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Palliative Care of the Infant and Child in the Paediatric Intensive Care Unit

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Abstract

In this chapter we discuss the delivery of palliative care in the paediatric intensive care unit environment. Illustrated by challenging cases, we describe the role of intensive care in symptom management for the child with terminal or life-limiting illness. We detail the importance of a multidisciplinary team and their roles in the provision of individualised care for the child and their family. The importance of family-centred care and advance care planning is expanded upon. In addition, we explore end of life issues that are particular to children in intensive care such as withdrawal of life-sustaining therapies and organ donation. Finally, we discuss how to ensure the delivery of high-quality palliative care in the paediatric intensive care environment.

Keywords: Paediatrics, PICU, Palliative Care, Family- centred, Symptom control

1. Introduction

Although modern medicine has undoubtedly improved survival among children with life- limiting disease, there remains a substantial requirement for paediatric palliative care. Approximately 21 million children per year need the input of palliative care medicine [1].

Infants, children and adolescents who may benefit from a palliative approach to their care fall into four patterns of disease progression [2, 3]:

1. Conditions for which potentially curative treatments have failed (e.g. malignancy)
2. Life- limiting conditions for which certain treatments may prolong life, but premature death still occurs (e.g. cystic fibrosis)
3. Conditions for which treatment is almost exclusively palliative but their progression may be slow and protracted (e.g. congenital cardiac defects, neurodegenerative disease)
4. Non progressive neurological conditions which result in an increased susceptibility to complications and premature death (e.g. cerebral palsy)

Paediatric Intensive Care has similarly seen the mortality amongst children decrease substantially in the last two decades to less than 5% [4]. With improved survival rates, we have also noticed an increasing need for palliative care in the management of the sequelae of chronic and progressive medical illness amongst our patients.

Palliative care in the Paediatric Intensive Care Unit (PICU) may therefore be used in the following contexts [5]:

- Life-threatening illness where life-sustaining therapies have been deemed futile and must be withdrawn.
- Uncontrollable symptoms requiring advanced care which is not available or practical on the regular ward.
- Significant morbidity secondary to progressive non-malignant illness or a chronic life-limiting condition [6].

Delivery of palliative care in PICU requires both acceptance by the child's family that their length of life will be short, and a holistic approach from a multidisciplinary team. A focus on symptom control and family-centred care at the end of a child's life may improve the experience of death for both patient and family unit [7]. We aim to facilitate a period of time for the family which will be associated with positive memories [8].

2. The role of PICU in symptom management

'Relief of pain and other symptoms' is one of the domains of high-quality palliative care in the PICU [9]. The purpose of symptom management is to maximise comfort and improve quality of life for the child in their final hours, days or months [10]. Optimal management requires an understanding of the underlying disease process and anticipation of symptoms that may arise. Symptoms are particular to each individual patient and can vary substantially [11].

Studies show that bereaved parents have rated the management of end of life symptoms poorly [12] and it is therefore important to provide individualized care which is both tailored to the patient's specific symptoms, and acceptable within the broader context of their family.

Symptom management may be provided with non-pharmacological or pharmacological means. Although a constellation of symptoms may be seen in the child receiving palliative care, here we discuss problematic symptoms that may arise in PICU.

2.1 Pain management

Pain assessment and management is fundamental to good palliative care practice. Our goal is to alleviate pain and the fear that it garners in the child and family [13].

Pain is assessed using age-appropriate tools [14], and attention is paid to the impact of pain upon the family unit [15]. We initiate pain management in a manner that is similar to that on the ward, with adherence to the WHO analgesic ladder [16] and utilisation of opioids as the cornerstone of therapy. We employ non-pharmacological measures such as physiotherapy and cognitive behavioural therapy (CBT) in conjunction with pharmacological therapies.

We are often presented with patients with recalcitrant pain where alternatives to opioid therapy are sought. These patients may have developed opioid tolerance, side effects with increased doses or may have infiltrative or neuropathic pain that is poorly responsive to opioids.

