

# Paediatric palliative care: challenges and emerging ideas



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Paediatric palliative care is an emerging subspecialty that focuses on achieving the best possible quality of life for children with life-threatening conditions and their families. To achieve this goal, the individuals working in this field need to: clearly define the population served; better understand the needs of children with life-threatening conditions and their families; develop an approach that will be appropriate across different communities; provide care that responds adequately to suffering; advance strategies that support caregivers and health-care providers; and promote needed change by cultivating educational programmes. Despite these challenges, advances in paediatric palliative care have been achieved in a short period of time; we expect far greater progress as the field becomes more formalised and research networks are established.

## Introduction

Paediatric palliative care (PPC) is focused on ensuring the best possible quality of life for children whose illness makes it likely that they will not live to become adults. Such care includes the family and extends into the domains of physical, psychological, social, and spiritual wellbeing. The frequency and circumstances of childhood mortality are geographically and socio-economically dependent, with some children having full access to the newest and costliest treatments and others little access to even basic medical care, food, and clean water. Applying the principles of PPC to a particular child and their family will thus vary depending on the availability of local resources and training. While recognising the need to improve access for the many children worldwide that lack basic medical care, we contend that all children facing the possibility of death would benefit from the application of basic, low-cost principles of PPC. We review six challenges in the field of PPC.

## Challenge 1: Defining PPC

While different definitions of PPC have been published,<sup>1-7</sup> the challenge remains to create a definition that is relevant across cultures and nations. The WHO definition provides a good starting point in encompassing the needs of children with life-threatening illnesses and conditions worldwide (panel 1).<sup>4</sup> Differences of opinion exist about whether the term “life-threatening” (where a cure is possible) or the term “life-limiting” (no realistic hope of cure) is more appropriate when defining conditions that merit PPC.<sup>8</sup> In this review we use the broadest term, “life-threatening”, since we believe that most illnesses and conditions are characterised by prognostic uncertainty, with no consensus among experts on which conditions have “no reasonable hopes for cure”.<sup>9</sup> The two case examples of children both with the genetic defect trisomy 18 and a potentially surgically-correctable congenital heart defect (panel 2), illustrate how the principles of PPC can be applied in the context of prognostic uncertainty.

Despite having the same underlying genetic disorder, these two children had different experiences, not just because of the varying phenotypic expression of the disorder,<sup>10</sup> but because of complex interrelated considerations that needed to be synthesised into a

comprehensive approach to care. The child, family, and care providers have overlapping but differing concerns in terms of personal factors such as personality, values (including spiritual, religious, and cultural), cognitive ability, well-being, personal history, and experience; sociodemographic factors, including age, education, and economic status; contextual factors ranging from peer influences to resource availability, or current events such as high profile media attention regarding an end-of-life controversy.<sup>11-15</sup>

Both data<sup>16</sup> and clinical experience favour a blended approach to care that includes disease-directed treatments together with palliative care. This approach is most often favoured by parents who commonly hope for their child's life to be prolonged, while also wanting their child to have as much comfort and as little pain and suffering as possible (figure).<sup>16</sup> Patients should not have to choose between life-prolonging treatments (such as chemotherapy for cancer) and palliative care. Rather, as in the cases of

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### Panel 1: WHO definition of palliative care for children<sup>4</sup>

Palliative care aims to improve the quality of life of patients facing life-threatening illnesses, and their families, through the prevention and relief of suffering by early identification and treatment of pain and other problems, whether physical, psychosocial, or spiritual. The principles of WHO's definition of palliative care for children with life-threatening illnesses also apply to other paediatric chronic disorders:

- Palliative care for children is the active total care of the child's body, mind, and spirit, and also involves giving support to the family
- Palliative care begins when illness is diagnosed, and continues irrespective of whether or not a child receives disease-directed treatment
- Health providers should evaluate and alleviate a child's physical, psychological, and social distress
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited
- Palliative care can be provided in tertiary-care facilities, community health centres, and at home

Jeremiah and Grace, palliative care should be integrated into an overall plan that is individualised and adaptable.

One aspect of palliative care for children that overlaps with that for adults is end-of-life care. Although some children with life-threatening conditions live into adulthood, those who reach the terminal phase can stay in this phase for hours, days, or even months. During this phase, the focus of PPC is on the physical, emotional, social, and spiritual needs of the child, as

well as in supporting the family who may continue to hope for a miracle cure. Although wishing for a miracle cure might seem incongruous with simultaneously accepting the reality of their child's impending death, these dual, opposing thoughts, can co-exist and do not necessarily signal underlying denial. The case in panel 3 underscores the definition of end-of-life care in the context of palliative care.

Garrett's end-of-life care lasted about 1 day, from the time his family agreed to the decision to discontinue ventilatory, to the time of death. However, PPC services were offered to him for several years before death, and continue through the provision of bereavement services.

Importantly, healthy children who are injured in a motor vehicle accident, for example, or develop an acute illness such as meningococcaemia, might also benefit from PPC principles appropriate to an intensive-care setting. At these times, PPC could be especially useful in arriving at complex end-of-life decision-making, as well as to address the bereavement needs of surviving family members.<sup>17,18</sup>

In considering PPC as a philosophy of caring for children who are seriously ill, one obvious conclusion is that it should be the standard of care for all children, whether or not their condition is life-threatening, or at a minimum for all children with chronic illness. However, when there is a possibility of death, the task of fully integrating the physical, emotional, social, and spiritual needs of children into the plan of care is more challenging. We believe that greater numbers of experts in PPC are needed to: (1) provide clinical advice and consultation in complex situations—not all primary clinicians have the education and clinical experience to achieve optimal symptom management and to provide anticipatory guidance;<sup>19,20</sup> (2) ensure curricular attention to basic PPC concepts in the education of health-care professionals;<sup>21</sup> (3) advocate for improvements, both within health care and in the community, that serve to enhance the effectiveness of PPC (eg, such as the provision of adequate home-care services;<sup>21</sup> (4) pursue research in order to advance the field of PPC;<sup>1</sup> and (5) serve as leaders in a field that is currently in the early stages of development.

