primary care provider and the tertiary care center in relation to the underlying chronic condition and morbidity. Third, communities should support and adapt to the functional limitations of CMC and their medical technology to maximise activities of daily living. Lastly, these patients should be part of an efficient system that coordinates their ongoing healthcare use in multiple specialties (19). Given these four domains of improvement of care, it is clearly understood that coordination of care is the responsibility of many different healthcare professionals navigating around the care of CMC and their families to ensure the best quality of care possible.

Continuity of care

The concept of continuity of care has evolved over the last 60 years and is associated with concepts of care coordination, integration of care, patient-centered care and case management. These elements are shown to improve quality of care and health outcomes in primary care settings (37). Recent models used to define continuity of care are multidimensional and formulated based on the patient's experience of care (38). Three main elements are included in the most contemporary definition of continuity: informational, relational and management continuity (39). First, informational continuity reflects the transfer of information regarding a patient among healthcare professionals. This implies verbal and written communication of the patient's preferences and health condition (39-41). Second, relational continuity is the quality of support available for a patient before, during and after admission. This is particularly important for families of CMC as it represents the network of professionals and services guiding and supporting parents through the illness (41). Those professionals become the reference points for families and ensure relational continuity of care (39, 41). Lastly, as many different teams and professionals are involved in the care of CMC, coherence is essential to ensure continuity in care management. This reflects the establishment of a shared plan among services and a complementary approach in care management while remaining flexible to adapt care to every circumstances.

In pediatrics, continuity of care is a central element while caring for CMC. Compartmentalization of care can occur even for children followed at one single center and impacts parents' satisfaction with care (39-41). Continuity of care therefore implies good interaction and communication between teams to ensure shared management plan (37). Roger Schwartz is a well-recognized organizational psychologist who has dedicated his career to improving team leadership and effectiveness by encouraging team members to reflect on their mindset in approaching conflicts. His goal is to lead people from a same organization to work together and use mutual learning to take advantage of each team members' skills and talents

(42). The mutual learning approach can be applied to medicine and offers the benefits of improving the well-being of team members and their performance by engaging in reflexive practices. The values of the mindset that are used include transparency, curiosity, informed choice, accountability and compassion (43).

First, transparency and curiosity are the values creating shared information between people by opening oneself to others' points of views and disclosing one's own thoughts and feelings. Transparency is about sharing common useful and productive information explaining why you are thinking what you are thinking with the goal of moving a group's reflection forward and not only wanting to control a situation. Curiosity is the other side of transparency and implies a desire to explore what others are thinking by asking them questions and by truly listening to what they have to say. Teams that show both transparency and curiosity develop a culture of collaboration and trust, are more comfortable dealing with uncertainties and have overall higher level of satisfaction with work (43, 44).

After having created a pool of information within and between teams, decisions have to be made to generate a commitment. The decision-making process requires that people be involved and informed all the way, and that they participate in creating a plan the whole team will be committed to, without necessarily aiming for consensus. Being accountable means acknowledging the responsibilities of a position, accepting to explain one's own actions and decisions and being dedicated to the well-being of the group's decisions. Accountability has the benefits of reducing judgmental attitudes towards other colleagues and improving relationships (43, 45).

Finally, compassion is the last core value of the mutual learning approach mindset and implies a sense awareness and connection to the frustrations and challenges colleagues might be facing. This enables an organisation to be supportive of others' stress and emotions without judgement. It has been shown that a team made better decisions when they not only focused on rationality but also on thoughts and feelings (43).

Pediatric Palliative Care

Pediatric palliative care strives to be integrated in the patient's medical care, serving as a whole the physical, psychological, social and spiritual components of every child and seeks to improve focus on quality of life for the patient and his family at any stage of the disease (46-48). PPC is an approach supporting and connecting with families facing the possible death of their child to promote hope and optimal care through illness and bereavement (47). While several models of PPC exist, it often consists of an interdisciplinary team including doctors, nurses, social worker, pharmacist and volunteers among others, working in close contact with families to promote shared decision making (22, 47, 48). A major element of this approach is to establish as early as possible the cultural and spiritual preferences and values of a patient and his family based on their unique personal context (48-51). These discussions will be referred to as determining the goals of care of a patient and his family as opposed to establishing pediatric advance care planning (pACP) given the lack of a well-defined and concordant notion of pACP in the literature (52). First consultations with PPC should be early in the disease course with subsequent outpatient visits to develop a relationship with the family and fill gaps in continuity of care. The team also provides support to the family to help them cope with the current burden of the illness and with eventual bereavement. Furthermore, PPC teams address the management of patients' distressing symptoms with a focus on improving quality of life. Finally, specialists in PPC often act as coordinators of care and facilitate communication between teams (4, 14, 49, 53).

Unfortunately, PPC specialists are not available in all healthcare settings and remain insufficient despite the required national goals of offering an accessible palliative care service at all times and for all children (14, 47, 54). In fact, only a small percentage of children who require palliative care are followed by a specialised PPC team (55). In 2013, a survey was conducted among 2500 pediatricians from the Canadian Pediatric Surveillance Program to assess their needs in PPC (54). First, it was found that 78% of respondents believed PPC intervenes at multiple levels and goes beyond only end-of-life. Most pediatricians recognized the need to refer their patients to a PPC team but only 35% admitted having done so. In fact, about one fifth of pediatricians mentioned the inability to have access to such a team and more than half of the respondents believed their patients didn't have appropriate services. Finally, participants reported that children with a wide variety of health concerns would benefit from PPC: (1) patients with an ongoing progressive condition where care is only of palliative intent, (2) patients with conditions where cure is possible but could fail, (3) patients with conditions causing severe disability and fragility to complications and (4) patients with conditions requiring long-term and intensive treatments with a goal to maintain quality of life.

In order to respond to the rising number of CMC and to their PPC needs, some studies have tried to describe models of palliative care interventions which could be used by general pediatricians in a primary care setting. A common shared role for all healthcare professionals in a palliative care model is to support decision-making processes with families. To reach this, professionals should aim to assess the goals of families and their needs, the impact of disease on their life, the baseline status of the child at home and families' understandings of their child's prognosis (14). Such an approach can empower primary care professionals with becoming more comfortable with PPC in addition to improving access to PPC for all patients.

Palliative care in the Emergency Department

Adult literature

The need to integrate palliative care into the ED has been well recognized (56-58). In fact, since 2006, the American Board of Medical Subspecialties has recognized Palliative Care Medicine as a subspecialty of Emergency Medicine (59). Further, the Education in Palliative and End-of-life Care in Emergency Medicine (EPEC-EM) initiative suggests a framework for PC for ED healthcare professionals and training has been developed for residents caring for the geriatric population in the ED (60). Four (4) main priorities of research have also been identified, including understanding patients at greatest needs of palliative care in the ED, the role of ED healthcare professionals in caring for patients with chronic illnesses, the health care utilisation impacts of integrating palliative cate in the ED and education needs of ED professionals in palliative care (58).

There are several limitations and barriers to providing palliative in the ED. First, the difference in culture between palliative care medicine and emergency medicine is such that staff in the ED have to change their mindset (61). The ED's traditional mission is to focus on the management of acute illness and resuscitation and some ED healthcare professionals report having trouble managing the emotional load and frustration of not being able to resuscitate (62). In the adult population, qualitative empirical research has been conducted to understand the trajectory of end-of-life care in the ED setting. It was found that patients who require care near death tend to be separated into two categories. First, the patients who suffer an acute unexpected illness or a traumatic event are classified into the spectacular category and usually receive most of the attention from the ED staffs. Second, the patients who present with a need for support and palliative care as their dying process is slower are usually left to the care of the nurses and receive less attention from ED physicians. This reflects the traditional mission of the ED to prioritize potential for survival (62). These patients and their relatives would nonetheless probably benefit the most from communication with ED physicians concerning end-of-life goals.

A second reason for the complex integration of palliative care into the ED includes structural factors such as an unsuitable environment and setting to provide the best care possible. ED professionals are driven by a fast-paced environment and see multiple patients per shift. EDs are designed to maximise patient flow, creating loud settings with lack of privacy, which can be challenging when the need for a peaceful moment or for delicate conversation with patients and their families arises (22, 63, 64). Also, EDs are often overcrowded and staffs have to make quick decisions regarding patient care and therapeutic plans, including discharge or admission (1). Finally, nurses in the ED have a high workload and need to care for multiple patients in a fragmented way. In contrast, they believe that patients in palliative care and at the end-of-life should be cared for on an uninterrupted manner, requiring devotion, compassion and extra time, which they seemingly do not have (61, 65). This fragmented approach impacts negatively the quality of interactions with families as some patients feel uncomfortable asking many questions given their healthcare professionals' workload (66). However, allowing slightly more time during an initial encounter has been found helpful to establish better contact with patients and to improve family involvement in the decision-making process (67, 68).

Third, the inadequacy of the training in end-of-life care in the emergency medicine curricula has also been described as being a limitation to quality palliative care (69). In fact, despite improvements in teaching about palliative care in the curricula, ED staffs still feel uncomfortable about managing end-of-life care for patients (56, 70). They report being confident in symptom management and in recognizing the holistic approach of palliative care but admit lacking skills in communication regarding end-of-life discussions and expertise in palliative care (63, 71, 72). Some ED staffs even remain uncertain about their role in palliative care in non-cancer diagnoses (70). In a survey of 228 residents in emergency medicine programs in New York City in 2008, 75% of residents reported having no clear understanding of what the role of an ED physician is in palliative care (73). Although some studies suggest that patients and families also need to be educated about what their goals of care are, physicians' knowledge deficits nonetheless contribute to preventing patients and families from initiating such discussions (65).

A final limitation to palliative care in the ED is the lack of communication with primary care professionals (62, 74). ED physicians do not usually have a previous relationship with patients and their families and find it hard to initiate important discussions about quality of life, patient preferences and symptom management with these unknown patients. Despite all these difficulties, every patient entering the ED should receive the best and most appropriate care possible, whichever their health concern. In fact, the ED has been described as the best healthcare setting for patients experiencing acute or urgent changes from a previously stable condition and requiring assistance with their health (22).

Pediatric literature

Little work has been done with regards to PPC in the ED. A retrospective study was conducted by Gaucher, Humbert et Gauvin from 2007 to 2012 at CHU Sainte-Justine in Montreal to characterise which children newly followed in PPC presented to the ED, and their visit's characteristics (75). The study showed that death occurs very rarely in the pediatric ED. Also, a recent qualitative study in Germany aimed at developing the understanding of pediatric medical and non-medical healthcare professionals on advance care planning for children (15). Healthcare professionals were from various specialties, including emergency medicine. One finding reported by the authors included the belief that advanced care planning improves the quality of care for patients by decreasing unnecessary interventions in the ED and giving security and control to families. However, this study also identified barriers to discussing end-of-life care as suggested by emergency physicians: not knowing the children they are caring for and lack of sufficient time to evaluate the situation. Intensive care physicians reported being scared of taking hope away from families, damaging a trusting relationship and negatively assessing a clinical situation, which may turn out well for the patient. Overall, it was thought that written documentation of advanced care planning should be established early after diagnosis, be revisited regularly and be provided to the ED (15).

