Children's Palliative Care Across a Range of Conditions, Settings and Resources

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Megan Doherty, Regina Okhuysen-Cawley, and
Lizzie Chambers

Key Learning Points

1. Palliative care (PC) should be provided for children with a variety of life-limiting conditions (LLCs) or life-threatening conditions (LTCs), which will vary depending on available resources.
2. Providing home-based PC is an important component of PC for children, feasible in high- and low-resource settings.
3. Hospital and hospice-based PC can provide critical support for children.
4. Prognostic uncertainty and continuation of life-sustaining treatment (called concurrent care in some countries) should not preclude a child from receiving PC.

M. Doherty
Faculty of Medicine, University of Ottawa, Ottawa, ON, Canada

Children's Hospital of Eastern Ontario, Ottawa, ON, Canada

Two Worlds Cancer Collaboration, Vancouver, BC, Canada

R. Okhuysen-Cawley
Texas Children's Hospital, Houston, TX, USA

Baylor College of Medicine, Houston, TX, USA
e-mail: reginao@bcm.edu

L. Chambers (✉)
Together for Short Lives, Bristol, UK
e-mail: Lizzie.chambers@togetherforshortlives.org.uk

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Case 1: A Child with a Degenerative Incurable Illness in a Low-Income Country

Ali is a 14-year-old boy with a neurogenerative illness which has slowly deteriorated with acute complications such as aspiration pneumonia. Each episode of pneumonia is more severe than the last, but his condition is improved with antibiotics and supplemental oxygen. Several days after being discharged from hospital, Ali develops respiratory distress and his family rushes him to the local district government hospital. He has difficulty breathing and signs of poor cardiac perfusion (cool extremities and weak pulses). He is admitted to the intensive care unit and is provided with supplemental oxygen and IV antibiotics. There is no mechanical ventilation available at this hospital and Ali's parents cannot afford a private hospital. After several days, it becomes clear that Ali's respiratory function is deteriorating, and the intensive care team explains to his family he is expected to die in the next few days. The intensive care team consults with the children's palliative care (CPC) team about how to support Ali's family at this stage of his illness.

3.1 Question 1. What Are the Possible Locations of Care for a Child in the Last Days of Life?

In both high- and low-resource settings, PC can be provided in a variety of locations, including home, hospice and in-patient health care facilities, and should be based on the child and family's preference as much as possible. This provision will depend on the resources available, but there are common principles that should be applied in all settings and resource levels. The World Health Organization (WHO) provides detailed guidance for health care planners and managers about the implementation of PC for children (WHO 2018).

3.1.1 Home

Previous studies report that parents often prefer to be at home for their child's death (Coyne et al. 2014). Home-based care generally involves visits from skilled nurses and other health care providers, with 24-hr phone access to a member of the care team (Weaver et al. 2016; Bona et al. 2011). Community-based PC teams have been implemented successfully in a number of resource-limited settings in the Americas, Asia and Africa (Kumar 2007; Harding et al. 2013). As a lower cost model of care, these may be well suited to resource-limited settings. Teams may also include trained volunteers and community health workers who provide regular visits to provide emotional, spiritual and practical support. Community health workers should be trained to screen for more severe symptoms and alert clinicians to the need for a visit from health care professionals.

3.1.2 Hospice

Countries from all income levels provide PC for children through free-standing hospices. These facilities offer end-of-life (EoL) care, respite, symptom management and bereavement support. Hospices generally have in-patient facilities where children can be admitted under the care of a dedicated team of PC nurses with oversight by a doctor (paediatrician/physician/general practitioner). They may also provide day and home-based care services. More of these facilities are needed throughout the world.

3.1.3 Hospital

In many children's hospitals, a paediatric PC team provides in-patient and outpatient consultation services. These teams provide multidisciplinary support and often include nurses, physicians, psychosocial professionals (counsellors, psychologists or social workers) as well as a variety of other therapists such as physiotherapists, occupational therapists, and play therapists.