Thus, there are two levels of PPC being considered in this review—the conceptual considerations that are applicable to all children with underlying life-threatening conditions and their families, and the need for experts to provide consultation for patients with more complex needs and to serve as leaders in a field that is unfolding.

## Challenge 2: Better understanding the needs of PPC

There is little outcome data about the needs and effectiveness of many PPC interventions—most existing publications are descriptive. Reasons for the lack of outcome data include the small number of children eligible to be studied in any one institution, the lack of standardised measurement scores for pain and quality of

### Panel 2: Jeremiah and Grace

#### Jeremiah

The PPC team met Jeremiah at 3 months of age when he was transferred from a subacute hospital to a tertiary care center for consideration of repair of a large ventricular septal defect in the setting of Trisomy 18.

Jeremiah's mother, a single parent with three other children including a supportive 22 year-old daughter, lived together in an urban neighbourhood and used public transportation to travel to the hospital. The Haitian mother had been in the US for 6 years and, although able to speak basic English, requested and benefited from a Haitian translator. Jeremiah's mother participated in health-care team meetings, understood that her son would probably die very young, and expressed her strong faith in "all things being possible with God". She believed in the power of prayer to "change any situation" and said that Jeremiah was a "gift of God".

Discussions with members of the PPC team, the cardiology department, and the mother, culminated in the decision to go ahead with surgical closure of the septal defect since this choice seemed to offer the best chance for Jeremiah to live with reduced symptoms of heart failure and less frequent need for hospitalisation.

However, despite surgery at 3 months of age, Jeremiah's post-operative course was complicated by intermittent respiratory distress and hypoxia because of a residual ventricular septal defect. Given his mother's plan to have him home, the PPC team and others worked to transition him home with nursing support, and when this was not successful, he was transferred to a chronic care facility. He finally died in hospital surrounded by his family, and with his dyspnoea symptoms well under control.

The PPC team helped in the process of balancing the risks and benefits of a myriad of potentially life-prolonging but also potentially burdensome high-technology procedures including advanced cardiac surgery within a tertiary care environment.

#### Grace

Grace's diagnosis of trisomy 18 was detected prenatally, at which time her parents contacted the PPC team for guidance. Grace's parents were both devout Catholics, her mother an intensive care nurse and her father a social worker. Before the birth they decided that they would not want Grace to experience any intensive medical interventions, even if she were to die at birth. If she were to survive however, their hope was to provide her with the best quality of life at home. Despite also having a substantial ventricular septal defect, her birth was uncomplicated and she was discharged home soon after.

Home care was arranged with weekly visits by an interdisciplinary PPC team. Grace thrived at home, her cardiac disease was managed medically, and she took all of her feeds by mouth. After several months, her parents faced a crisis having felt pressured to accept one team's medical opinion that Grace should undergo surgical repair of her septal defect. With the help of the PPC team her parents were able to obtain other medical opinions that supported their desire not to pursue surgery. At 7 months of age, given Grace's continued stability and good quality of life, her parents elected to discontinue the PPC team's services, knowing they had the option of re-enrolling at any time. Grace remains stable, is being followed-up by the cardiology team, and at 3 years of age has not needed to be admitted to hospital.

life in young children, and the fact that the need for such research in PPC has only been recognised in the past few years.<sup>22</sup> Despite the limitations of research-derived data to date, there have been some important findings. First, a substantial number of children have pain and other distressing symptoms, and data suggest that these symptoms are not well managed.<sup>19,23–32</sup>

Second, most children die in hospital,<sup>23,27,28,33,34</sup> several of these in intensive care units.<sup>24,25,29,30,35</sup> Moreover, although DNAR orders are in place for most children at the time of death, they are frequently instituted very close to the actual time of death.<sup>24–26,28–30</sup> Whether these children could have been better cared for if they had been discharged home earlier from the hospital, or whether more could have been done to ensure their comfort while they were dying in hospital is unknown.

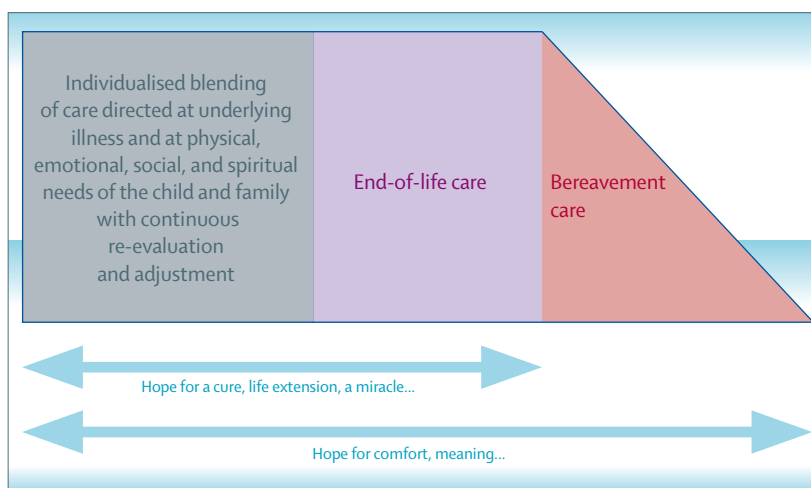
Third, initial studies indicate parental dissatisfaction with staff as a result of confusing, inadequate, or uncaring communications regarding treatment or prognosis<sup>36</sup> and discrepancies in understanding of the terminal condition between physicians and parents.<sup>16</sup> Particular problems also arise in meeting the needs of siblings and other family members who do not speak English.<sup>36</sup>