Despite the absence of convincing evidence for their efficacy [17, 18], adjuvant agents such as clonidine, ketamine and intravenous lignocaine [19, 20] may produce a significant improvement in pain.

Other specific pain therapies may also be employed for intractable pain or to mitigate against intolerable effects of analgesic agents. Peripheral nerve blocks can be used for discrete, well-defined areas of pain secondary to tumour infiltration [21] and, may encompass neurolytic methods for permanent pain relief. Spinal administration of opioids, local anaesthetics, baclofen or other adjuvants may also be used to good effect [22]. Involvement of specialties such as anaesthesiology, pain medicine and neurosurgery can support the institution of these therapies.

2.2 Psychological support

Many children, regardless of age, will experience psychological issues at the end of life. PICU staff must actively seek and attempt to address these matters as research has shown that psychological issues at the end of life are often under recognised by staff [12, 23]. A clinical psychologist should be involved and can provide evidence-based interventions for emotional or behavioural symptoms [24]. Therapeutic interventions such as cognitive behavioural therapy and relaxation strategies are used in conjunction with pharmacological treatment for relief of distressing symptoms.

Although anxiety may be present throughout a life-limiting illness, it may be particularly pronounced at the end of life. The child may express a fear of death itself, or a fear of uncontrolled pain and suffering around the time of death [25]. Parental anxiety and fear can strongly influence this. Management is dependent upon the age and understanding of the child. Guided by the parents, a degree of open communication about their condition and provision of verbal reassurance may alleviate anxiety significantly. Conservative strategies such as relaxation, meditation, or music therapy are also beneficial. This complementary therapy can play a significant role in the provision of holistic care to patients and their families. If drug therapy is deemed necessary, benzodiazepines may be useful anxiolytics.

Cerebral irritability is occasionally a feature in the paediatric patient receiving palliative care. The child may be agitated and inconsolable. Reassurance, and the creation of a peaceful environment can be complementary to pharmacologic strategies. Gabapentin has been shown to be effective in these cases [26], but may not always be practical due to its enteral route of administration. Alternative drugs which may be utilised in cases of severe distress include; levomepromazine; clonidine; chloral hydrate and lorazepam. Formulations can be made specifically by pharmacy to allow rectal or buccal administration.

2.3 Other symptoms and their management

2.3.1 Bleeding

Thrombocytopenia, coagulopathy or local tumour effects may cause bleeding in the dying child. Simple measures can be utilised in the case of haemorrhage. The child can be nursed on dark coloured bedding. Tranexamic acid-soaked gauze can be applied to bleeding mucous membranes and adrenaline-soaked gauze can be applied directly to bleeding points. Occasionally, blood transfusion may be

administered. Although this could be seen as controversial in the dying patient, justification is based on whether transfusion has the potential to improve the patient's symptoms [27]. Catastrophic bleeding, as may be seen in acute pulmonary haemorrhage, can be both a distressing and terminal event. Subcutaneous or intravenous morphine and midazolam should be administered in this scenario to ensure comfort of the patient.

2.3.2 Dyspnoea and secretions

Dyspnoea refers to the subjective sensation of finding it difficult to breathe and, may be a particularly distressing symptom for the child and family. It is important to rule out treatable causes of dyspnoea in the dying child, such as pulmonary oedema, pleural effusion, anaemia and anxiety. Simple supportive measures that may improve the child's comfort include gentle suctioning, positioning and mouth care. More specific therapies such as bronchodilators and diuretics may be administered. Interdisciplinary discussion should take place regarding the relative benefits and risks of more invasive interventions such as pleural drain or blood transfusion.

Excessive secretions are common in all stages of palliative care. Gentle suctioning and positioning to allow drainage can also be helpful here. Pharmacological measures for excessive secretions include hyoscine hydrobromide or glycopyrronium bromide.