Goals of care discussions with families

Decisions and discussions related to care management often occur in acute critical settings, as described by Levetown since 1994. In fact, pediatric intensive care unit is an environment where decision about withdrawal or restriction of care occur because of the likelihood of imminent death (11). Multiple studies including a meta-analysis were conducted to review parents' needs when discussing end-of-life decisions in different settings and demonstrated families' desire to be involved in discussions about the care of their children and be informed about specific medical information (23, 50, 76). Moreover, involving parents in these important steps helps them in their bereavement process (12, 51). Effective communication has been demonstrated when a shared approach was used, meaning when parents are involved in every decision-making step in the care of the child. It was shown that despite the anxiety and intense emotions surrounding an acute illness, parents appreciate details concerning the medical and technical condition of their children and are still capable of expressing their preferences (51). Such an approach represents the ideal scenario where information is being shared from both the professionals and the families. However, in acute settings, time is also a constraint and decisions sometimes have to be taken within seconds (77).

Conflicts can emerge while discussing goals of care for different reasons and dissatisfaction from families and healthcare professionals have both been reported in the literature. First, some children have poorly understood medical conditions and their family becomes the expert in the understanding of their child's health needs on a daily basis. Family may therefore have difficulty accepting the opinions of medical teams and might feel misunderstood when goals of care are discussed in acute settings (3). Other factors described as contributing to families' distress include the inability to get answers for all their questions, dealing with prognostic uncertainties and receiving conflicting opinions from different healthcare professionals regarding management (23). Written medical documentation, including potential complications of the underlying illness, have been suggested as a way to reduce many of these distressing factors in discussing goals of care (23).

From the perspectives of the healthcare professionals, discussing goals of care also represents a challenge for different reasons (15, 77, 78). First, an emotional load surrounds these complex discussions considering families' strong emotional responses to the disclosure of bad news; some healthcare professionals perceive this intense moment as uncomfortable and are reluctant to initiate conversations (15, 77). They may also feel guilty from an inability to offer more curative treatments to the patient and be unsure about responsibilities. Furthermore, some cases are very acute with no time to establish a relationship with families and this can be challenging for professionals as it may impact on the trustworthiness and credibility of the treating team. Another important factor is the uncertainty of prognosis, which prevents treating teams from providing clear outcomes to guide the family in their decisions. Finally, staffs have reported discomfort from inadequate training and education in palliative care (77).

Summary of Knowledge Gap

Little is known about the role of the pediatric ED in PPC The need to understand and implement care models to better coordinate PPC for CMC is however recognized in the literature (4, 14, 17, 19, 54). As the ED is often a place where life-saving measures are initiated, there is also a need to better document the complexity of PPC in this setting (56). Since it has been shown that patients and families in the ED benefit from early palliative care interventions to improve their quality of care and satisfaction, the role of the ED in PPC necessitate exploration (62). Perspectives from healthcare professionals involved in the care of CMC at different moment in the illness trajectory are required to understand and situate the role of the ED in the continuum of PPC. This include professionals from acute care and long-term care services such as the ED, the pediatric intensive care unit, the complex care service and the PPC team.

Research question and objectives

This study will aim to answer the following question:

What is the role of the Emergency Department in Pediatric Palliative Care according to the perceptions of the healthcare professionals at the CHU Sainte-Justine in Montreal?

The main objectives of this research seek to: (1) understand the ED, complex care service (CCS), PPC team and pediatric intensive care units (PICU) professionals' beliefs about the role of the ED in PPC, (2) explore the experiences and challenges in continuity of PPC between acute and long-term care services and (3) provide solutions to improve the quality of PPC for CMC during acute deterioration.

Chapter 3: Methodology

Qualitative methodology is used for this study as the research objectives seek to understand the experiences of the healthcare professionals at the CHU Sainte-Justine in Montreal rather than trying to demonstrate an objective measurable reality (79, 80). Qualitative methodology in health research includes studies aiming at developing or enhancing an understanding of human health or illness, health as a whole or health services from various social approaches. Qualitative research differs from quantitative research by the initial objective and research questions. In fact, qualitative research seeks to offer an answer to questions related to "how", "what" and "why" as they want to explore the meanings developed by participants in reaction to their world (79).

This research refers to an epistemological philosophy which assumes reality and knowledge cannot be separated from subjective human perceptions (80). Palliative care in the pediatric ED seeks to be understood from the unique point of view of participants and their experiences. The authors believed that these subjective meanings are created by the interactions between participants and by the culture in which they live (24). The authors purposefully did not address the perspectives of the families in this study. In fact, as little is known about the topic, it was believed to be ethically responsible to first explore professionals' opinions and better situate the problem, before interviewing patients in PPC, parents of children in PPC or bereaved parents.

Research design

This project is a cross-sectional study using a strategy of triangulation involving multiple data sources to understand a complex problem with institutional and clinical implications (79, 81).

Triangulation 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 (81). In this project, different professionals from acute care units and long-term care units were interviewed for several reasons; interviewing professionals from such diverse backgrounds was an important strategy to triangulate perspectives and data and generate a more comprehensive overview of the research question. First, the research question required an exploration of the perspectives of the majority of the actors involved in the care of CMC to provide concrete practical tools for healthcare professionals. Second, to understand the role of the ED in providing PPC, the study called for an exploration of the perspectives of professionals involved before, during and after an acute deterioration of CMC to better situate the ED in the continuum of PPC. Third, given that continuity of PPC is very important to explore in the context of the research question, the chosen strategy of triangulation was a means to ensure aggregation of data and reveal data as closed to reality as possible (81).

There were two important and distinct methodological steps in the design of this research. First, social constructivism was used as the initial interpretative framework, whereby a theory emerges from the cultural, social and historical context surrounding the participants rather than from a tested assumption from an existing theory (79-81). This was an inductive approach using subjective meanings of the participants involved in the study to further understand the research question. Some methods of grounded theory were used in data collection and analysis to generate knowledge on this particular phenomenon. For instance, open coding and in vivo codes were used to first analyse the data, which was then combined into small categories of nodes and minor themes (80). Theoretical sampling was also used to test emerging themes from the direct coding after each focus group within the subsequent focus groups and compare the tentative data and participants' propositions (81). Constant comparative method was done as part of data analysis as codes were being compared between emerging categories to understand their relationships and relevance. Some codes were then removed as part of this process. The process was further enriched and facilitated by the comparison of each focus groups' open coding between the two main authors. Discussions took place between the authors to understand why a particular section of the transcription was coded in one author but not the author. In some instances, discussions led to the identification of new codes and categories.

Second, following the very inductive analysis of the data, the authors identified unexpected emerging themes which prompted a desire from the authors to re-analyse data with the aim of providing concrete practical tools to improve care. A second review of the literature was therefore done and guided the choice of two ethical frameworks for the analysis: continuity of care and mutual learning approach. The interpretative framework of this second part to the study was therefore based on pragmatism as it focused on providing outcomes and solutions to a concrete problem. The authors used a more deductive approach for this step to use existing themes in the literature and guide the secondary data analysis.

Eligibility Criteria

There were no specific criteria for participants to be eligible. However, they had to be staff working in the ED, in PPC, in the complex care service or in the PICU at the CHU Sainte-Justine in Montreal. Participants included pediatric physicians, fellows, nurses, respiratory therapists, social workers, patient attendants, psychologists, dieticians, physiotherapists, spiritual care provider and clerks. The choice of multiple types of actors was used to maximize the perspectives on the topic being explored and address the complexity of the problem by examining a conclusion from multiple points of view. All participants shared common qualities and competencies in working in an acute setting or in long-term care.

Participants selection

All staffs were made aware of the study through posters, emails or weekly journal in the ED (Annex 1). Staffs were enrolled in a first-come first-serve basis. However, purposeful sampling was used to include a wide diversity of professionals within the units interviewed with more experience and interest in innovating practices. In the PPC and complex care service groups, almost all members of the naturally occurring group were present and no selection had to be done. The study was not able to include all the staffs working in the ED since there are too many. However, more interviews were conducted with this group to accommodate the large number of staffs in this unit. Three (3) focus groups were done with the ED team given the large number of professionals in this naturally occurring group and one focus group was done with each of the other teams given the smaller number of physicians in each of these groups.

Methods for Collecting Qualitative Data

Semi-structured group interviews were conducted to explore the experiences of healthcare professionals from naturally occurring groups in the ED, in PPC, in Complex Care Service (CCS) and in PICU to encourage divergence and convergence in opinions. Groups were not mixed with professionals from different units in order to encourage the discussions of more sensitive issues occurring in this setting and to avoid silent members (82). The demographic data of each participant was collected using a questionnaire distributed at the beginning of each focus group (Annex 2).

Overall, this study comprised 6 focus groups: 3 in the pediatric ED to include most ED physicians, 1 with staffs involved in PPC, 1 with staffs in complex care and 1 with staffs in PICU. Each focus group included on average 10 participants, for a total of 58 participants.

Each interview was one hour each and meals or snacks were provided as compensation for taking part in the research. Interviews were guided by a facilitator who was a Master student researcher in Clinical Ethics (A.J.C.). Another researcher with experience in qualitative research and emergency medicine was present to help if any technical issues arose (N.G.). In one focus group for instance, N.G. had to redirect the discussion as one theme was being saturated in the discussion and further themes had to be explored.

Questions were elaborated by the two moderators to guide interviews. Participants were explained the aim of the focus group with a reminder to respect opinions and refrain from divulging the content of the focus group. The discussion was conducted by the facilitators by moving forward with the questions and encouraging participants to share their thoughts and comments with the others.

All participants from all the focus groups were first asked to explain their beliefs and perceptions about PPC in order to have a shared understanding of the definition of PPC. Commonly used definitions of PPC were then reviewed with participants during the group discussion. Next, participants from the ED were asked about previous experiences with palliative care in the emergency department. Other professionals from PPC, CCS and PICU were asked to elaborate on experiences about PPC in their practice and share positive or negative clinical cases where they cared for patients who visited the ED. The interviews included questions aiming at understanding possible cases where the ED staffs were confronted to initiating discussion about goals of care. Further questions aimed at identifying difficulties and limitations of PPC in the ED. Some questions were modified from one group to the other based on the emerging themes over the discussions. For the group in PPC, they were first asked to describe what palliative care in the ED means for them as the definition of PPC was believed to be already established in this group.

Interviews were recorded using a microphone and the application ShurePlus MOTIV with consent from participants, for transcription purposes. All interviews were transcribed verbatim by the main author and reviewed by the second researcher. Recordings have been kept in a secured looker in the researchers' office in the ED and no one except the main researcher has access to it.

Methods for Analyzing Qualitative Data

The methods used to analyse the data first started with thematic analysis and aimed to report the views of the participants and explore their experiences and behaviours towards PPC in the pediatric ED.

Data recorded during the focus groups was transcribed in full by the study's main researcher (A.J.C.). Interviews were transcribed as soon as completed. All the data was then entered into NVivo (QSR International Inc.). In order to be familiar with the data, all transcribed interviews were first read. The interviews were then coded into codes and nodes by two of the researchers (A.J.C. and N.G.). These nodes were regrouped into 2 main categories: PPC in the ED and PPC practice across acute and long-term services. Both researchers' codification process was compared using the constant comparative method for quality and reliability of the analysis.

Disagreement in the analysis process was resolved by consensus and by going back to the original data. Discussions with the third author (A.P.) were rarely required to resolve disagreements. Furthermore, a specialist in qualitative data analysis and NVivo from CHU Sainte-Justine also met with the two main authors to review the themes and the interpretation of codes. This then led the authors to reorganise some themes and analyse data by crossing other themes together.