Finally, the death of a child affects the physical and psychological wellbeing of family members for the rest of their lives, and events that occur around the time of death, both positive and negative, are highly important.<sup>27,36–39</sup> Families who are able to care for a dying child at home may be more likely to cope with the bereavement period.<sup>40–43</sup>

Some of the basic needs regarding end-of-life care, as expressed by families who have lost a child, include the need for honestly communicated and complete information, good access to staff, emotional expression and support by staff, coordination of services, preservation of the integrity of the parent-child relationship, faith, and meaningfulness.<sup>18,38,44</sup> Emerging data suggest that family perspectives are critical to advancing the field of PPC.<sup>45</sup>

Research into the child's perspective has been especially neglected, presumably related to numerous concerns such as developmental differences, emotional fragility, and an overwhelming sense of not wanting to upset the child.<sup>46</sup> Despite these concerns, Hinds and colleagues<sup>47</sup> have shown that when asked in a sensitive manner, children as young as 10 years are able and willing to talk about their experiences and end-of-life decisions.

Data and clinical experience indicate there are several barriers to the ideal delivery of PPC (table).<sup>25,29,35,48–53</sup> Emerging models of PPC strive to overcome barriers while incorporating recommendations from international PPC initiatives.<sup>5,8,54,55</sup> In wealthier countries, where curative treatments are available to most children, PPC often translates to an interdisciplinary team of health-care professionals identified as having expertise in addressing the needs of children with a life-threatening illness, and their loved ones.<sup>56,57</sup> This specialised PPC team offers expertise and services to other health-care professionals



**Figure: Stages of palliative care**

Paediatric palliative care includes individualised integration of palliative care principles to manage expectations of life extension and comfort, both of which can be important issues throughout the child's life. End-of-life care is an important component of palliative care when the focus is almost entirely on comfort, though hope for a miracle can persist. Bereavement care needs can be intense and long-lasting, gradually lessening over time.

### Panel 3: Garrett

Garrett was a 12-year old boy with advanced cystic fibrosis, being cared for by an interdisciplinary pulmonary team. Because of their long-standing relationship with Garrett and his family, and limited experience with symptom management, the primary team found it difficult to recommend interventions aimed at increasing Garrett's comfort level. PPC consultation facilitated greater integration of strategies aimed at ensuring his comfort, such as introduction of self-hypnosis for easing anxiety related to dyspnoea. At the same time, there was continued attention to Garrett's underlying disease, and he was listed for a lung transplant. His condition continued to worsen, and several months later the PPC team facilitated the decision that a DNAR (do not attempt resuscitation) order be written on his behalf, and recommended opioid dosing to improve his comfort.

Several days later, as the family was gathered to be present with Garrett during this phase of his life, word came that he would receive a lung transplant. The surgery was successful, and the PPC team continued to follow-up Garrett and his family closely, despite the shifting focus of care, to ensure his overall wellbeing. For the next 2 years, he was in and out of the hospital, including a stay of several weeks in the intensive care unit, and the PPC team visited him both at home and while in the hospital. He was subsequently readmitted, with a respiratory exacerbation and eventually intubated. With time, disseminated aspergillus was diagnosed, and though efforts were made to begin treatment, Garrett's condition continued to decline. After extensive conversations between his family, members of Garrett's primary-care team, and the PPC team, a decision was made to discontinue ventilatory support. Garrett received appropriate pain relief and died 20 minutes after extubation. The PPC team is providing ongoing bereavement support to his family.

(eg, the oncology team treating a child with refractory leukaemia) or directly to the child and family.<sup>1</sup> In some large paediatric health-care centres, PPC teams assign staff who respond to a significant number of consultations and provide direct care to children with advanced illnesses, both within the hospital and in the child's home. In settings with lower numbers of children, the PPC team may consist of members with a primary link to

	Consequence
<b>General barriers<sup>8</sup></b>	
Emotional considerations	Avoidance
Defiance of the natural order when children die	
Provider's sense of failure when a child dies	
Immeasurable parental distress at loss of child	
Prognostic uncertainty	Delayed focus on palliative care
Diversity of illnesses, rarity of death in childhood, and little formal education of caregivers	Inexperienced providers, and thus poor quality of care
Absence of developmentally appropriate assessment tools, and no pharmacokinetic data for children taking symptom-relieving medications	Poor assessment and palliation of symptoms
Poor reimbursement for time and labour-intensive, bio-behavioural palliative care	Under provision of services
Lack of universal health-care coverage for all children	Lack of access to palliative care
<b>Community barriers<sup>8</sup></b>	
Geographic diversity and lack of reimbursement for critical services such as in home psychosocial support	Underserved populations
Hospice-specific limitations (USA)	Delayed involvement of hospice
Requirement of life-expectancy fewer than 6 months	Inexperienced providers, and thus poor quality of care
Lack of experienced paediatric clinicians	Underprovision of palliative care
Low daily reimbursement rates (US\$120 per day)	
Not offered if "extended-hour nursing" already supports the child at home	
<b>Hospital barriers<sup>25,29,35</sup></b>	
May require emergency department visit	Disruption in continuity of care
Caregiver team	Poor assessment and palliation
New, less familiar	Inexperienced providers
Varying levels of experience	Underprovision of services
Frequent changes	Conflict
Differing values	
Stay might be extended and care can be intensive even if patient has declined intensive care	Added cost
<b>Barriers specific to developing nations<sup>49-53</sup></b>	
Unmet basic needs of children and families, including food and shelter	Palliative care is not prioritised
Increasing orphan population with advanced illnesses such as HIV	Limited availability of family caregivers
Limited access to pain-relieving medications	Poor palliation of symptoms