When entering the terminal phase, secretions may pool in the upper airways and cause particularly distressing sounds, also known as the 'death rattle'. When secretions are linked with dyspnoea, administration of morphine or midazolam can be considered. Dosing intervals are based upon a perceivable change in the child's dyspnoea or distress.

To illustrate the role of paediatric critical care medicine in symptom management, a series of case vignettes are provided below. Each is a challenging case where symptoms have been difficult to optimise on the regular ward, necessitating referral to the PICU team.

Case 1:

A 4-year-old with ALL who was referred from the ward team with severe chemotherapy related mucositis and painful dermatitis. His pain had been difficult to control despite using IV morphine boluses and regular clonidine. The patient was distressed and unable to take oral fluids. A ketamine infusion was commenced with a good improvement in patient comfort. This infusion was continued over a period of days until improvement was seen in his dermatological condition. The infusion was gradually weaned and discontinued, and the patient was suitable to be transferred back to the oncology ward.

Case 2:

A 2-year-old with a terminal pelvic malignancy had invasion of her lumbosacral plexus and severe neuropathic pain. Standard palliative analgesic regimens had been unsuccessful. An intravenous infusion of lignocaine was commenced with some improvement in her symptoms. An intrathecal catheter was sited, and infusion of opioids with local anaesthetic provided her with greatly improved pain relief in her final days.

Case 3:

A neonate with central respiratory depression, seizures and limb contractures was admitted to PICU for non-invasive ventilation. A palliative care referral was made, and gabapentin was commenced for central irritability. He was subsequently discharged to the ward.

3. Communication

Communication plays a key role in the delivery of high-quality end of life care in PICU [28, 29]. In this highly technical environment, the discussion of diagnoses, interventions and prognoses must be delivered using language that the patient and family will easily understand.

When the clinical trajectory shifts and the goals of care are realigned to focus upon comfort measures, this can be a particularly stressful and disorientating time for the family. High-quality communication during this time can reduce the risk of stress-related disorders in the bereaved family [30].

As discussion shifts from procedure-oriented conversations to planning the initiation of palliative care, the PICU clinician may be out of their comfort zone [31]. Research shows that clinicians prefer to discuss technical medical issues rather than emotional issues pertaining to quality of life [32]. It is, however, important for us to recognize that by building an empathic relationship based on information sharing, we foster a supportive relationship with the family [33].

Family conferences are an essential communication platform when a child is undergoing palliative care in the PICU [34]. Members of the team and the family have the opportunity to discuss goals of care in the context of the patient's clinical condition and the family values. A trusting relationship can be built with the family and this can facilitate the transition from critical care provision to the delivery of palliative care.

Although clinicians attribute considerable importance to family conferences [35], communication with the family in PICU most frequently occurs at the bedside [33]. Regardless of location, every interaction with the family is an opportunity to build trust and understanding. The team may consider appointment of one reliable point of contact, such as a specialist nurse for the family. This will facilitate relationship building with the family and provide for consistency in communications [36].

The PICU team must be cognisant of the following barriers to effective communication that can exist: delivery of inconsistent messages regarding the care plan; time constraints; the stressful environment; and a deficit of communication training [37].

Communication strategies that have been shown to improve the end of life experience for families in PICU include: participation of the family in decision-making; limiting the use of medical terminology; displaying honesty when a child has a poor prognosis and compassionately sharing family grief [38].

4. Family-centred care

The delivery of palliative care to a child in PICU often represents a shift away from technical critical care interventions and cure-focused management. Emotional support and quality of life become key priorities, in addition to a focus upon family-centred care.

End of life decision-making for a child is a complex and emotional process and encouragement of a family-centred approach has been shown to result in greater family satisfaction [39]. Information sharing with the family and their participation in the decision-making process are both important.

The medical team should pay close attention to the information needs and preferences of patients and their families [40], particularly when providing technical information within the often stressful PICU environment. Difficult conversations

may take place during a challenging and exhausting time for the family, and professionals should provide measured and consistent communication.