Further analysis of the data used theoretical sampling whereby hypotheses generated in the first focus groups were then tested in the subsequent ones. The interprofessional nature of these focus groups aimed to capture a wide understanding of the problem in each of the interviews, which facilitated validation of some previous themes.

Demographic data was entered into an Excel database (Microsoft Inc., Richmond, WA) to generate descriptive results. Data will be kept secured in the A-347 room in the ED for 10 years.

Ethics

This research project protocol was submitted to the CHU Sainte-Justine Ethics Review Board from the CHU Sainte-Justine and obtained approval in August 2015. Participants in the focus groups provided written informed consent to participate in this study (Annex 3). Focus group participants were asked to keep discussions confidential within focus groups and to not divulge the information shared during interviews outside of the session.

Chapter 4: Results

Manuscript intended for a peer-reviewed Emergency Medicine Journal

Given the fragile health of CMC and their likelihood of acute deteriorations, this first article intends explore the role of PPC in the ED. It was designed to reflect the perspectives of a variety of healthcare professionals involved in the care of CMC toward the potential roles of the ED in PPC. The participants involved were purposefully coming from different specialties caring for CMC at distinct moments in their illness to vary and maximise the perceptions on the role of the ED in PPC. This manuscript aims to describe the difficulties faced by the ED in the provision of palliative care for the pediatric population. It also seeks to offer an approach to the healthcare professionals working in the ED when caring for a CMC who is critically ill and is unknown to them.

A comprehensive approach to Palliative Care in the pediatric Emergency Department: findings from a qualitative study

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Meetings:

- CAEP Conference, Whistler, June 4-5th 2017
- Canadian Pediatric Society Annual Conference, Vancouver, June 1rst, 2017
- Pediatric Academic Societies meeting, San Francisco, May 6th, 2017
- 8th Annual Canadian Bioethics Society Conference, Montreal, May 26th, 2017
- 7th Annual joint Pediatrics Resident and Fellow Research Day, March 23rd, 2017
- 21rst International Congress on Palliative Care, October 20h, 2017
- 7th International Congress in Pediatric Palliative Care, September 30th, 2017

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Authors contribution:

AJC, NG, and AP conceived the study, designed the research protocol, and applied for funding. AJC and NG participated in participant recruitment, data collection and data analysis. AP supervised participant recruitment and provided advice on data analysis. AJC and NG contributed to dissemination of knowledge in different meetings. AJC drafted the manuscript but all authors contributed substantially to its revision. AJC takes responsibility for the paper as a whole.

Abstract

BACKGROUND
Children with medical complexity (CMC) represent a fragile population and account for the majority of patients followed in pediatric palliative care (PPC). Little is known regarding the role the emergency department (ED) in caring for the families of CMC.

METHODS
Semi-structured focus groups were held with healthcare professionals from pediatric emergency medicine, palliative care, complex care and intensive care to explore their perspective on PPC in the ED. Data was transcribed and analyzed using NVivo© software and thematic analysis and theoretical sampling were performed.

RESULTS
From January to October 2016, 58 participants were interviewed. Difficulties providing PPC in the ED are related, on the one hand, to characteristics specific to the ED, such as its culture and its healthcare professionals' strong emotional responses when caring for CMC, 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 healthcare teams, remain open to families' preferences, alleviate distressing symptoms and create a caring environment. Communication between teams is a targeted area by healthcare professionals to facilitate improved patient flow and care.

CONCLUSION
Although perspectives differ regarding how to provide care for PPC patients in the ED, several barriers to providing high quality emergency PPC can be overcome.

Introduction

Definitions of pediatric palliative care (PPC) include children with life-threatening medical conditions and focus on caring for the patient and his family as a whole (1, 2). While several models of PPC units exist, they often consist of an interdisciplinary team including doctors, nurses, social workers, pharmacists and volunteers, among others, working in close contact with families (22, 47). Many pediatric patients requiring PPC are children with medical complexity (CMC) and they represent a population susceptible to visiting the emergency department (ED) on a recurrent basis (3, 4). 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 (3, 19, 26-28). In Canada, guidelines recommend discussing advanced care planning for these children as early as possible to anticipate critical life decisions (6) but this is rarely done when patients are well and stable (7-12). However, pediatric healthcare professionals report uneven education in PPC and discomfort while communicating with families regarding end-of-life care (15, 46).

Since 2006, the American Board of Medical Subspecialties has recognized palliative care as a subspecialty of emergency medicine (59). Several barriers to providing high quality palliative care in the ED have been identified and include improper settings, lack of pre-existing relationships with patients, fast-paced environments and a culture of intense resuscitations (1, 61-64, 74). 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 (61, 65). Many healthcare professionals still receive inadequate training in end-of-life care in emergency medicine curricula, which contributes to their discomfort in caring for patients in palliative care and their uncertainty about their role for these patients (56, 70, 73).

In pediatrics, little is known about PPC in the ED. One small qualitative study identified some challenges, such as unknown patients and lack of time. This study also suggested that ED healthcare professionals believe advanced care planning may improve quality of care for these patients by decreasing critical interventions in the ED (15).

PPC in the ED for CMC is a multifaceted organizational problem and needs to be better understood to facilitate coordination and high quality care during a patient’s acute changes in health status. The objective of this study is to explore the challenges of providing PPC in the ED and to describe potential roles for the ED in PPC as perceived by the main services involved in the care of CMC. This study also aims to provide concrete solutions to better implement PPC in the ED.

Methods

Qualitative approach and research paradigm

This research used social constructivism as the interpretative framework and was not based on a tested assumption (79-81). A cross-sectional study using a strategy of triangulation was designed to include different healthcare professionals from acute care units and long-term care units, who were involved in the problem being studied. Some aspects of data collection and analysis were inspired from grounded theory.

Researcher characteristics and reflexivity

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

Context

The research was conducted in the CHU Sainte-Justine, a specialized Pediatric tertiary care university-affiliated center in Montreal. Its pediatric emergency department is one of the busiest in Canada and receives about 85 000 visits per year. The interdisciplinary PPC team provides consultations to all healthcare teams and is available during regular working hours.

Sampling strategy

Participants were selected based on their area of expertise. Healthcare professionals from the pediatric ED, the PPC team, the complex care service (CCS) and the pediatric intensive care unit (PICU) at CHU Sainte-Justine were invited to participate in this study. The focus groups conducted involved a variety of professionals from teams working together on a daily basis, looking to represent the group: healthcare professionals from all fields were purposefully sought to maximize the perspectives and address the complexity of the problem. Healthcare professionals were enrolled in a first-come first-serve basis, but purposeful sampling was used to ensure those with an interest in PPC participated. As the focus of this study was on ED personnel, sampling was deemed acceptable when most of the ED physicians had participated in the study.

Ethical issues pertaining to human subjects

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 methods

Six semi-structured group interviews of 1 hour each were conducted with naturally occurring groups in the ED (n=3), in PPC (n=1), in the CCS (n=1) and in the PICU (n=1). Groups were not mixed between the different units being studied, as there are naturally occurring and previously established trusting group dynamics in each unit that likely maximized participant participation within each focus group. In contrast, mixed groups may have led to more silent members (82). Baseline demographic data were collected. Each focus group included on average 10 participants and was intended to be a representative sample of healthcare professionals from each service. Interviews were guided by the two main authors (A.J.C. and N.G.).

Data collection instruments and technologies

Only a few open-ended questions were pre-established by the two main authors as interviews aimed to explore participants' perspectives without influencing their answers. Questions aimed at identifying previous experiences and challenges with PPC in the ED, beliefs about the role of the ED in PPC and potential areas of improvement. Some questions were modified from one group to the other based on the emerging themes. Interviews were recorded using a microphone and the application ShurePlus MOTIV.

Data processing

Interviews were transcribed verbatim by the main author (A.J.C.) and reviewed by the responsible researcher (N.G.). Participants remained anonymous and were identified by their profession. Transcriptions were entered in full into NVivo (QSR International Inc.). Recordings were kept in a secured locker in the CHU Sainte-Justine ED. Demographic data was entered into an Excel database (Microsoft Inc., Richmond, WA).

Data analysis

Transcribed interviews were coded by thematic analysis after each focus group by two of the researchers (A.J.C. and N.G.). Codes were used to generate nodes and themes. The codification process was compared using the constant comparative method for reliability of the analysis. Theoretical sampling was done whereby hypotheses generated in the first focus groups were tested in the subsequent ones. After data collection was completed, a specialist in qualitative data analysis was met to review the codification process and theme generation.

Techniques to enhance trustworthiness

The triangulation strategy used for the focus groups aimed to capture a wide understanding of the problem in each of the interviews, which facilitated validation of previous themes. Constant comparative method improved data analysis by maximizing the emerging themes. Disagreement in the analysis process were resolved by consensus.

Results

Demographic data

From January to October 2016, 58 participants were included in the 6 focus groups (Table 1). Data analysis lead to three main themes, namely barriers to providing PPC in the ED, roles of the ED in PPC and comprehensive approach of PPC in the ED.

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

	Characteristics	***No (%)***
Gender	Man	11 (19%)
	Woman	47 (81%)
Age	21-30	12 (21%)
	31-40	16 (28%)
	41-50	16 (28%)
	51-60	14 (24%)
Ethnicity	Caucasian	55 (95%)
	Other	3 (5%)
Religion	None	46 (79%)
	Catholicism	9 (16%)
	Other	3 (5%)
Profession	MD	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 trainings in PPC	19 (33%)

Barriers to providing PPC in the ED

Healthcare professionals from the ED raised many struggles in providing PPC, mainly related to their own culture of care and emotions when interacting with CMC. Other healthcare professionals from PPC, the PICU and the CCS 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.

Table 2 : Barriers to the provision of high quality PPC in the ED

Characteristics	**Barriers**	**Participants' verbatim**
Specific to the ED	1. ED culture (multitasking, sporadic healthcare 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, you are always being interrupted."* (ED professional)
	2. Healthcare 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)
	3. 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)
	4. 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)
	5. 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	1. 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)
	2. Families' reactions	*"Palliative care suffers from its label. As soon as you pronounce the term, parents think you are abandoning their child."* (PICU professional)

	3. PPC stigmatisation	*"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.*" (CCS professional)
	4. PPC organisation in the Hospital	*"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)

Roles of the ED in PPC

Each group suggested important dimensions of PPC which 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 teams included elements of a reflective practice with increasing sensibility toward palliative care and adopting a non-judgmental 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. Table 3 presents a summary of each discipline's main perspectives on the potential roles of the ED in PPC.