Table: Effect of barriers to provision of adequate palliative care

other services. For example such a PPC team might consist of a neurology nurse, an oncology social worker, a paediatric psychologist, and a paediatrician with expertise in pain control, who are all available to respond when the need arises.<sup>58</sup> Outside the hospital setting, there are a small number of freestanding paediatric hospices that are staffed by personnel with PPC expertise.<sup>59-62</sup>

The most common form of home-based palliative care in the USA is provided by hospice programmes, most of which are reimbursed through a "hospice benefit" with very precise specifications.<sup>63</sup> Many children, however, are not referred to a hospice because their illness experience is inconsistent with hospice specifications—ie, prognosis is uncertain, there are mixed goals (which can result in more costly health care), and providers lack paediatric expertise. In a survey of 632 paediatric oncologists, Fowler and colleagues<sup>64</sup> showed that continued

disease-directed therapy was cited as the most common reason for not making a referral, especially when the hospice did not admit children receiving chemotherapy. Thus, in most settings, there is no specific focus on PPC in hospital or community, and this leaves children with advanced illnesses and conditions to be cared for on an ad hoc basis by less experienced practitioners.<sup>1</sup>

To overcome barriers to PPC and enhance comfort for children with advanced illness, it is important to be creative and resourceful in how palliative care principles might be applied in different settings. For example, in a resource-poor country where a newborn with a severe chromosomal abnormality and subsequent respiratory failure has no access to neonatal intensive care, local health-care workers would benefit from training about the principles of PPC including the provision of comfort and counselling bereaved families. In a wealthier country, an adolescent with end-stage cystic fibrosis who is on a waiting list for a lung transplant in a tertiary-care paediatric hospital, could have their suffering reduced through symptom management and counselling or guidance on the high possibility of death, regardless of whether the final outcome is a successful transplant.

### Challenge 3: Integrating culture and spirituality into palliative care

There are serious concerns about whether the core principles of palliative care, initially developed in the UK and USA as a response to an increased institutionalisation of the dying, represent the values of different cultures.<sup>65</sup> Core principles involve: (1) open disclosure and honesty; (2) patients' autonomy through their active participation in decision-making; and (3) open expression of feelings, concerns, and needs to be able to work through unfinished business, ensure quality of life, and achieve a "good death" for the dying and enabling the bereaved to cope with the death.<sup>66</sup> These principles, formulated for the care of adults, are also important in the care of children in some Western cultures, even though minors (younger than 18 years) are not legally considered competent to make decisions that may irreversibly affect their life. Nevertheless, children are encouraged to openly voice their feelings, concerns, and desires and, whenever assessed as developmentally mature, they are invited in decisions concerning their care.<sup>6,47,67-70</sup>

The question remains as to whether such prevailing principles are relevant to children and families of different cultural origins. Medical research is replete with recommendations about how physicians should break bad news to parents,<sup>71-75</sup> and how to address such topics with children.<sup>73,76-78</sup> In some cultures however, children are not included in discussions of disease diagnosis and death.<sup>79</sup> Studies in China,<sup>80</sup> Japan,<sup>81,82</sup> and Greece<sup>83</sup> describe a protective approach towards the sick child that prohibits such communication, and limits the child's involvement in decisions about care. In China, for example, talking about the possibility of death in front of a sick person is

often viewed as cursing them or hastening death. Moreover, the display of emotions or discussions of family issues with non-family members is discouraged, while the use of subtle and non-verbal ways of expressing emotions (such as body language and eye contact), is encouraged.<sup>84</sup> In some of these cultures, honesty about dying is perceived as a brutal invasion that deprives the patient of a protective cocoon against adversity, and threatens the culturally prescribed roles and functions normally assumed by parents.

The lack of disclosure in these cultures, however, does not necessarily imply lack of communication. Findings suggest that the ill child and family members engage in behaviours, practices, and rituals that indirectly acknowledge the threat of death or impending separation, but avoid directly addressing topics which are considered taboo.<sup>83</sup> Children adapt to the values and rules that govern interactions in their immediate environment. They use codes and indirect channels of communication to direct questions and concerns to parents, care providers, and peers with the same disease.<sup>85,86</sup> In this way they develop culturally appropriate ways to express their concerns to staff members and are able to maintain the rules of mutual pretence with their family.

McKinley and Blackford<sup>87</sup> illustrated this clash of values in their assessment of the PPC services that were offered in an Australian paediatric intensive care unit to families of people of non-English speaking background. They noted that nurses unconsciously imposed their own cultural constructs of what constituted a meaningful death on these children and parents, and used controlling practices to ensure that families conformed to the values and rules of their unit. For example, the nurses' normative practice aiming to ensure privacy for parents and opportunities for intimate contact with their child by restricting the number of people allowed at the patient's bedside, was in conflict with some families' need for a communal approach towards their dying child. Offering care based on assumptions from their own personal and ethnic backgrounds, these health-care professionals misunderstood the needs of children and families, and enforced privacy and exclusive decision-making on parents who had other preferences and priorities. Rebagliato and colleagues<sup>88</sup> explored doctors' attitudes towards neonatal end-of-life decision-making in ten European countries, concluded that different cultures, legal systems, and religious contexts influenced physicians' attitudes towards end-of-life care.