Key to collaborative decision-making is a steadfast and trusted relationship between the family and those involved in the child's care. It is important to recognize that not all families will want to lead the decision-making process, particularly regarding end of life care [7]. We see a spectrum of preferred decision-making roles with some families expressing a preference for delegation of decisions to clinicians, and others wanting a more prominent role in the process [41].

Family-centred care should also focus on maintaining the dignity of the family throughout the child's PICU stay. The physical and cultural environment in PICU exerts a contextual influence on the delivery of care [42] and, even simple institutional efforts can have a profound impact on the family. Forgoing visiting restrictions to allow parental presence at the bedside, provision of family accommodation and simple measures such as covering the cost of car parking and meals will support the family during this difficult time.

5. Advance care planning

Children and their families should be provided with support in developing an Advance Care Plan (ACP) which is reflective of their wishes concerning management of their illness and end of life care. An ACP will allow families and care providers to plan for the management of both reversible deteriorations in health and irreversible changes at the end of life. This individualised approach to care has the potential to improve patient quality of life and satisfaction [43].

The ACP should be documented in the patient's medical record where it can be shared amongst all caregivers. The family and medical team may wish to update the ACP to reflect redirection of care and reprioritisation of treatment goals as the child's illness progresses.

Ideally the ACP will be in place before the child is referred to PICU, but this is not always feasible, particularly in the case of an acute deterioration. PICU medical staff should be aware of any ACP that is in place and, if there is none, provide honest and clear communication to families regarding the perceived benefits, risks and invasiveness of critical care interventions [23]. This discussion can be particularly distressing for the family and all members of the multidisciplinary team will be invaluable in providing them with support in their decision-making.

In certain circumstances, a child may have an antenatal diagnosis of a life-limiting condition and ACPs are devised with the parents in antenatal period.

6. Re-direction of care on PICU and withdrawal of life-sustaining therapies

The re-direction of therapeutic goals in PICU requires careful planning, knowledgeable staff and high-quality communication. Following the decision to prioritise the patient's comfort, certain invasive therapeutic measures are electively ceased. Staff must anticipate symptoms or problems that may arise during this period and support the family in this stressful time.

6.1 Withdrawal of ventilatory support

The initiation of invasive ventilation is prompted by severe physiological derangement or the inability of the patient to protect the airway. Mechanical

ventilation may be provided via an endotracheal tube or tracheostomy and is typically anticipated to be a temporising measure until clinical stability is restored. In cases where it has been decided that invasive ventilation is no longer in the child's best interest, the process of withdrawal of ventilatory support commences.

PICU staff must be familiar with the appropriate incorporation of extubation into the end of life care. Post-extubation symptoms such as dyspnoea, secretion retention and agitation must be anticipated and managed appropriately [44]. Not every extubation will be a terminal event and staff should anticipate that the child may survive for a period of hours or days following the withdrawal of ventilatory support [44].

There should be clear communication with the family around this time. It is essential to explain the practicalities of tracheal extubation, the anticipated patient response to extubation and to decide upon a plan for symptom management in the period following extubation.

On occasion, PICU may facilitate the withdrawal of ventilatory support outside of the intensive care unit. The provision of choice in location of end of life care is increasingly advocated [45] and the child or family may express a wish to die on a ward, in hospice or at home [46, 47]. Meticulous interdisciplinary planning is required if an out-of-hospital setting is chosen [48]. The practicalities of transferring a dying child, with the potential for terminal physiological instability during transfer, must be communicated to both family and caregivers.

In some cases of life-limiting illness, we have performed tracheostomy in intubated patients to facilitate discharge to the ward or home [49].

6.2 Withdrawal of extracorporeal life support

Extracorporeal life support (ECLS), or extracorporeal membrane oxygenation (ECMO), provides mechanical circulatory support to children with cardiac or respiratory failure refractory to maximal conventional medical therapy. Although ECMO outcomes have improved [50], a number of patients will have persistent cardiac or respiratory dysfunction and cannot be successfully liberated from ECLS. Withdrawal of ECLS will be a palliative measure in these cases.