PC can be provided throughout the health care system (Fig. 3.1). At a foundational level, all health care staff can be trained in basic PC principles, to

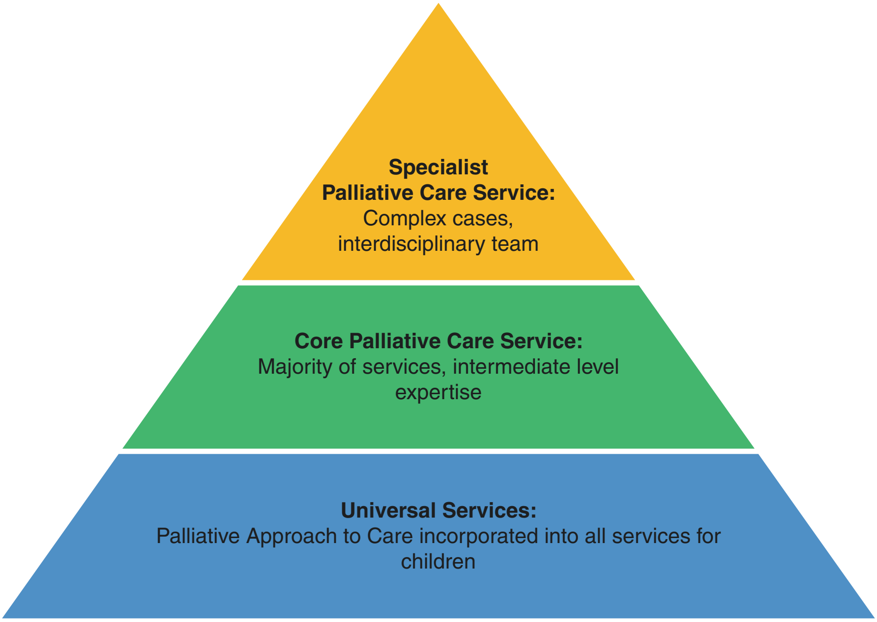

Fig. 3.1 Different levels of PC service in paediatrics (adapted from McCulloch et al. 2008)

ensure that a palliative approach to care is adopted universally throughout the health care system. Core PC services form the majority of services for children. At this level, health care professionals will have intermediate levels of expertise. Complex cases may be referred to a specialist PC service, where more staff, training and resources are available. Specialist teams are generally inter-disciplinary, under the direction of a specialist PC physician and can be found in hospitals, hospices and primary care settings (McCulloch et al. 2008; WHO 2014, 2018). Within low- and middle-income countries (LMICs) there are however, few CPC specialist doctors or nurses, and limited specialist CPC training, thus those working within specialist teams may be developing their specialist role, whilst not actually having been trained at the specialist level (WHO 2018).

Case Study

Ali's family has exhausted their limited financial resources during this hospitalisation and they share Ali's wish to go home for EoL care. The hospital's PC team develops a plan in coordination with a local home-based PC team.

Ali goes home by ambulance with oxygen therapy. He receives oral morphine and other medications to manage his symptoms. A nurse visits him daily and the team provides 24-hr telephone support. Two days later, Ali's mother calls the team at night, when he develops what she describes as wet and raspy breathing. The physician explains how to treat this respiratory congestion. The next day, Ali dies peacefully surrounded by his family.

3.2 Question 2. What Are the Benefits and Challenges of Providing Home-Based Palliative Care?

Hospitals can be frightening for children, and home is often preferred as a familiar and comforting place. At home children can continue with their normal family activities, socialise with friends and may be able to go to school. In LMICs, the high out-of-pocket costs of hospitalisation mean that many families choose to return home once they learn that their child cannot be cured. Hospitalisation can mean that families have to bear the direct cost of medications, investigations and supplies, but also transportation, food and childcare at the same time as income and livelihood may be lost.

In resource-limited settings, seriously ill children return home from hospital after their parents are told that there is "nothing more that can be done". In reality, there is always something that can be done. Home-based care teams can provide basic resources and support families to feel less isolated and helpless in caring for their child. Whilst not everywhere has access to a home-based care team, families may still take their child home, due to cultural and/or financial reasons. Having a child in hospital can cause additional financial challenges for many reasons such as needing to have a parent caring for the child in hospital; parents being unable to work as they are at the hospital; the cost of being away from home and child care for the remaining children at home.

In high income settings, supporting families to plan for home-based care is associated with fewer hospital admissions and less intensive care usage, which generally correlates with improved quality of life (QoL) and reduced suffering in the terminal phase of illness.