Spiritual issues are central to the family's experience and narrative. Robinson and colleagues<sup>89</sup> reviewed qualitative data from a survey of parents of 56 children who died in three paediatric intensive care units in Boston, Massachusetts, USA. They recorded that spiritual or religious themes emerged in 73% of responses to questions about what had helped them most during the child's last phase of life and what advice they would offer

#### Panel 4: A hypothetical example of culturally sensitive palliative care

Sumalee was a 4-month old female when she was admitted to the hospital with a profound failure to thrive. A magnetic resonance image (MRI) showed a hypothalamic brain tumour with spinal metastases. The clinical presentation and findings were consistent with diencephalic syndrome, a rare disorder characterised by emaciation, emesis and euphoria in the context of a hypothalamic brain tumour.<sup>93</sup>

Sumalee was the only child of a young Thai couple living temporarily in the USA while her father pursued graduate studies. Her parents expressed their hope that Sumalee would be cured of her tumour, despite the medical prognosis that this would be unlikely. Her parents also made it clear that they were not concerned with their child's cognitive outcome, but rather with her long-term survival. Sumalee had chemotherapy, but not surgical resection since this would have been associated with high morbidity. However, when she was about 9 months old, still showing no improvement, her parents asked about re-addressing the possibility of surgical debulking. Since there was little support for this intervention from her primary clinical team, the family sought out another neurosurgeon who agreed to proceed with surgical resection. Despite an uncomplicated operation, Sumalee was in a coma afterwards, but was able to breathe without assistance. A gastrostomy tube was inserted, she began to gain substantial amounts of weight, and was discharged home.

Sumalee's primary oncology team were advised that further neurological recovery would be unlikely. On several occasions, her primary oncologist wanted to provide the parents with anticipatory guidance about potential life-threatening events. She explained the risk of aspiration pneumonia that might lead to death, especially without ventilatory support. Despite what felt like a good therapeutic relationship and the parents' previous willingness to speak openly, throughout these conversations they always remained silent. They would not agree or disagree with the recommendation to write a DNAR order. Their only clearly expressed hope was that she should not ever be readmitted to the hospital. Given their desire to keep Sumalee at home, she was referred to home-based hospice care. There was still no explicit DNAR order, and her home-care providers were concerned about what her parents would choose for Sumalee in the event of a life-threatening emergency.

One evening, her primary oncologist received a page that Sumalee seemed ill. She made a home visit, saw that she was in substantial respiratory distress and cyanotic, and told her parents that she would probably die without transfer to the hospital. The child remained at home, an act that was non-verbally approved by her parents, since they did not request for an ambulance to be called. Her primary oncologist sent DNAR and morphine orders to the staff of the hospice agency who provided symptom-relieving support at home. Sumalee died in the early morning hours.

to other parents whose children are dying. The themes that emerged included: prayer, faith, access to and care from clergy, and belief that the parent-child relationship transcends death. In another qualitative study of 36 children aged 8–15 years with cancer, one of the most common themes that emerged as essential to quality of life was “the meaning of being ill”, validating the notion that children also have existential needs.<sup>44</sup> Health-care professionals untrained in how to address the religious and spiritual concerns of their patients, often feel uncomfortable with these issues and may inadvertently neglect an important aspect of care. Barnes and others<sup>90</sup> have proposed general guidelines for appropriate integration of spiritual and religious resources in their practice, and Davies and colleagues<sup>91</sup> have developed an assessment tool to help professionals assess the spiritual needs of children with life-threatening conditions, and their families.

To adequately respond to the vast cultural and spiritual variation in disclosure, decisionmaking, and quality of life issues, clinicians should ask parents and children about their preferences and beliefs before confronting them with bad news and critical decisions regarding end-of-life care. Gatrads and colleagues<sup>92</sup> suggest that a culturally sensitive approach requires fundamental changes on at least three fronts: (1) tackling institutional discrimination in the provision of palliative care; (2) incorporating cultural issues in the medical and nursing curricula; and (3) embracing complexity and developing a richer appreciation of how minority communities achieve a dignified end of life. We believe that anthropological and sociological perspectives on the experiences of being ill and dying can broaden understanding of the multiple personal, familial, social, and cultural dimensions that caregivers attach to illness, suffering, and death. The hypothetical case in panel 4 highlights an individualised approach to caregiving.

In this theoretical example, when discussions were about “curative therapies” Sumalee’s parents were vocal, however, when it came to discussing the possibility that she would die, they remained silent. For the medical team, this communication style was extremely distressing, since it was not the team’s practice to rely on indirect communication when establishing goals of care. The family’s approach to end-of-life care, which was affected by cultural, ethnic, and religious factors, differed greatly from that of the medical team’s. However, by embracing the need to individualise communication and to respect the parents’ approach to end-of-life care, Sumalee and her family received compassionate care.

The challenge for care providers who work with families of different ethnic origins is to understand both how and why patients and families create their own “stories” and attribute meanings to illness, suffering, and death, while situating each story into a broader cultural and social context.

#### Challenge 4: Reducing suffering, and promoting hope and healing

Adult palliative care research on suffering,<sup>94,95</sup> hope,<sup>96</sup> and healing<sup>97</sup> has much to offer both in how to better care for children and their families as well as in how to support and sustain PPC health-care professionals in their work.

##### Suffering

The definition of palliative care<sup>4</sup> espouses the prevention and relief of suffering by addressing pain and other physical, psychosocial, and spiritual problems. Cassell<sup>98</sup> defined the concept of suffering as an experience that results from a threat to any part of an individual’s personhood, wherein personhood refers in part to personality traits and character, life experiences, cultural background, and the individual’s inner life (eg, dreams for the future). Aspects of personhood might also be threatened in children and adolescents, however emphasis is primarily placed upon suffering caused by the loss of life as yet unlived. While suffering in children, and especially in the very young, remains poorly understood, work that uses non-verbal means of expression such as in drawings (eg, mandala technique) indicates the depth and complexity of cognition and emotion in even very young children.<sup>86</sup> Suffering and anticipatory grief can also be expressed verbally in the context of a therapeutic relationship as described here between Sourkes—a psychotherapist—and an ill-child.<sup>86</sup>

Therapist: Are you in any pain? Does anything hurt?