Table 3 : Individual groups' suggested roles for the ED in PPC

ED	**PICU**
• 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 to 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*	• Initiation of discussions about with-holding 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 sown in the ED, so that after, management continues in the same direction."* (PICU professional) • Ownership and devotion to palliative care patients *"I know there is a 6 hour wait, but this patient requires as much attention from an ED physician as the patient you are currently resuscitating."* (PICU professional)

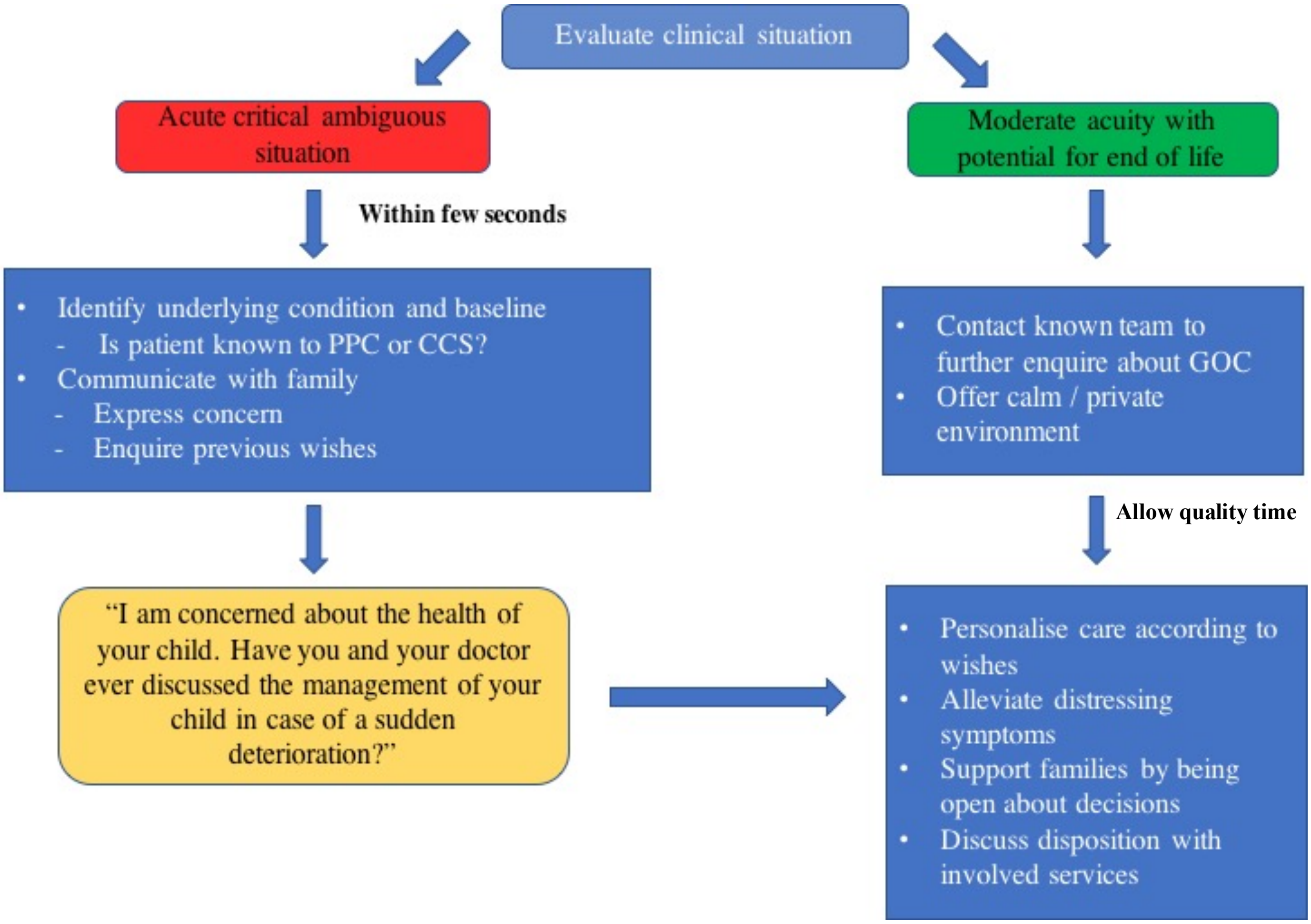
hospital]. We don't have to leave them in resuscitation rooms." (ED professional)	
CCS	**PPC**
• Continuity of management *"I am not sure discussions [about goals of care] lead to anything, except maybe disrupting the relationship with the emergency physician from the start. (…) Maybe contact a treating physician when possible to verify if they've already had discussions?"* (CCS professional) • Non-judgmental 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 non-negligible."* (CCS professional) • Individualized care • Decision support *"[The mother] was really anxious, she was scared he would die that night. She wanted the doctor's assurance. 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."* (CCS 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)

Improving communication between teams was targeted as an important theme throughout all focus groups to better organize PPC 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. For instance, PPC, PICU and ED groups insisted on the importance of strengthening primary care and community physicians' education in discussing goals of care early in the illness trajectory. These groups suggested that families could be prepared beforehand in case they needed to consult the ED. However, CCS and PPC groups highlighted that there exists a paradox regarding discussions about goals of care: it is difficult to find a right moment to initiate critical discussions with families as they all progress along different paths and pace through the illness of their child. They therefore suggested healthcare professionals in acute care settings develop an awareness and empathy towards the reality of families caring for CMC. Some experts from the PPC group suggested ideas and cues for healthcare professionals to open up discussions with families during acute deteriorations. The vocabulary employed in these cases needs to be delicate, precise, and open (Figure 1 yellow box).

Comprehensive approach to PPC in the ED

All groups suggested an understanding of the key dimensions required in the ED to provide high quality palliative care. Figure 1 offers a comprehensive approach integrating these different points of view on the role of the PPC in the ED setting (see above). This approach implies an active participation of the physicians, nurses, respiratory therapists, social workers and patient attendants in the ED caring for CMC visiting the ED. Roles varied slightly depending on two complex clinical situations well identified by the ED focus groups: (1) the critical deterioration of a patient with medical complexity, and (2) a CMC who is not imminently unstable. This approach seeks to offer support for healthcare 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.

Figure 1. Comprehensive approach to PPC in the ED



Discussion

This was a qualitative study with interprofessional focus groups reporting the experiences and beliefs of healthcare professionals involved in the care of CMC on the provision of PPC in the pediatric ED. This was the first study to explore the organization of PPC in the ED by using a triangulation strategy and to develop an understanding of this complex problematic combining multiple points of view.

In this study, many barriers to providing PPC were described; these contribute to professionals' malaise when caring for CMC. 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 (61-65, 67, 70, 71, 73). 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 for a more comprehensive understanding of the sources of professionals' discomfort and to target areas of improvement consistent with the realities of the involved practitioners.

Professional education about the meaning of palliative care, aiming to correct its misconceptions and address its stigma, for all healthcare professionals is likely a first step in empowering the ED, who is but one element in the continuity of PPC. Also, a comprehensive approach to PPC calls for primary care professionals to prepare families for unplanned ED visits to facilitate continuity of care management. This reflects a transversal philosophy of PPC, whereby all professionals are recognized as important actors in supporting families along the way and at different moments throughout illness (83). For such an approach to palliative care to be possible, basic knowledge about palliative care by all parties and shared responsibilities are essential; these ensure continuity not only between healthcare teams, but also between clinical visits or health events.

Discussions about goals of care were an important theme for all participants in this study. From a healthcare professional's perspective, there seems to never exist a "good moment" in a pediatric patient's life to discuss goals of care. In contrast, participants felt that goals of care were likely not addressed enough throughout the continuum of care, i.e. before acute deteriorations, during, and after. 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 since it is well recognized that an acute event can precipitate a change in the families' preferences (84). Moreover, earlier studies have demonstrated families' desires to be involved in discussions regarding the care of their children and to be informed of specific medical information (23, 50, 76). Parents also appreciate being involved in the care of their child during the dying process as it helps them with bereavement (12, 51). 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.

Finally, we showed that professionals from various backgrounds involved in the care of CMC emphasized different dimensions required for a good practice of PPC in the ED. These dimensions varied according to each group's expertise and relationships with families and should be integrated when considering the role of the ED in PPC, to reflect the heterogeneity of families' experiences with illness. For instance, identifying a patient known to a primary team in the institution, expressing concerns to families, personalizing care management to a patient's needs and remaining open about a family's decisions are the main practical dimensions to develop while caring for CMC who may be eligible for palliative approach to care. Such an approach calls for a will to share responsibility in providing palliative care and recognizing the significant contribution of each professional in the ED. This is intrinsically required for a comprehensive approach to PPC in the ED where all team members collaborate congruently with the same goal of preserving a patient's and family's comfort and facilitating continuity of care. This would likely reduce moral distress and possibly burnout for all professionals involved by improving their satisfaction with the provision of high quality palliative care (1). Further studies should aim to explore the experiences of CMC's families' during their ED visits and their beliefs about the role of the ED in PPC to assess the quality of such a comprehensive approach to palliative care.

This study has some limitations. First, this study was performed in one tertiary care center and its findings are not generalizable to all settings for two important reasons. First, given that the participants in our focus groups all worked in ultra-specialized pediatric teams, our findings cannot be generalized to less specialized institutions. Second, PPC is a highly value-laden clinical field and practice: institutional, as well as local and professional culture likely modulate our findings. Finally, the majority of the participants in our study mentioned having an interest in PPC 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 as this led to high quality discussions, reflections and team brainstorming.

The main strength of this study lies in its interprofessional data collection to provide a comprehensive overview of the problem of PPC in the ED and offer potential system-wide solutions. By addressing the role of the ED within the continuum of care that is palliative care, many novel solutions to previous problems can be suggested. Many of our findings suggest a need for a transversal approach to PPC 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. Future studies should explore patients' and parents' perspectives regarding the role of the ED in PPC.

Chapter 5: Results

Manuscript intended for a peer-reviewed General Pediatrics Journal

Throughout the initial data analysis using a constructivist approach to describe the role of the ED in PPC, the authors identified major themes related to the perspectives of pediatric healthcare professionals with regard to the provision of palliative care in the institution. Themes included discussions about goals of care with families and elements required for high quality PPC. A secondary analysis was therefore performed using a more deductive approach according to the existing concepts and definitions of continuity of care and the mutual learning approach. These concepts were judged pertinent by the authors to develop an analysis aiming to understand the practice of PPC and its difficulties in the institution. The second article therefore aims to provide concrete and practical tools for pediatric healthcare professionals to improve continuity of care for children in PPC and to improve their satisfaction with the care provided.

Pediatric palliative care in practice: Contrasting perspectives between acute and long-term healthcare teams

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Key points

Question: What are the experiences of pediatric professionals with palliative care?

Findings: This focus group study involved pediatric professionals from emergency medicine, critical care, complex care and palliative care. Definitions of palliative care are similar for all but different teams meet patients at specific moments of their illness, influencing their practice. Teams are concerned about goals of care discussions, continuity of care and communication with families/professionals; these are all potential sources of conflicts.

Meaning: Being curious about complexity of pediatric palliative care practice in different settings and being accountable for continuity of care are priorities in improving the practice.

Abstract

Importance: Continuity of care in pediatric palliative care is complex, especially during acute unexpected health events.

Objective: To explore and compare acute care and long-term care professionals' perspectives and experiences about pediatric palliative care.

Design: A cross-sectional qualitative study using a strategy of triangulation with focus group interviews was conducted in 2016-2017.

Setting: The study was done in a pediatric tertiary care university-affiliated center in Montreal with a specialized pediatric palliative care team.

Participants: Professionals from acute (Emergency Department and Intensive Care Unit) and long-term care (Complex Care Service, Palliative Care) teams were invited to participate on a voluntary basis.

Intervention/Exposure: Semi-structured focus group interviews were conducted with interprofessional groups of participants from the same pediatric subspecialty. A total of 6 focus groups were held: 3 with the emergency department as they had the largest number of staffs and 1 for each of other groups.