When discharging a child home from hospital, it is important to establish contact with the local home-care team prior to discharge, to enable a smooth transition and ensure that there are adequate services to support the child's needs. The hospital team should develop an EoL care plan which incorporates the family's goals and wishes and ensures access to an emergency symptom kit to ease distress if symptoms develop. Emergency kits should contain the following medications:

- Morphine (or other opioid) for pain and dyspnea.
- Haloperidol for nausea and delirium.
- Hyoscine butylbromide (or other agent for oral secretions/congestion) for secretions.
- Midazolam (or other benzodiazepine) for seizures, catastrophic bleeding and acute respiratory distress.

Ensuring 24-hr phone access to a member of the care team is important to ensure that the family can manage symptoms and to enable the child to die at home if this is the family's wish.

It is important to ensure that PC services in these settings are integrated with other social and community-based care organisations to enable families to have access to comprehensive support.

Case 2: A Child with a Life-Threatening Critical Illness in a High Income Country

Zara is a 13-year-old adolescent girl with myocarditis, placed on heart-lung bypass after suffering a cardiac arrest. Her heart has not recovered, and she has developed gastrointestinal and pulmonary haemorrhage as complications of bypass therapy. The intensive care team consults with the children's PC team to support Zara's family and the team as they decide how to proceed.

Since Zara is awake, a collaborative decision between the family and the medical team is made to proceed with insertion of a left ventricular assist device (LVAD), which attaches to the main pumping chamber in her heart and is connected to a console at Zara's bedside until a heart transplant can be performed.

3.3 Question 3. Does Zara Have a Condition Where Palliative Care Is Appropriate?

PC should be provided in situations where a child's illness is life-threatening (where cure may be possible and PC interventions can help the child stabilise and tolerate treatment) or life-limiting (LL) (where the illness has no realistic hope of cure) (Wolfe et al. 2011).

In Zara's case, her condition appears to be life-threatening due to poor cardiac function, with the need for high-level invasive support. Despite the potential for significant improvement with heart transplantation, Zara has a substantial risk of death prior to transplantation due to organ shortages and declining health status which may make her ineligible for transplantation. Zara's intensive treatment has a significant impact on her physical health, as well as her and her family's psychological, social and spiritual health. PC can provide support in all of these domains, ensuring that suffering is addressed, and QoL is optimised.

Globally, the most common types of conditions where children need PC include neonatal conditions and congenital anomalies (Connor and Sepulveda 2014). Figure 3.2 illustrates the global distribution of disease groups where PC at EoL is needed (Connor and Sepulveda 2014).

In high income settings, children who need PC often have complex chronic conditions (CCC). CCC are defined as those conditions which are expected to last for at least 12 months, and involve either several organ systems or one organ system so severely that specialty tertiary paediatric care is expected to be required (Feudtner et al. 2001). These conditions are frequently associated with congenital and chromosomal anomalies, often requiring complex and costly treatments. Cancer, which is often strongly associated with PC, constitutes only about 20% of

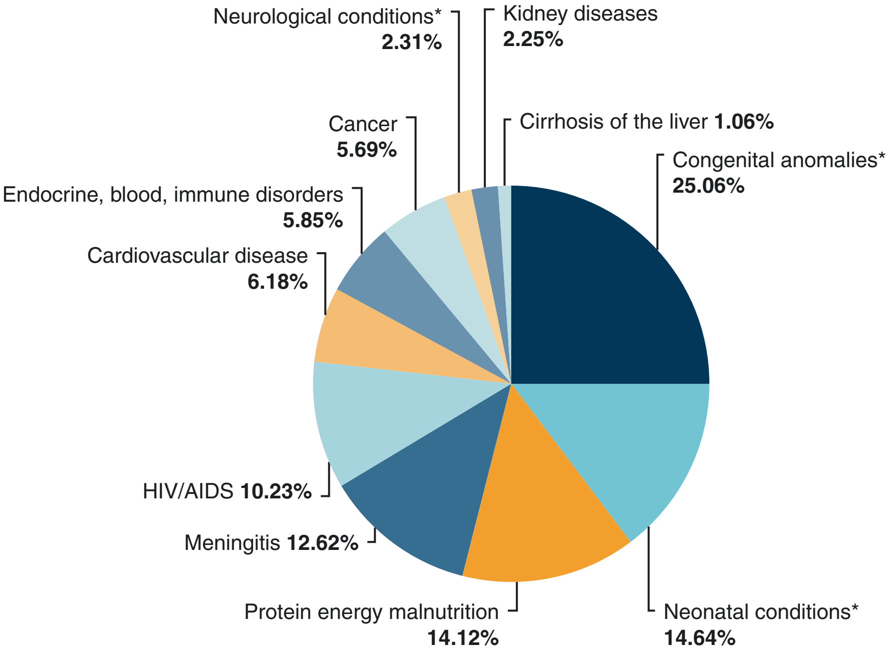

Fig. 3.2 Distribution of children in need of PC at EoL. From Global Atlas of PC at EOL (Connor and Sepulveda 2014, p. 20)