Child: My heart.

Therapist: Your heart?

Child: My heart is broken...I miss everybody.

##### Hope

“Don’t give up hope.” “The parents have false hope.” “The child’s condition is hopeless.” These frequently used statements suggest that, although the concept of hope is poorly defined and the subject of ongoing debate, the notion is pervasive in health care, and especially in palliative care. That hope has become a clinical entity that might be altered by therapeutic intervention seems to be represented in the striking increase in the number of articles investigating its role in health care in the PubMed database from 1970 onwards.<sup>96</sup> Although the word has multiple connotations, hope is broadly defined as a subjective belief state that combines expectation with desire and imbues living with meaning and sense of purpose.<sup>94,96</sup>

Adults aware of their impending death might maintain hope by shifting from a hope for cure to hope for what they define as a good death (eg, as pain free and comfortable as possible) and with a focus on leaving a legacy. How to support hope for children with life-threatening illness is less clear. An additional challenge is the struggle for parents and other loved ones to maintain hope. What remains unexamined is the role of “healthy denial” in maintaining hope for cure despite a

very poor prognosis. It is possible that for some children and parents “unrealistic hope” in the face of overwhelming disease is a functional coping mechanism that does not necessarily signify pathological denial. At times, people might hold beliefs that although seemingly discordant with each other (eg, the knowledge that one is about to die at the same time as maintaining hope for a last-minute reprieve from death) could instead represent healthy coping.

In the documentary *Making Every Moment Count*,<sup>99</sup> a paediatric hospice nurse talks about a 17-year-old girl called Rachel who underwent lung transplantation for cystic fibrosis and who was very likely to die in the next few years from chronic rejection of the transplant. According to the nurse, “Rachel said very seriously that when she is to die, she wanted to be here in Canuck Place (paediatric hospice facility), in a hospice surrounded by friends and family, and surrounded by people that knew how to take care of her...and she was talking about the nurses and the doctors that can help her not feel scared. And then she said: ‘But I have another way that I’d like to die...I would like to be sitting on my front porch, wrapped in an afghan in a rocking chair and my husband holding my hand.’”

Hopelessness, the opposite of hope, is highly correlated with depression and is not expected in the dying.<sup>94</sup> For adults nearing death, hopelessness was not tied to knowledge of their condition but rather to loss of meaning and purpose. For parents who know that their children will soon die, hope may be fostered by helping to find meaning in their child’s life. Clinicians that ask questions such as “what are you most proud of about your child?” may encourage child and parent meaning making.<sup>100</sup>

### Healing

Healing is the process of moving from suffering towards a sense of wholeness or integrity that depends neither upon the functioning of organ systems or homeostasis, nor on the cure of disease. According to Kearney<sup>97</sup> healing is dependent on an innate potential within the ill person. Healing is not the result of external action upon the disease (eg, radiotherapy to a tumour site), but rather comes from within the ill person to establish wholeness even in the face of persistent disease. Healing can be fostered, or hindered, by the actions of health-care professionals. Actions that health-care providers may take to create the possibility of healing include:<sup>101</sup> (1) accompanying those in suffering—to be present in the face of suffering, to stay with the sufferer and listen, is an act that reduces suffering; (2) reducing physical pain and other distressing symptoms—with pain alleviated and symptoms controlled, a space is created in which healing may begin; (3) supporting the sufferer as they seek hope in the face of a probable early death—this can include a shift from hope for cure to other hopes (eg, to enjoy more time at home); and (4) helping sufferers to

re-frame their experience, to find some meaning in a part of what they are going through—re-framing involves helping children and parents consider alternative views and narratives for their own experience (eg, by creating a legacy).

To feel whole again, to be healed, need not be the only goal in PPC, but rather provides a frame of reference as to what may be possible, even if only partially realised. Quality of life can be seen as varying on a spectrum from suffering on one end to being healed or feeling whole on the other end. The task in PPC is to help the child and their loved ones find their way as far as they can along this continuum from suffering to wholeness.

### Challenge 5: Acknowledging professionals’ responses and need for support

Caring for children with life-limiting conditions, their family, friends, and peers, is highly stressful, yet can also be very rewarding.<sup>102–106</sup> Even though little is known about how health-care professionals cope with the challenges of PPC, studies suggest that they are at risk for developing compassion fatigue and burnout.<sup>102–111</sup> Some common stressors, reported by American, Canadian, Greek, Chinese, and Israeli health-care providers<sup>103,105,107,111–113</sup> include exposure to childhood suffering and death, communication difficulties with young patients and parents, team conflicts, and the inadequacy of support systems for care providers. These stressors are often aggravated by high workloads and staff shortages.

Of particular interest are qualitative studies that go beyond the investigation of stress and burnout, and explore the ethical challenges that professionals experience in end-of-life care. Davies<sup>103</sup> described the “moral distress” that Canadian nurses underwent when curative efforts meant that they were unable to provide a comfortable death to a child. Their findings are supported by Olson<sup>104</sup> who pointed out the dissonance that American care providers experience when the child’s needs for palliative care conflict with the continued provision of active treatment imposed by institutional regulations and by the family’s or team’s goals of care. Along similar lines, De Graves and Aranda<sup>114</sup> have described how the prognostic uncertainty of most childhood life-threatening conditions, and the continued hope for survival, make decisions to shift from cure to palliation difficult and distressing for Australian paediatricians, nurses, and social workers.