Main outcome: An exploration and comparison of different groups' experiences with pediatric palliative care to identify key areas for quality improvement in continuity of care and interprofessional collaboration in pediatric palliative care.

Results: Fifty-eight (58) participants were enrolled. Palliative care definitions were similar throughout groups: to provide active complementary care early in the illness, focusing on the child as a whole and supporting families. However, each group perceived a different role in the patient's illness trajectory, reflecting their own culture of care. Thus, they demonstrated important differences in their approach to palliative care in practice. Disagreements regarding when or how to discuss goals of care were expressed. Acute care professionals reported discomfort when having to introduce these discussions for the first time, while long-term care professionals perceived negative judgments about their patients' quality of life by acute care teams during acute health events. Personalized care, communication with families and continuity of care were thought to be key elements to improve quality of care and professionals' satisfaction. This challenges clinical behavior and collaboration to facilitate patients' and families' transitions between care units in complex health trajectories.

Conclusion: Pediatric palliative care is well recognized by healthcare professionals from different specialties, yet continuity of care is challenged by different groups' roles and interventions in a patient's illness trajectory. A reflective and mutual practical approach is key to improve quality of care and professionals' satisfaction.

Introduction

Pediatric Palliative Care (PPC) has evolved considerably over the last 15 years to provide a broader approach of active care integrating the patient's physical, psychological, social and spiritual components throughout an illness trajectory while also caring for each family's specific needs·(46, 47, 85, 86). The majority of pediatric patients requiring palliative care are Children with Medical Complexity (CMC) and they represent a very fragile population susceptible of being admitted on a recurrent basis (3, 4, 87, 88). These children live with ongoing multisystem illnesses, congenital or neurological diseases and have functional impairments requiring technology for daily living (3, 19, 26-28). Given their needs for many specialized services and healthcare support (29, 88), they are at risk of suffering from fragmented and suboptimal care from lack of coordination, communication and continuity of care (3, 17, 36). Continuity of care is defined by the patient experience and refers to the provision of coordinated and coherent care over time in 3 main dimensions (informational, relational and management).

Despite many initiatives in research and education for CMC, studies show that pediatric healthcare professionals still report discomfort communicating with families regarding end-of-life care, complicating continuity of care within involved services (15, 46). Palliative care consultations provide insight regarding patients' cultural and spiritual preferences to assist in shared decision making to guide short and long-term treatment plan and improve quality of life (22, 47, 89). These discussions are often referred to as goals of care or advance care planning. Unfortunately, PPC specialists are not available at all times in all healthcare settings (14, 47, 54, 55)·. Moreover, more recent approaches in palliative care aim to empower non-palliative care physicians and residents with improved symptom and pain management, and with better competencies in communication to meet patients' needs (90). Different healthcare professionals often have conflicting opinions regarding management and this can impact quality of care for families navigating the healthcare system during changes in clinical status or end-of-life situations (23). In fact, each profession is known to have its own values, experiences, practices, training and roles in the care of children and their families; these create unique groups of professionals who share a common and very specific culture (24).

Providing palliative care to CMC and their families therefore remains a complex institutional problem with impact on delivery of care. Previous studies have identified a need to develop research about organisational, cultural and clinical practices to increase knowledge about the care for these children (85). Our study aimed to understand the experiences, perspectives and challenges in the provision of palliative care for CMC from diverse professionals in one healthcare setting. As CMC often navigate in and out of acute and long-terms services as their clinical state evolves, the targeted services for this study were the PPC service, the Complex Care Service (CCS), the Pediatric Intensive Care Unit (PICU) and the Emergency Department (ED). This research also sought to identify weaknesses in continuity of care between services and potential areas of improvement.

Methods

This study obtained approval from the Ethics Review Board of the CHU Saint-Justine in August 2015. Methods are reported according to the Consolidated criteria for Reporting Qualitative studies (COREQ) (91).

Research team and reflexivity

The main author and the responsible author both conducted the focus group interviews. The main author (A.J.C) is a female Master's student in clinical ethics and a pediatric resident who had obtained the MDCM credential. The responsible author (N.G.) is a pediatric emergency medicine staff at the studied hospital. She is a graduated PhD researcher with experience in qualitative research, clinical ethics and palliative care. Relationship was established with participants prior to each focus group; authors were introduced to the group and explained their reason for their interest in the field. The importance and goal of the study were also shared with the group.

Study design

The research was designed as a cross-sectional study using a strategy of triangulation by including a variety of healthcare professionals from both acute and long-term care units to maximize the perspectives on the problem.

Participant selection and setting

Professionals from acute and long-term care teams with interest toward PPC were invited face-to-face and via email to participate in the study. Participants were therefore purposively recruited based on their area of expertise. Professionals were enrolled from the ED, the CCS, the PPC service and the PICU. Non-participation was mainly secondary to non-availability at time of focus group. Focus groups were held during lunch time in the conference room of each respective group.

Data collection

A total of 6 semi-structured focus groups were conducted and were approximately 60 minutes long. Three (3) focus groups were done with the ED team given the large number of professionals in this naturally occurring group and one focus group was done with each of the other teams given the smaller number of physicians in each of these groups. The authors wanted enough participants to obtain a sample representative of each team. Interviews sought to explore participants' perspectives without influencing them, therefore only a few open-ended questions were prepared beforehand by the two main authors. Questions aimed at understanding the participants' definitions and perceptions of PPC, their daily practice with palliative care and its challenges. Professionals were also asked to reflect on priorities for improvement of palliative care in the institution. On rare occasions, participants were prompted by the second interviewer when pre-established questions had all been discussed. Interviews were recorded with the written consent of participants. A microphone and the application ShurePlus MOTIV were used. Notes were taken during focus groups to facilitate participant recognition during the transcription process. Transcriptions were made verbatim by the main author and were not returned to participants.

Given the single center nature of the study and the delicate nature of the interviews, direct citations are reported as being from either acute care professionals (ED and PICU) or from long-term care professionals (PPC and CCS). This was done to ensure participant confidentiality.

Analysis and findings

Data analysis occurred in two steps for this study. The first step in qualitative data analysis borrowed elements of grounded theory to generate themes. The main and the principle authors individually coded each focus group after every interview using thematic analysis with NVivo software. Codes were then compared between the two researchers using the constant comparative method. Hypotheses generated in the first focus groups were tested in subsequent ones to ensure reliability. Overall, nodes were grouped together and organized into 5 main themes.

At the end of the data collection process, the researchers met with a qualitative research specialist to review the codification process. The main author also met with the third author (A.P.) to validate findings and guide the analysis. Participants were not asked to provide feedback on findings although results were disseminated on several occasions at regional and national meetings where many of the enrolled participants were present.

The second step of the data analysis focused on two of the 5 main themes. Indeed, two central themes emerged with regards to interprofessional collaboration in PPC that were also recognized as crucial in the medical literature review regarding high quality PPC: (1) continuity of care and (2) the mutual learning approach. Therefore, these two theoretical approaches were used to inform a secondary deductive analysis of the qualitative data. The interpretative framework of this secondary analysis is based on pragmatism as it focused on providing outcomes and solutions to a concrete problem.

Theoretical frameworks

The three dimensions of continuity of care (informational, relational and management) were used to classify data pertaining to this theme. Informational, relational and management continuity respectively imply that patient information is transmitted, therapeutic relationship is established over time and consistency of care plans occurs between all services (39). Second, the researchers referred to the values of the mutual learning approach to identify potential areas for improvement in the face of interprofessional conflict and include transparency, curiosity, informed decision, accountability and compassion. Collaborative communication, of which mutual learning is one facet, has been proposed as a foundation on which to build PPC by experts in the field (84).

Results

Demographic data

Fifty-eight participants were enrolled in the study, 81% were women, distributed evenly across age groups. Most (55%) participants were Caucasians and 46% reported not having a religion. Participants were divided equally among professions, with one-third being physicians, one-third nurses and one-third other professions. The majority had an interest in PPC, but few had formal training.

Five major themes were identified in the analysis and include healthcare professionals' definitions of PPC, key elements of high quality PPC, individual group culture, complexity of discussing goals of care and elements of care dissatisfaction between professionals.

Definitions of Pediatric Palliative Care

Participants were invited to explain their understanding of PPC and definitions were overall very similar. The main themes discussed across groups encompassed providing support to families and children along their illness, maximizing comfort and wellbeing throughout the child's life and offering personalized management according to goals of care. For many healthcare professionals, palliative care has evolved in the past decade and is now initiated early when the purpose of care becomes non-curative. The PPC service specified the importance of helping all family members in their grieving process after death. Most professionals also emphasized that palliative care is an integrated and interdisciplinary practice for which many different professionals are involved and not necessarily only a specific person or team. Finally, an academic dimension of palliative care was suggested by some participants in CCS, PPC and PICU. They believed there was a need to share the palliative care experiences of a tertiary care centre to peripheral centers to provide feedback to community pediatric teams involved in the care of CMC.

Key elements of high quality PPC

Having described a shared theoretical understanding of PPC, participants further reflected on key elements required to develop an ideal approach to palliative care in practice. Table 4 presents the major suggested themes with their minor nodes to facilitate and implement high quality PPC in the institution.

Table 4 : Elements required for high quality PPC in the institution

High quality PPC in practice	**Participants' verbatim**
1. Continuity of care	Management: *"Ideally, I think there should always be someone from CCS or palliative care who already knows the child, or the oncology team or other teams, who can give you insight, a 3-minute overview of what is happening with the child."* (Long-term care professional to acute care teams) Informational: *"If there could be a mechanism (…), a little pop up saying "patient known to palliative care" (...), or something to alert. And also that the letter [about goals of care] that was written by the palliative care team be integrated (…) to the electronic record."* (Acute care professional) Relational: *"It is everybody's responsibility. (…) But the main part of the follow up - with everything that comes with palliative care and the repeated discussions - has to be with the primary care team. (…) Disease progression is a process, it is a pathway, and we can't do this periodically."* (Acute care professional)
2. Communication with families	Informed decisions: "*What is the alternative if ever we don't do everything we can do in the resus room? This I think it often not said, and it is important to say that we will heal, it is important to say that we will relieve*." (Long-term care professional) Repeated discussions: *"At diagnosis, you will say everything, the full disease progression, and then year after year (…), you never come back to the possible upcoming complications."* (Long-term care professional) Education: *"We learn to deliver bad news, we learn to disclose care errors, well maybe we should also learn to communicate in those kinds of situations (…) because sometimes even with the best intention in the world you will say a wrong word that will haunt parents for weeks."* (Acute care professional)

3. Personalized care	Families’ own pathway: “*It is a big challenge to provide good care to parents and a child somewhere in their care process, appropriate to what they want at this time, because the week before it might not have been the same. (...) So it requires time, empathy and sympathy.”* (Long-term care professional) Child’s best interest: *“It is a group of factors that make us take a decision and the medical diagnosis may not be the major element here. Maybe it will be what the child likes to do on a daily basis, what joy he takes from certain things and we base our decisions on that.”* (Long-term care professional)

Group culture and daily practice in palliative care

Although healthcare professionals shared both a similar theoretical understanding of PPC and an ideal for PPC, each group’s daily practice in palliative care was overall different. Each group demonstrated a specific culture and underlying values that guided singular approaches to palliative care. Also, these healthcare teams met with CMC and their families at various moments in the illness trajectory, thus developing relationships that focus on different aspects of care deemed most important at that time.