children in high income settings, each Canada, who receive PC due to advances in curative treatment (Widger et al. 2007).

In resource-limited settings, there are conditions for which it is not possible to provide the potentially curative treatments that would be available in high-income countries (HICs). This may be due to the high cost of treatments, a lack of health care system capacity and the complexity and toxicity of the treatment regimens themselves (Amery 2009). In many parts of the world there are significant numbers of children with Human Immunodeficiency Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS), and PC is an essential component of their treatment, it may be provided alone or in combination with anti-retroviral therapy (ART). Severe malnutrition also contributes significantly to the global need for PC, with malnutrition estimated to contribute to 45% of all child deaths (WHO 2019).

Case Study

Five days after an LVAD is placed, Zara suddenly develops an intense headache and becomes unconscious. Imaging reveals an extensive haemorrhagic stroke. Zara is placed on a respirator to support her breathing, but no longer has normal brainstem reflexes. The team sadly informs Zara's parents that she has had a devastating neurological injury and a joint decision is made to discontinue ventilatory and LVAD support. Zara's parents spend the night at her bedside. Zara remains comfortable as these interventions are withdrawn. The chaplain leads family, friends and staff in prayer as she dies.

After Zara dies, her family and friends spend time in her room. The chaplain and PC team counsellor stay with them, providing emotional support and helping with arrangements for the funeral. They continue to provide bereavement support to Zara's family, including her siblings, over the coming years.

3.4 Question 4. What Are the Challenges in Determining Which Children Can Benefit from Palliative Care and How Can This Be Addressed?

Health care providers commonly cite prognostic uncertainty, clinician or the family's unwillingness to acknowledge the child's condition is incurable, and preference for life-sustaining treatment as barriers which limit access (Davies et al. 2008).

Prognostic uncertainty is common in children with life-threatening or life-limiting conditions, but should not preclude referral, since all children and families in this situation can benefit from the support provided by a PC team. Children's illness trajectories are typically much less predictable than adults with advanced incurable illness, due to lower incidence of cancer, the higher incidence of rare diseases and the relative health of unaffected organ systems (Wolfe et al. 2011).

CCCs include a broad range of conditions, including those caused by prematurity, congenital disorders of every organ system and neurodegenerative conditions. Prognostication is difficult with many of these rare conditions; and unlike adults, children receiving PC often receive services for several years. In Canada, more than half of all children who received PC were alive after 1 year (Widger et al. 2007).

Zara's case illustrates the complexity of prognostication for children with serious illnesses. Children with LTCs may die suddenly when the child is still receiving active or intensive treatments aimed at cure or life-prolongation. Indeed, the use of life-sustaining treatment is not a contraindication to PC, and PC will support families facing the challenges of providing intensive treatment for their child. Clinicians often view PC as a distinct model of care which must be separate from aggressive medical management, but this is not the case.

Given the challenges faced by clinicians in determining prognosis and life expectancy, clinicians should present PC to families early, as an important component of their child's treatment which will enhance the care being provided, ensure comfort and provide holistic support for the whole family. Clinicians should not expect families to acknowledge the incurability of their child's condition to begin receiving PC.

In many cases, PC consultation occurs very close to the EoL, once clinicians feel certain that death is imminent. This can lead to a loss of opportunities for palliative intervention for the child and family (Hays et al. 2006), so the recommendation is for referral at the time when a child is diagnosed with a life-threatening or life-limiting condition to ensure that the child and family can be supported throughout the illness trajectory, whether the outcome ends in cure or death (American Academy of Pediatrics 2000). Zara received a PC referral early, when her condition was deemed to be life-threatening, allowing the team to develop a relationship with the family and provide support, even though at that stage Zara was receiving intensive cure-oriented treatment and her family was hoping for her to return to good health after heart transplantation.