Other researchers have explored the emotional impact that the dying process and death of a child has on care providers, and have identified a wide variety of grief responses.<sup>103,105,112,115–117</sup> Grieving of health-care professionals remains hidden and disenfranchised, however, because society expects them to remain strong and stoic in the face of death, while institutional regulations strongly discourage the appearance of vulnerability through the expression of grief. According to Doka,<sup>118</sup> disenfranchised grief is when people cannot

openly acknowledge their loss because the importance of the relationship is not socially recognised; therefore, they cannot publicly mourn and are, consequently, deprived of social support.

Care providers' grieving process, according to Papadatou and colleagues, has unique characteristics that are common to clinicians even though they may work in different environments and cultures.<sup>105,117,119</sup> The process is triggered by the loss that professionals feel when their young patients die. Some health-care professionals might grieve over the loss of a personal bond they have developed with a child, some over the non-realisation of their efforts to cure or control the disease, and others over unresolved personal loss that surfaces with the death of child. Characteristic of the health professionals' grieving process is an ongoing fluctuation between experiencing grief by focusing on the loss, and avoiding or repressing grief by moving away from it. Such fluctuation is healthy and adaptive and helps professionals attribute meaning to the death of their patient, as well as to their contribution to the care of the child and their family. Complications occur when care providers do not have fluctuating feelings and are either submerged in their grief, or systematically suppress and deny it.

A variety of coping strategies have been described to help professionals manage the stress of caring for seriously ill children who eventually die. Some coping strategies are personal and beneficial in the short term (eg, engaging in self-care activities such as exercise, meditation, or journal-writing) or beneficial in the long term (eg, developing a personal philosophy of care, engaging in self-reflection and self-awareness, committing to taking care of one's self). Other coping strategies are work-related, with the most important being the development of supportive professional relationships that promote debriefing and enhance mutual support;<sup>107</sup> health professionals seem to rely more on their colleagues, than family and friends, for support. The nature of this support differs, and includes the exchange of information (informational support); the clinical collaboration to meet patient needs (clinical or instrumental support); the sharing of personal feelings and experiences (emotional support); and the reflection and attribution of meaning to one's work experiences (meaning-making support). Opportunities for formal support (eg, participation in support groups, stress-debriefing sessions, or supervision meetings) and informal support (eg, time-out for discussions) are encouraged in different work settings, depending on the philosophy and goals of care as well as on rules and regulations with regard to the team's functioning in the face of their patients' death.<sup>120</sup>

According to the basic principles of PPC<sup>121</sup> and recommendations proposed by the International Society of Paediatric Oncology,<sup>122</sup> professionals who provide PPC services should receive formal and informal support to

prevent burnout and to be able to cope with the challenges and grief they encounter when providing end-of-life care. However, comprehensive interventions that aim to prevent compassion fatigue and burnout, or to support professionals through their grieving process, are rarely documented in medical reports.<sup>113,116,123</sup> Moreover, their long-term outcomes remain unknown, which suggests that this is an important area of future investigation.

### Challenge 6: Integrating knowledge of PPC into basic curricula and training programmes

A major challenge in PPC is to integrate growing knowledge into educational programmes in medicine, nursing, and allied disciplines. Surveys undertaken in the USA, Canada, and the UK and other countries in western Europe<sup>124–132</sup> indicate that education in palliative care, especially in bereavement care, remains sporadic and fragmented.<sup>133</sup> Faculty members say they feel unprepared to teach key components of end-of-life care, while medical students report a lack of role models and mentors who offer feedback and support when they care for dying patients.<sup>125</sup> Residents and practising paediatricians also report feeling unprepared to cope with end-of-life issues<sup>134–136</sup> and tend to avoid or withdraw from situations in which they feel uncomfortable.<sup>129,137</sup> They disregard what Jellinek and colleagues<sup>138</sup> have referred to as “the dark side” of working with seriously ill children. While distancing themselves from stressful situations, they concurrently report difficulties in their communication and interactions with dying children and parents.

Clinicians are aware, however, of these difficulties and often request education and training in PPC as a way of coping with the stress that accompanies caring for dying children and bereaved families.<sup>20,137,139,140</sup> In a large survey of 228 paediatric oncologists from the USA, Canada, and the UK, respondents reported a lack of formal courses in PPC, with 92% admitting that they had learned to apply palliative principles of care by trial and error in clinical practice. Some, however, seemed to benefit by observing colleagues or other role models during their fellowship training and residency.<sup>20</sup> This finding underscores the urgency to develop alternative models of training and education, and highlights the importance of providing role models in this field. Equally important is allowing undergraduate students to come into contact with dying people, since it helps them learn how to develop a meaningful connection through reflective practice, and how to develop a humane approach towards their patients.<sup>141–143</sup> Gaining experience in caring for the dying can help young doctors learn to tolerate the degree of intimacy and personal engagement that other aspects of medical training may subvert or undermine.<sup>144</sup> Sahler and her colleagues<sup>3</sup> emphasise expanding on “teachable moments” (spontaneous opportunities that arise in day-to-day caring of patients that reveal important lessons) as an effective PPC educational strategy. Learning



experiences that occur outside the context of a course or training programme, offer valuable opportunities for students in health care to develop the competencies required to be fully present and accompany a patient and family throughout the illness.<sup>145</sup>

A review of medical articles reveals a strikingly small number of publications on the education and training of professionals in PPC (panel 5). Comprehensive training in PPC cannot be aimed solely at the acquisition of knowledge and skills that will enable professionals to act effectively; it must also address moral beliefs and attitudes. As Olthius and Dekkers<sup>141</sup> suggest, effective medical education has three interrelated aspects: theoretical knowledge, practical skills, and a moral attitude that comprises a capacity to respond to others humanely. Moral attitudes reflect the personal motivation and commitment of the health-care provider to act in the interest of others and requires a commitment to the caring process. It is therefore important that educational curricula offer structured opportunities for a process of reflection and exploration of personal experiences, attitudes and responses to death, dying, and bereavement. Some innovative learning approaches that encourage trainees to spend time with dying patients and families, and later reflect on, record, and discuss their experiences, have proved promising in palliative care education and training.<sup>142,144</sup> Browning and Solomon<sup>21</sup> argue that because educational initiatives in PPC must always be grounded within the context of relationships between children, their families, and practitioners, what is needed is a relational learning approach. They encourage educators to involve patients and families in the educational process and allow their voices to be heard through videos, the sharing of personal stories, or the discussion of research findings that illuminate their needs and experiences.