Emergency Department

The ED groups described themselves as being the doorway to the hospital and serves patients on an episodic manner, therefore lacking long-term relationships with families. Their traditional mission is to manage acute deteriorations, take rapid decisions and multitask. This usual approach to care, along with unsuitable physical environments, were identified as the main difficulties to providing palliative care in the ED. Nonetheless, on a day to day basis, emergency healthcare professionals understood their role in palliative care as communicating with primary care teams, managing distressing symptoms and organizing appropriate dispositions for children acutely unwell.

Complex Care Service

The complex care program defined their work as interdisciplinary, to support and accompany CMC and their families on a daily basis. The majority of children encountered in the program have an uncertain prognosis requiring flexibility from the CCS to offer care based on families' preferences. Participants highlighted the use of the best interest of patients and the importance of quality of life as guiding principles in their practice of palliative care, which is understood as an intrinsic part of their daily practice. By creating significant relationships with families, this team support patients and families throughout their decision-making process, at all times.

Pediatric Palliative Care service

The palliative care service is involved in the care of children with various backgrounds, from patients with chronic diseases with uncertain prognoses to acutely unwell children, and unexpected death. This team highlighted that their work focuses on ensuring integrated and optimal care management for each of their patient, mainly focusing on relieving symptoms and improving comfort. They also served as a support system for other healthcare teams within the institution and beyond, by providing clinical knowledge and educational initiatives. Establishing goals of care was an important part of their practice and shared decision-making was an essential tool for families to not carry the burden of the decision alone.

Pediatric Intensive Care Unit

The PICU team based many of their decisions on the best interest of the child. However, as the professionals of the most invasive medical technologies, their understanding of the best interest was explicitly value-laden. They reported being torn between providing life sustaining technologies to CMC and the feeling of inflicting overt suffering to patients with a palliative approach to care. They believed part of their mandate in palliative care was to ensure consistency of care between families, the PICU and primary care professionals and to ensure children preserve their dignity and die peacefully.

No “*good moment*” to discuss goals of care

The complexity of discussing goals of care was a recurrent and important theme for all focus groups interviewed and seemed to be a crux for all teams involved. Because of each group’s distinct culture and their practical experiences with PPC, acute care (ED and PICU) and long-term care (CCS and PPC) teams expressed conflicting perceptions regarding timing and motivations to initiate discussions about goals of care with the families of CMC.

On the one hand, acute care services rely mostly on the severity of clinical situation and need for advanced care to enquire about previous wishes. They however feel it is not their mandate to initiate first time discussions with CMC’s families:

> *“In general, when I am the one who has the first discussion with a family for a limitation of care, it means many people did not do their work.”* (Acute care professional).

Another challenge faced by acute care teams is having to take a critical decision about imminent management without knowing a child’s pathway of care and previous wishes. Most acute care professionals recounted tragic cases where treatment prolonged suffering of children and for this reason, they tend to ask earlier rather than later to avoid those situations and provide care consistent with parents’ wishes. Acute care professionals also believe it is everybody’s role to gain insight about a child’s best interest and signal to the team when a life-sustaining treatment is inappropriate:

> *“Sometimes, we find ourselves in those situations. It happens regularly that we have patients who stay in the intensive care unit for months and we close our eyes, and we don’t have discussions [about goals of care].”* (Acute care professional).

On the other hand, CCS and PPC are both teams that have adapted their practice to the heterogeneous pathways of the families coping with chronic illnesses. They have significant relationships with families yet initiating discussions about goals of care remains challenging:

> *“If you try introducing it before the child has deteriorated, parents don’t see it. Yes, they know the child is severely ill, he has a syndrome limiting his life, but it is a theoretical knowledge in their mind.”* (Long-term care professional).

As the child grows up, parents are more confronted to the impairment of the illness in the child's life and become more open to discussion. It was thought that there will never be a right moment to open up discussions and sometime families are just not ready to project in the future:

> *"I don't think it is an unwillingness of the teams, whether it be us or other teams who follow these patients, it is practically impossible to approach."* (Long-term care professional).

Furthermore, one long term care team reported families' frustration when rapidly asked about goals of care by unknown acute care services:

> *"The first thing the PICU does when entering the room is to ask me about levels of care. They did not evaluate the baby and already they have made a judgement on his quality of life."* (Long-term care professional quoting one of their patient's mother).

Elements of care dissatisfaction between professionals

In addition to conflicting perceptions about goals of care discussions, healthcare professionals from all teams have expressed different elements of dissatisfaction regarding quality of palliative care provided by other professionals from or even within their team. The main themes are presented in table 5.

Table 5 : Elements of dissatisfaction between professionals

Themes	**Participants' verbatim**
Perception of need for palliative care	"*Primary care physicians have the best relationship with families and if they are not 100% on board (...), we will never be able to bring families to share our vision of the child's management.*" (Acute care professional)
Dichotomous view of palliative care	*"It seems to be an all or nothing. Either we intubate, and we do everything (…) or we don't intubate, and we let him go."* (Long-term care professional)
Transmission of information about the patient	*"Obviously, we want to be prepared (…). If you know he is coming you will be able to look at the chart, find out who knows him, make a plan with the nurses for where he will go and who will receive him…"* (Acute care professional)

Vague understanding of care management within/between teams	*"Sometimes the level of care is a little bit vague for us (…) It is true that we are not as present as the nurse who is at the bedside of the patient, so sometimes we are not aware of everything that has been said, decisions that have been taken. Sometimes we find out as we go."* (Acute care professional)
Sensitivity for families' suffering	*"We can picture the emergency doctor or the nurse seeing the very severely handicapped child arrive in distress; the first question that comes to mind is the level of care."* (Long-term care professional)

Discussion

This was a qualitative study with focus groups involving a variety of professionals caring for CMC at different moments of their illness and reporting on their experiences and beliefs on the provision of PPC in the institution. The study design purposely used a triangulation strategy to maximize the points of view on this complex problem with four interprofessional groups in one institution. Five major themes emerged in the data analysis: the definition of PPC, key elements of high quality PPC, the specificity of group culture, the complexity of discussing goals of care and elements of care dissatisfaction between professionals. To our knowledge, this is the first study to offer an institutional portrait of PPC using a diversity of healthcare professionals and teams and to explore the implications of services' values and culture on the practice of PPC and its difficulties.

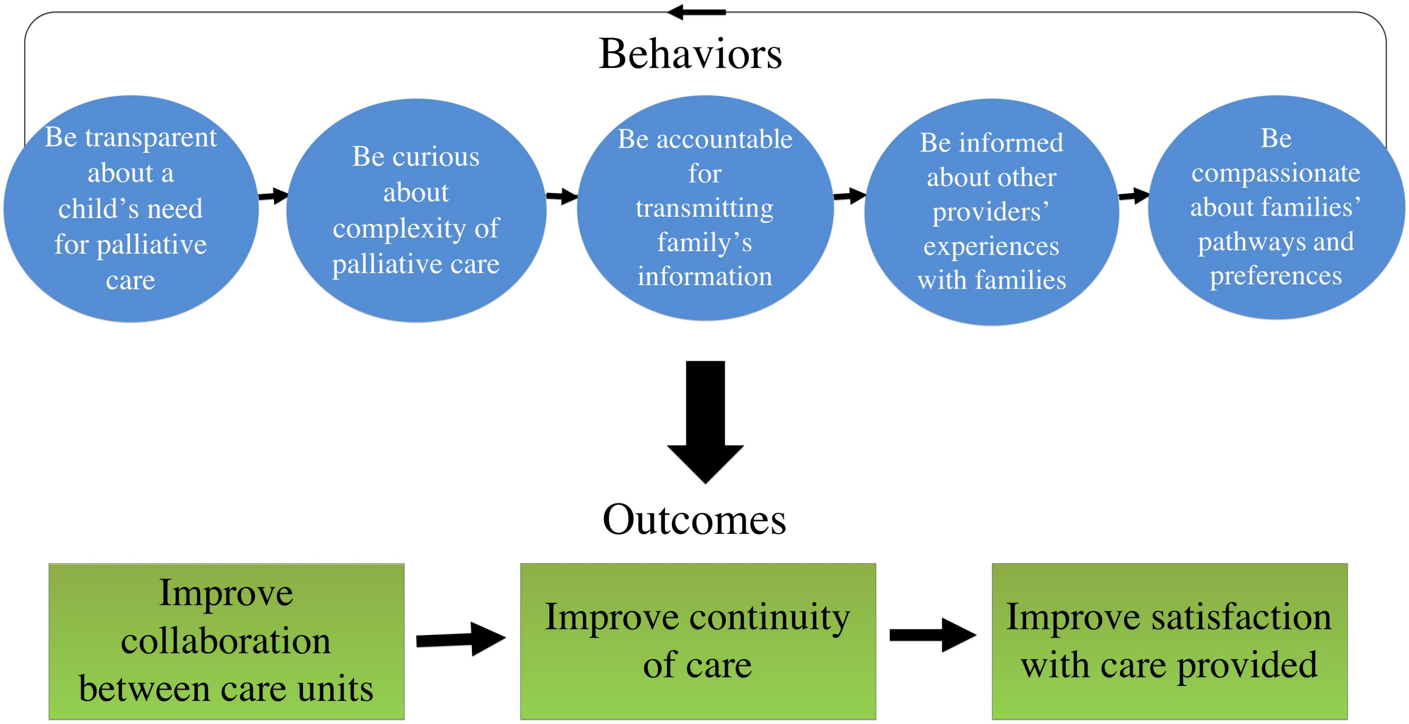
Our study shows that PPC is a well-recognized and understood concept in our institution. According to our findings, PPC is an integrated and non-curative complementary approach focusing on maximizing comfort early in the diagnosis while supporting families through the illness. These results are consistent with the latest provincial and national standards in PPC, which emphasize a comprehensive approach focusing on quality of life (47, 48). Local standards also highlight the importance of respecting families' goals during their first palliative care consultation and pursuing curative therapeutic treatments and maintaining hope while maximizing comfort care (92). Furthermore, professionals from all focus groups homogeneously identify key practical elements in delivering consistent and high quality palliative care in the institution. Those elements include continuity of care, communication with families and personalized care to a child and family's pathway in illness and are consistent with focused areas of care improvement during palliative care consultation for CMC and parents' perspectives of good quality end-of-life care (14, 93).

Despite this excellent understanding of the theoretical mission of PPC, professionals from our study expressed different team values, relationships with families, daily practices and roles in palliative care. Anthropological and sociological studies have identified that different group cultures exist between disciplines. Indeed, when students and professionals enter a group, they undergo a socialization process by which each specialty learns to behave to the acceptable standards of practice of that specific group (24, 94). These meaningful differences in culture can lead to conflicts between groups. In our study, we empirically demonstrated that group culture complicates discussions about goals of care, and that, in the context of interprofessional collaboration, participates in creating negative assessments of the care delivered by other healthcare teams. Two distinct points of view contrast between acute and long-term care teams. On the one hand, CCS and PPC highlight the need for non-judgmental interactions with families as they have difficulties anticipating their preferences for their child before a concrete acute event. On the other hand, PICU and ED tend to enquire early about previously established wishes to prevent unnecessary invasive intervention. Although both these perspectives have been suggested in the literature, ours is the first study to empirically demonstrate this phenomenon. Indeed, the Canadian Pediatric Society recommends early care planning to prevent palliative care becomes a last resource equating failure of treatment or abandoning the child (95). However, Feudtner explains that an acute change of clinical status leads to a complete reframing of a family's priorities and discussions about their preferences should take place again at that time for this reason (84).