Together for Short Lives have defined four broad groups of life-threatening or life-limiting conditions which identify the wide range of conditions likely to benefit from a PC approach. The groups are intended to be a helpful tool in determining which children could benefit from PC. These are not fixed and a child with one condition may be in more than one group, or in a different group depending on the resources available where they live (Together for Short Lives 2018). However it is a guide and can be useful in helping determine which children would benefit from PC (Table 3.1).

3.5 Question 5. What Are the Key Considerations of Providing Hospital-Based End-of-Life Palliative Care?

Hospital-based care, including intensive care, is becoming more frequent as children live with CCC for longer. Children may have prolonged and repeated hospital admissions, and in the United States, more than half (56%) of all child deaths occur in hospital with the majority in the ICU setting (IoM et al. 2003; Feudtner et al. 2007). In LMICs, deaths are much more likely to occur at home; in Africa, an estimated 80% of all child deaths occur at home (Amery 2009).

Table 3.1 Four groups of life-limiting and life-threatening conditions (Together for Short Lives 2018, p. 11)

Category 1	*Life-threatening conditions for which curative treatment may be feasible but can fail,* where access to PC services may be necessary when treatment fails, irrespective of the duration of that threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for PC services.
	Examples: cancer, organ failures of heart, liver, kidney, transplant and children on long-term ventilation.
Category 2	*Conditions where premature death is inevitable,* these may involve long periods of intensive disease-directed treatment aimed at prolonging life and allowing participation in normal activities. Children and young people in this category may be significantly disabled but have long periods of relatively good health.
	Examples: cystic fibrosis, Duchenne muscular dystrophy and spinal muscular atrophy (SMA) Type 1.
Category 3	*Progressive conditions without curative treatment options,* where treatment is exclusively palliative and may commonly extend over many years.
	Examples: Batten disease, mucopolysaccharidoses and other severe metabolic conditions.
Category 4	*Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death.* PC may be required at any stage and there may be unpredictable and periodic episodes of care.
	Examples: severe cerebral palsy complex disabilities such as following brain or spinal cord injury.

For children who are seriously ill for a long time, hospitals often become safe and familiar locations, and for this reason, parents may wish to come to hospital when their child is at EoL. Hospitals, however, separate children from normal life and can be challenging environments in which to provide comfort-focused care. Staff are typically more familiar with providing all possible medical care measures to extend life. Also, many countries severely restrict visiting hours—even when death is imminent—which is upsetting to families.

Providing cardio-pulmonary resuscitation (CPR) in acutely and terminally ill children is not as helpful to seriously ill children as it is in previously healthy adults, with less than 27% of children with an in-hospital cardiac arrest surviving until discharge, a fact many healthcare professionals and families do not understand (Wolfe et al. 2011). For families who decide to forgo resuscitation, it is important that clinicians assure them that this does not mean that less care will be given, but instead that the focus of care will shift to comfort-focused treatments.

In situations where a continued life-sustaining treatment will not provide a meaningful QoL and may prolong suffering, it is ethically appropriate to withhold or withdraw these interventions. Although confusion is very common, this is very different from euthanasia or medical assistance in dying. It is important to involve the family in the decision-making process and it may also be necessary to involve religious or cultural leaders and a medical ethicist. After withdrawal of ventilatory support, children may die immediately or live for a brief period of time (minutes or hours, a few days, or longer); clinicians should plan for both possible outcomes to ensure appropriate symptom control and minimise distress.

Case 3: A Child with an Incurable Condition in a Middle-Income Country
Ram was a 15-year-old young man who had been diagnosed with Duchenne muscular dystrophy (DMD). Ram's older brother, Joseph, died from DMD five years ago, at the age of 14. Ram had some learning difficulties which complicated his care. By the age of 12, he was no longer able to walk, and he had developed progressive heart failure from cardiomyopathy, a feature of DMD.

Ram's mother noticed that he snored loudly at night and had morning headaches. A sleep study was recommended by his neurologist, but the family was unable to afford it. Instead a friend loaned Ram a pulse oximeter which showed that his oxygen saturation dropped into the 70's when he fell asleep. Armed with this information, his mother was able to get a Continuous Positive Airway Pressure (CPAP) machine from the local district hospital. Ram hated the CPAP machine and would argue endlessly with his mother saying "Let me be! I know I am going to die, just like Joseph did!".