While such learning approaches seem promising, there remains a need to pay more attention to personal attitudes and responses to the care of dying children and bereaved families as well as to the interdisciplinary dimension of teamwork to meet the varied and complex needs of children, siblings, parents, close friends, and peers at an institutional and community level.<sup>131,138, 167,148</sup>

Assessment tools to evaluate palliative care curricula<sup>168–170</sup> and alternative methods of teaching that facilitate learning in this field are only starting to be developed.<sup>141,142</sup>

## Conclusion

There remain many more questions than answers about how to best care for children who will probably die before adulthood. An example of such basic questions include: how to best control physical symptoms such as pain and fatigue; how to communicate with children and appropriately involve them in decisionmaking; how to ensure that invasive efforts to prolong life in intensive-care units do not inadvertently increase suffering and prolong dying instead of living; and how to provide care that

### Panel 5: Educational strategies for paediatric palliative care

#### Courses or lectures offered through undergraduate curricula<sup>141–143</sup>

Corr and co-workers describe to undergraduates two decades of experience with children and death.<sup>146,147</sup> Block and Billings have been co-directing a course for first and second year medical students entitled “Living with life-threatening illness” for over 10 years.

Volunteer patients, all with life-threatening illnesses and several of whom are children, serve as teachers in the course, teaching the medical students important lessons about the power of listening and bearing with suffering.<sup>144</sup>

#### Postgraduate education and specialist training programmes<sup>140,148–150</sup>

In a longitudinal study, Vazinari and colleagues<sup>140</sup> identified that while paediatric house officers begin their training feeling uncomfortable with death and dying issues, it takes 4 years before they change their attitude and feel comfortable with coping with issues in PPC. The authors suggest that even though training programmes might inform and familiarise participants with end-of life issues, it is supervised clinical practice and increased professional and personal experience that contribute to the paediatricians’ preparedness and comfort.

#### Postgraduate longitudinal training

Paediatric palliative care is becoming a specialty in its own right, recognised by the Royal College of Paediatrics and Child Health, and the Royal College of Nursing.<sup>151,152</sup> Subspecialisation is also under way in the USA.<sup>153,154</sup> There are specialist registrar programmes in the UK, in London and Cardiff, for paediatricians who wish to specialise in PPC, and a paediatric component of the distance learning postgraduate course in palliative care at Cardiff University. There are year-long paediatric palliative medicine fellowship programmes in the USA.<sup>155</sup>

#### Workshops, seminars, or training programmes for skilled professionals

Most seminars or workshops last a few days and focus on various issues of PPC.<sup>123,156,157</sup>

Even though informative, their long-term effects upon the clinical practice of participants are hardly ever assessed. The Harvard Medical School Center for Palliative Care course “Palliative Care Education and Practice” is an exception, consisting of 2 weeks of intensive training in large and small groups, with some PPC content. Impact of this training opportunity has been highly positive.<sup>158,159</sup>

#### Curriculum

Examples include: The ChiPPS Project (Children’s Project on Palliative/Hospice Services) sponsored by the National Hospice and Palliative Care Association ([www.nhpco.org](http://www.nhpco.org)); IPPC (The Initiative for Pediatric Palliative Care) sponsored by the Education Development Center, Inc ([www.IPPCweb.org](http://www.IPPCweb.org));<sup>161</sup> End of Life Education for Nurses—Pediatric Palliative Care ([www.aacn.nche.edu/ELNEC/Pediatric.htm](http://www.aacn.nche.edu/ELNEC/Pediatric.htm)).<sup>162</sup>

#### Textbooks

There are several comprehensive PPC textbooks currently in print or press.<sup>1,163–166</sup>

reduces the suffering of the bereaved. While recognising the challenges that remain, we believe that PPC is a holistic field that has much to contribute to the care of seriously ill children and their families. The knowledge already exists to improve the implementation of PPC at the clinical, educational, institutional, and research levels, that can help children with life-threatening illnesses and their families live meaningfully and support professionals in offering quality services and derive satisfaction from their work. No single organisation can promote the needs of children with life-limiting conditions and their families worldwide. Over the past decade, several organisations and international projects have contributed to the

improvement and development of PPC within their host countries and, more recently, across the world. These include Children's Hospice International; The Association for the Care of Children with Life-Threatening Diseases and their Families;<sup>6</sup> the National Hospice and Palliative Care Organization through its ChiPPS Project,<sup>160</sup> and The Association of Children's Hospices. The collaboration of some of these and other palliative care organisations led to the formation of the International Children's Palliative Care Network (ICPCN) that aims to promote and facilitate communication and co-operation between all individuals and organisations throughout the world that are providing or supporting care to children with life-threatening conditions. Through these and other collaborative initiatives, we are confident that the field of PPC will continue to advance and improve the care for children with life-threatening illnesses and their families.

#### Contributors

All authors contributed to the literature review, writing, and editing of the manuscript.

#### Conflict of interest statement

We declare that we have no conflict of interest.

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