The challenges raised by interprofessional collaboration in PPC will likely persist and call for clinical tools to prevent and overcome conflicts. The five values of the mutual learning approach developed by Schwarz et al. can be applied to the current problem to develop skills and behaviors for all professionals to reduce tensions, improve collaboration between groups and improve satisfaction with the care provided (42, 43). Figure 2 presents those behaviors that respond to many of the interprofessional elements of care dissatisfaction highlighted in the interviews. First, transparency is required from healthcare professionals when they feel a child may benefit from a palliative approach to care; transparency is necessary to engage a team in important discussion by explaining one's thoughts about a patient's situation with others. Second, curiosity and humility are needed by healthcare professionals to gain insight from others' perceptions of a clinical situation and to continually develop their knowledge about the complexity of PPC. Third, accountability requires of healthcare professionals that they reflect on their role in PPC and that they transmit important patient information to colleagues to facilitate care management through all units. Fourth, keeping oneself informed throughout the continuum of care is necessary to stay aware of other teams' interactions with families and discussions about their preferences. Last, compassion could not only be part of all interactions between team members, it could also be offered to families at all times while accompanying them through their unique experience of illness.

Such a mutual and compassionate approach was shown to be beneficial in the field of management and could potentially be equally favorable in pediatrics to enhance trust between different healthcare teams and increase a shared devotion to provide PPC of the highest quality (43, 96). Similar desirable behaviors have been previously suggested for clinicians to adopt a reflective, opened and engaged approach during communication with families of newborn with neurological injury (97). In the pediatric ED, this approach could be lead to a sustainable continuity of care between healthcare professionals by focusing on organizational changes such as easier access to patient information and devotion to providing holistic care to an unknown patient.

Figure 2. Healthcare professionals' skills to foster collaboration in PPC



This study has some limitations. First, this study was performed in a specialized tertiary care center and its findings cannot be generalizable to less specialized institutions. Nonetheless, engaging primary care physicians involved in the care of CMC has been found to be part of improving continuity of care and this is certainly a generalizable message. Second, the majority of participants enrolled in the study reported having an interest toward palliative care and therefore, their professional values could have modulated the findings. Third, the study suggests professional behaviors to improve continuity of care, but those findings should be validated with families' perspectives. This limitation was known from the beginning of the study and was accepted as the goal of the research was to first explore the experiences of the professionals in the institution, before enrolling fragile families.

The biggest strength of this study is to provide concrete and practical tools for all healthcare professionals to improve the quality, the consistency and the competency of PPC inside and outside of the institution. This collaborative approach aims to actively engage professionals from various services in reflecting on their own role in improving quality of PPC practice and on other professionals' experiences with PPC. It ultimately addresses areas of potential conflicts between different services, directly impacting professionals' satisfaction with care provided to families.

Chapter 6: Conclusion

This was a qualitative research with a strategy of triangulation primarily aiming at exploring the role of ED healthcare professionals in PPC from different professionals' perspectives. The second aim of this study was to create an understanding of the experiences and practices in PPC of acute and long-term professionals involved in the care of CMC. The final objective of the study was to provide practical solutions to improve and facilitate palliative care for CMC in our institution.

PPC is readily recognized by all healthcare professionals interviewed in this research and its understanding is overall similar across groups: to provide active complementary care early in the illness trajectory, focusing on caring for the child as a whole and establishing trustful relationships with families. However, each interprofessional group demonstrates specific culture with various experiences, practice, relationships with families and timing of interventions in the illness course of the children. They therefore have distinct practices with PPC with own struggles and vision on the role of other teams in caring for children requiring a PPC approach.

Although these particular characteristics and philosophies influence professionals' beliefs about PPC in the ED, it is overall thought that the ED could be better organized while caring for children in PPC. Multiple roles are suggested and can be integrated together to create an interprofessional approach to PPC during acute deterioration of CMC with potential for end-of-life. ED professionals could first rapidly evaluate the clinical situation to assess acuity of medical condition. If time is limited, they need to enquire about previously established wishes with families and expressed their concerns. They could then try to contact a team known to the patient to have further support and seek to maintain continuity of care by listening to families' preferences, find a quiet and private space, alleviate distressing symptoms and organize admission toward appropriate unit. This approach emphasizes the different dimensions of PPC intrinsic to some of the main acute and long-term care teams in the institution caring for children in palliative care before, during and after an acute deterioration. These areas could be the focus of the ED to improve the environment and be better prepared to receive CMC at any time in their illness trajectory.

As acute episodes in the health of CMC will continue to happen, healthcare professionals from different specialties could develop a reflective practice to become aware of their own role in PPC with families and with other services involved. This reflection begins with a sensibility toward the main complex elements intrinsic to high quality palliative care, including continuity of care, communication with families and personalization of care to each child's quality of life and preferences. Practitioners from and outside the institution are all part of the illness trajectory of families of CMC and the findings of this research can be generalizable to them. In fact, our focus groups reveal gaps in PPC practice at our institution, calling for a need to develop practical tools facilitating an interprofessional collaborative approach to PPC. These tools aim to improve the continuity and quality of PPC as well as the satisfaction of the professionals with care delivered. The practical skills of this collaborative approach include being transparent about a child's need for PPC to initiate care early, being curious about complexity of PPC, being accountable for transmitting patient's information to colleagues, being informed about a family's pathway in other services and demonstrating compassion for a family's preferences. Such a mutual approach implies the active involvement of physicians, nurses, social workers, respiratory therapists, psychologists and physiotherapists among other professionals to work together toward the delivery of consistent, compassionate and competent pediatric palliative care.

Future direction of this study will aim at exploring the experiences of the families of CMC who faced acute deterioration in the two pediatric hospitals in Montreal to assess if this approach is consistent with the families' needs. This will ensure data validation and will further guide education to professionals toward PPC practice.

Dissemination of knowledge

Results of this qualitative research have been disseminated on multiple occasions from 2016 to 2018. Two scientific manuscripts are in preparation and aim to be publicized within the next few months in Emergency Medicine and Pediatrics journals. Results were presented to local, provincial and national conferences: the International Congress in Pediatric Palliative Care, the International Congress on Palliative Care, the Annual joint Pediatric Residents Research Day, the Annual Canadian Bioethics Society conference, the Pediatric American Society meeting, the Canadian Pediatric Society conference and the Canadian Association of Emergency Physicians conference.

Direction for future research

As the goal of the study was to first understand the perspectives of the healthcare professionals at a tertiary care center on what the role of the ED could be in PPC, families have not been involved in the project. In order to further contribute to new guidelines in practice, further research will aim to understand the experiences of patients and families of children with medical complexity during their passage in the ED. The objective of this subsequent research should be to include more than one pediatric center as cases of acute deterioration and discussion about goals of care are not routine and this would maximise the number of families, and the generalizability of the data. Furthermore, families can have experiences at more than one hospital, for instance when requiring a second opinion. Such a study will also help expand the knowledge about PPC in the ED and create cooperation between healthcare institutions to develop and implement pathways of care in the provision of PPC in pediatric emergency medicine. Finally, this future research will enable to validate the mutual approach suggested and will facilitate the development of education courses on PPC for healthcare professionals inside and outside of the institution.

Reflection of own practice

As a second-year pediatric resident rotating through different units in the institution, this study certainly made me self-reflect on my own role in caring for CMC. This research exposed me to the complexity of providing consistency in care management and coherent messages to families in a difficult context of high professional turnover, different levels of training in PPC and pressure to enhance patient flow in the hospital. After having completed this research project, my personal conclusion is that although a visit to the ED will remain an acute and emotional event in a patient's illness trajectory, continuity of care can and should be ensured to improve quality of care for the family. Elements of continuity of care are well described in the literature and were also found to be major themes of our data analysis across acute and long-term care services. On the other hand, maintaining consistency of care appears very challenging to me as clinical decisions can vary from physician to physician and nurse to nurse, especially in an environment with high staff turnover and need for rapid intervention. Variability of decision will continue to happen depending on cultural differences between healthcare professionals and healthcare services. The concept of continuity of care is more concrete and can facilitate organizational changes in the ED with easier access to patient information, sensibility to reaching out to the appropriate support for a family and desire to become involved in the management of an unknown patient. Focusing only on consistency in care management leaves less opportunity for flexibility and clinical intuition, which makes the practice of medicine an art in my eyes. Clinical judgment is always required in acute situations and there might be times where a healthcare professional feels the need to reassess a family's preferences and challenge the previous care plan with new information. Healthcare professionals should however always ensure to offer compassion to families and approach them with respect and open mind to facilitate good relationship and communication.

Finally, this project certainly encouraged me to develop more expertise in PPC during my residency training and to share this interest with my colleagues. Developing an awareness toward the perceptions of physicians, nurses, social workers, respiratory therapists and other healthcare professionals' practice in PPC made me gain confidence in my own role for CMC and children with potential for end-of-life. I recall cases where I felt confident asking the team to pause and take time to discuss family’s preferences and possibility of palliative care support despite not having ownership on this particular patient. Caring for families and children should always remain the priority of all conflictual situation and any professional has the duty of advocating for them at any time.

I will conclude this master’s thesis by mentioning that completing graduate studies in clinical ethics confirmed my interest for a practice in an acute setting. I thrive in the possibility of rapidly developing significant interaction with families during critical moment and for the opportunity to become a front-line healthcare professional guiding the children and their family through the institution.

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Annex 1: Sample of a recruitment poster

PROJET DE RECHERCHE :

LE RÔLE DE L'URGENCE PÉDIATRIQUE EN SOINS PALLIATIFS PÉDIATRIQUES

QUI ?
TOUS LES SOIGNANTS TRAVAILLANT À L'URGENCE

- Médecin
- Infirmier/ère
- Préposé(e)
- Inhalothérapeute
- Travailleur social

QUOI ?
GROUPE DE DISCUSSION D'UNE HEURE

QUAND ?
15h20, MERCREDI 6 JANVIER 2016

OÙ :
A-360

COMMENT PARTICIPER ?
INSCRIRE SON NOM SUR LA FEUILLE D'INSCRIPTION

DU CAFÉ ET VIENNOISERIES SERONT FOURNIS LORS DU GROUPE DE DISCUSSION

POUR PLUS D'INFORMATIONS VOIR :

DR. NATHALIE GAUCHER
ANNE-JOSÉE CÔTÉ

Annex 2: Demographic Questionnaire (French / English)

1. Quel âge avez-vous? ______ ans

2. Quel est votre genre ?   Homme   Femme

3. Êtes-vous (choisissez la réponse correspondant le mieux à votre pratique) :
    1. Médecin (précisez votre spécialité : ________________________)
    2. Infirmier/ère (précisez votre spécialité : _____________________)
    3. Préposé aux bénéficiaires (précisez votre spécialité ____________)
    4. Résident (précisez votre spécialité : ________________________)
    5. Autre (précisez : _______________________________________)

4. Depuis combien d'années exercez-vous ce métier ? ______ années

5. Encerclez la réponse qui correspond le mieux à votre pratique :
    1. Une majorité de ma pratique clinique se déroule à l'urgence pédiatrique.
    2. Je travaille majoritairement à l'urgence pédiatrique, mais une minorité de ma pratique clinique se déroule dans un autre service.
    3. Je travaille occasionnellement à l'urgence pédiatrique, mais une majorité de ma pratique clinique se déroule dans un autre service.
    4. Je ne pratique jamais dans une urgence pédiatrique.