His mother provided all of Ram's personal care and was physically exhausted, so his neurologist referred Ram to the Paediatric PC Team at a local children's hospice. The team helped Ram and his mother to talk about the CPAP machine and explained to Ram's mother how QoL should be emphasised over quantity of life and the importance of respecting Ram's wishes. The hospice had a community-based care team who visited Ram at home, initially monthly and then more frequently when Ram's respiratory status declined. This improved QoL for Ram and his mother. Brief hospice admissions were arranged for respite, and the team engaged Ram and his family in discussions about his preferred location for EoL care.

3.6 Question 6. What Support Can Palliative Care Teams Provide for Children with Progressive, Incurable Conditions in This Setting?

Children like Ram with incurable illnesses, which are progressive from the time of diagnosis should be referred for PC early in their disease trajectory to ensure that PC can provide the maximal benefit for the child and family. For some, especially in LMICs, they may never receive a definitive diagnosis, in which case they should still be referred for PC early.

Especially in resource-limited settings, where physicians may lack confidence and skill in explaining complex medical conditions to patients and families, PC teams are particularly valued for their communication abilities. Skilled communication can help families to fully understand their child's illness and treatment options, which allows them to make properly informed treatment decisions which match their wishes for their child. This is particularly relevant as families may go into significant debt to pay for costly and unnecessary treatments, leaving them unable to afford basics such as food or school for siblings. In Ram's case, his mother struggled to access a sleep study or CPAP machine. If Ram had been able to share his wish not to use CPAP earlier, these tests and interventions may have been avoided.

PC teams in all locations have expertise in the management of pain and other physical symptoms, using pharmacological and non-pharmacological approaches. Depending on locally available resources, the team may provide free or subsidised medications and medical equipment to patients.

Other community support services, such as respite care and education, can be organised. Respite, where available, provides a short break for parents or caregivers and can be provided in hospices, other health care facilities or in the child's home depending on the types of services available locally. PC teams can support children to continue attending school, by helping schools understand the child's condition and develop appropriate emergency treatment plans.

Case Study

Following discussions, Ram's mother felt that providing EoL care at home was more than she could handle. A plan was made for Ram to remain at home as long as he was comfortable, with home visits by the PC team and to move to the hospice in-patient unit when he was reaching the end of his life.

A few days later, Ram was brought to the hospice with laboured breathing and low oxygen levels. He was offered an oxygen mask but refused it. He found it helpful to have a fan at his bedside and he received oral morphine which helped his breathing feel more comfortable. Ram's mother stayed in the hospice with him until he passed away the next day.

The CPC team did not have dedicated bereavement resources but kept in touch with Ram's mother via telephone and home visits. She expressed how helpful the team had been, in terms of practical support, helping her resolve her feelings of guilt, and empowering Ram to participate in decisions about his care.

3.7 Question 7. What Are the Benefits of Hospice-Based Palliative Care?

Hospices offer an alternative to hospitalisation, which may be more appropriate for some children and families. Hospice staff are more likely to be familiar and experienced in the use of morphine and other essential PC medications, which may improve symptom management for children in these settings. In contrast, hospital clinicians in LMICs are often unfamiliar with the use of morphine.

Many hospices provide additional support services, including counselling, spiritual support, education and a range of therapies (e.g. physio, occupational, speech, art, music, play) depending on local resources and the needs of the children whom they serve. Through the course of the child's illness, families may have already developed trusting relationships with hospice providers, and thus hospices are often well placed to provide bereavement care in the form of counselling and peer support groups.

Similar to Ram's case, many hospices have expanded to provide out-patient care and home-care services to support children to remain at home as long as possible. Sustainable models of hospice care have been described in resource-limited settings; most notably, South Africa which has a network of 60 hospices which support children and families. Many of these hospices have in-patient care units, as well as day care and "drop-in" centres (Drenth et al. 2018).

3.8 Conclusion

CPC should be available for children with a wide range of conditions and in a range of settings e.g. at home, in hospital and in a children's hospice where they exist. Often within CPC there is an uncertainty about prognosis, but this should not prevent a child and their family from receiving care. It is important to try and support the child and their families wherever they are and to integrate CPC into existing programmes such as community-based care organisations.

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