6. Quelle est votre langue maternelle ?
    Français   Anglais   Autre : __________________

7. Quelle est votre origine ethnique ? ______________________________

8. Est-ce que la spiritualité occupe une place importante dans votre vie?
    Oui   Non

9. Pratiquez-vous une religion?
    Oui   Non
    Si oui, précisez laquelle : ________________________________

10. Selon vous, avez-vous un intérêt pour les soins palliatifs pédiatriques ?
    Oui   Non

11. Avez-vous déjà assisté à des formations (congrès, cours, présentations, etc.) sur les soins palliatifs pédiatriques ?
    1. Aucune
    2. 1 à 3 formations
    3. 3 à 6 formations
    4. Plus de 6 formations

12. Avez-vous un ou plusieurs patients qui ont déjà été suivis par une équipe de soins palliatifs ?   Oui   Non

13. Un de vos proches a-t-il déjà été suivi par une équipe de soins palliatifs ? Oui Non

1. How old are you? _____ years old

2. What is your gender? Men Woman

3. Are you? (Chose the answer corresponding to your practice):
    1. Physician (specify your specialty: _________________________________)
    2. Nurse (specify your specialty: ___________________________)
    3. Patient attendant (specify your specialty: ___________________________)
    4. Resident (specify your specialty: _________________________________)
    5. Other (specify: ____)

4. How many years have you practiced in this field? _____ years

5. Circle the answer corresponding best to your current practice:
    1. The majority of my practice is in the pediatric ED.
    2. The majority of my work is in the pediatric ED but a minority of my practice is with another service.
    3. I work occasionally in the pediatric ED, but a majority of my practice is with another service.
    4. I never work in the pediatric ED.

6. Which is your primary spoken language?

    French English Other: _______________

7. What is your ethnic origin? _________________________

8. Does spirituality have an important place in your life? Yes No

9. Do you practice a religion? Yes No

    If yes, please specify which one: ___________________________

10. According to you, do you have an interest toward pediatric palliative care?

    Yes No

11. Have you ever attended formal training sessions (conference, class, presentation, etc.) on pediatric palliative care?
    5. None
    6. 1 to 3 sessions
    7. 3 to 6 sessions
    8. More than 6 sessions

12. Have you ever been the primary healthcare provider for one or several patients who was/were followed by a pediatric palliative care team?

    Yes No

13. Has one of your close friends or family members ever been followed by a Palliative Care team? Yes No

Annex 3: Consent form

CHU Sainte-Justine
Le centre hospitalier
universitaire mère-enfant

Université de Montréal

INFORMATION SUR LA RECHERCHE ET FORMULAIRE DE CONSENTEMENT

Titre : Quel est le rôle de l'urgence dans les soins palliatifs pédiatriques ?

Personnes responsables :

- Anne-Josée Coté, étudiante à la maitrise en Sciences biomédicales, option Éthique clinique, Université de Montréal
- Dr. Nathalie Gaucher, MD, Section de l'urgence, Département de Pédiatrie, Université de Montréal
- Dr. Antoine Payot, MD PhD, Service de néonatalogie, Département de Pédiatrie, Université de Montréal

Source de financement : Fonds personnels.

POURQUOI ÊTES-VOUS INVITÉ À PARTICIPER À CE PROJET DE RECHERCHE ?

Le département d'urgence pédiatrique participe à des projets de recherche dans le but d'améliorer les soins chez les enfants souffrant de maladies complexes et chroniques. Nous sollicitons aujourd'hui votre participation en tant que soignant. Nous vous invitons à lire ce formulaire d'information afin de décider si vous êtes intéressé à participer à ce projet de recherche. Il est important de bien comprendre ce formulaire. N'hésitez pas à poser des questions. Prenez tout le temps nécessaire pour décider.

POURQUOI MÈNE-T-ON CE PROJET DE RECHERCHE ?

- Contexte et pertinence de la recherche

Un enfant dont la qualité de vie est affectée par une maladie complexe et chronique peut se présenter à l'urgence à tout moment dans la trajectoire de cette maladie à la suite d'une détérioration aigue de sa condition. Actuellement, le rôle de l'urgence pédiatrique dans les soins palliatifs pédiatriques n'a jamais été étudié. Mieux comprendre la vision des soignants en urgence pédiatrique et en soins palliatifs pédiatriques est nécessaire afin d'améliorer les soins pour ces enfants.

- Objectifs de la recherche

Nous vous invitions à participer à une étude visant à développer des connaissances sur la compréhension du personnel de divers départements du CHU Sainte-Justine (urgence et soins palliatifs pédiatriques) sur le rôle de l'urgence dans les soins palliatifs pédiatriques.

COMBIEN DE PERSONNES PARTICIPERONT AU PROJET DE RECHERCHE ?

Environ 40 participants prendront part à ce projet de recherche.

COMMENT SE DÉROULERA LE PROJET DE RECHERCHE?

1. Participant de l'équipe de l'urgence pédiatrique
   - Participer à des groupes de discussion incluant différents professionnels travaillant à l'urgence du CHU Sainte-Justine. Chaque groupe de discussion sera d'une durée de 1 heure et de déroulera dans la salle de conférence du département de l'urgence. Les groupes de discussion ont lieu soit pendant l'heure du midi ou avant/après un quart de travail. Chaque groupe de discussion sera formé de 10 soignants de différentes professions.
   - Répondre à un questionnaire démographique.
2. Participant de l'équipe des soins palliatifs pédiatrique
   - Participer à un groupe de discussion incluant différents professionnels travaillant en soins palliatifs au CHU Sainte-Justine. Chaque groupe de discussion sera d'une durée de 1 heure et de déroulera dans la salle de conférence du département de l'urgence sur l'heure du diner entre novembre 2015 et mars 2016.
   - Répondre à un questionnaire démographique.

COMBIEN DE TEMPS DURERA LA PARTICIPATION À CE PROJET DE RECHERCHE ?

Les participants à cette recherche seront tenus de participer à un groupe de discussion d'une heure entre novembre 2015 et avril 2016.

QUELS SONT LES RISQUES?

Il n'y a aucun inconvénient autre que le temps requis pour participer au groupe de discussion ou remplir le questionnaire.

Y-A-T-IL DES AVANTAGES À PARTICIPER À CE PROJET DE RECHERCHE?

Nous espérons que les connaissances acquises grâce à ce projet de recherche vous seront personnellement bénéfiques. Un avantage potentiel que nous souhaitons est d'améliorer les soins à l'urgence d'un enfant souffrant d'une maladie complexe chronique.

Y A-T-IL UNE COMPENSATION ?

Une collation (café, viennoiseries) ou un repas léger seront fournis aux participants des groupes de discussion mais ils ne recevront aucune compensation financière pour leur participation.

COMMENT LA CONFIDENTIALITÉ EST-ELLE ASSURÉE ?

Tous les renseignements recueillis demeureront confidentiels dans les limites prévues par la loi. Votre identité sera protégée en remplaçant votre nom par un code de recherche. Seule l'équipe de recherche aura accès au lien entre le code et votre nom. Il est possible que les thèmes discutés pendant le groupe de discussion soient répétés par les participants après le groupe de discussion, à l'extérieur du contexte de la recherche. Pour tenter de prévenir ce phénomène, les chercheurs demanderont spécifiquement aux participants de garder toute l'information partagée au sein des groupes de discussion confidentielle.

Si les résultats généraux de ce projet de recherche sont publiés ou présentés lors de conférences scientifiques, votre nom et vos autres renseignements personnels ne seront pas utilisés.

Afin de vérifier le bon déroulement de la recherche et d'assurer votre protection, le comité d'éthique de la recherche du CHU Sainte-Justine (ou une personne déléguée) pourrait consulter les dossiers de recherche.

Les données de recherche seront conservées pendant 7 ans de façon sécuritaire sous la responsabilité du chercheur principal de votre hôpital, dans un bureau barré sous clef.

Les questionnaires seront détruits 7 années après la fin du projet de recherche.

ÊTES-VOUS LIBRE DE PARTICIPER ?

Oui. La participation à ce projet de recherche est volontaire. Vous êtes libre de refuser de participer à ce projet de recherche. Vous pouvez décider de cesser de participer au projet de recherche à n'importe quel moment.

Nous vous communiquerons toute nouvelle information qui pourrait avoir des conséquences pour votre bien-être ou votre volonté de prendre part à ce projet de recherche.
Si vous vous retirez du projet, aucune nouvelle donnée ne sera recueillie à votre sujet. Les données déjà analysées seront conservées.

PERSONNES-RESSOURCES

Si vous avez des questions concernant le projet de recherche ou si vous éprouvez un problème que vous croyez relier à votre participation au projet, vous pouvez communiquer avec le chercheur responsable du projet de votre hôpital :
-CHU Sainte-Justine : Dr. Nathalie Gaucher (514-345-4931, poste 5212) ou Anne-Josée Coté (514-616-5236)
Pour tout renseignement sur vos droits, vous pouvez vous adresser au Commissaire local aux plaintes et à la qualité des services :
-CHU Sainte-Justine : 514-345-4749.

OÙ PUIS-JE OBTENIR PLUS D'INFORMATIONS ?

Une affiche sera exposée au département de l'urgence pour expliquer le projet de recherche et vous inviter à participer. Le projet sera présenté lors des réunions du service de l'urgence pédiatrique du CHU Sainte-Justine et lors d'une réunion de l'Unité mobile de soins palliatifs pédiatriques.
Vous pourrez demander un résumé des résultats du projet de recherche ; ceux-ci ne seront disponibles que lorsque le projet sera entièrement terminé.
Vous recevrez une copie signée de ce formulaire. En tout temps vous pouvez poser des questions à l'équipe de recherche.

COMITÉ D'ÉTHIQUE DE LA RECHERCHE

Le comité d'éthique de la recherche au CHU Sainte-Justine a approuvé ce projet de recherche et en assure le suivi.

CONSENTEMENT

Titre du projet de recherche : Quel est le rôle de l'urgence dans les soins palliatifs pédiatriques?

On m'a expliqué la nature et le déroulement du projet de recherche. J'ai pris connaissance du formulaire de consentement et on m'en a remis un exemplaire. J'ai eu l'occasion de poser des questions auxquelles on a répondu. Après réflexion, j'accepte de participer à ce projet de recherche.

En signant ce formulaire de consentement, vous ne renoncez à aucun de vos droits prévus par la loi. De plus, vous ne libérez pas les investigateurs de leur responsabilité légale et professionnelle advenant une situation qui vous causerait préjudice.

___________________________________ ___________________________________ ______________

Nom du participant Consentement (signature) Date
(Lettres moulées)

J'ai expliqué au participant tous les aspects pertinents de la recherche et j'ai répondu aux questions qu'il m'a posées. Je lui ai indiqué que la participation au projet de recherche est libre et volontaire et que la participation peut être cessée en tout temps.

___________________________________ ___________________________________ ______________

Nom de la personne qui obtient le consentement (signature)
Date
(Lettres moulées)