Withdrawal from this highly technical life-sustaining therapy requires collaboration with our surgical colleagues who may facilitate 'bridging' or separation from the ECMO circuit, or surgical removal of ECMO cannulae.

Patients who have had ECLS for a period of time may have received prolonged high dose benzodiazepine and opioid infusions [51]. Issues such as tolerance and dependence should be anticipated as the patient may survive for a period of time after ECMO decannulation.

6.3 Transition to the ward or home

Some patients may be able to transition to the ward or to their home for their final days. This period of transition should be managed with care due to the potential for creation of additional distress for the family. The family may be concerned that the patient will not get sufficient attention on the ward and can be upset at the realisation that discharge from PICU is a definite move away from active medical treatment.

The palliative care team should be involved in this process and can provide continuity of care for the patient on the ward or, refer to community-based services. Ideally, they will already have been involved in the care of the patient and attended family conferences during the patient's stay in the PICU.

Discharge should be planned and occur in daytime hours as much as is feasible. All members of the multidisciplinary team should be aware of the planned discharge and give advice with regards to ongoing care.

7. Special considerations in paediatric palliative care

Certain aspects of palliative care management of the child differ from that of the adult. Home care is generally preferred by the child and family [3, 52]. Research suggests that parents of children who die at home have less adverse psychological effects following the death of their child than those whose children die in the hospital setting [53]. The European Association of Palliative Care provides expected standards for paediatric palliative care and advocates for the provision of palliative care within the chosen setting of the child and family [54].

Whilst family are usually involved in the palliative care of every patient, the family unit is particularly central to paediatric palliative care. Parental presence is more frequent and their dual role as direct caregivers and legal guardians can contribute to more complex and emotionally fraught end of life decisions.

Consideration must also be given to siblings of the child who is receiving palliative care. The loss of a sibling can be devastating, and so too can the course of their sibling's illness and the series of events that has led to the decision to pursue palliative care. Feelings of isolation and distress can be compounded by an emotionally distracted and sometimes physically absent parent. Unresolved, these feelings may manifest as emotional or behavioural disturbances, disengagement from school, or psychosomatic complaints [55].

The lasting after-effect of the death of a child can be devastating and life-changing for both parents and siblings. A robust bereavement care plan is important in the context as a form of preventative health intervention.

8. Bereavement support

A family's experience of the death of a child in PICU can have significant and long-lasting impacts on their bereavement journey [56]. Attention to supportive bereavement practices within an institution is critical to assuage lasting, pathological ill effects.

Bereaved parents have recommended many low-cost resources that can support other families going through the same process [57]. These include simple interventions such as provision of a private room, creation of photographic mementos, and direct assistance to parents after the death of the child.

It is impossible to standardise bereavement aftercare as every family will have an individual response. It should be routine practice to offer information and services. The family should be provided with written information regarding the practical aspects of the mortuary or post-mortem examination process, if applicable. Information regarding counselling or bereavement support groups should also be provided.

In our institution, we routinely have a meeting with bereaved families in the months following their child's death. This provides an opportunity for the family to ask lingering questions and for healthcare professionals to offer further bereavement support or identify the requirement for specific psychological support.

9. Organ donation

Organ donation may be considered if criteria are met and if the family wishes for this. Donation may occur after brainstem death or in certain cases after death has been confirmed using circulatory criteria.

Donation can be a difficult subject to discuss with the family and, family refusal, or reluctance of practitioners to broach the topic, can be barriers to organ donation in children. Prior studies have shown that families who did not consent to donation did so due to: religious or cultural beliefs; believing that the child had suffered enough; or feeling that the donation process was too lengthy [58]. It is important to remember the sensitive nature of these concerns when discussing organ donation with the family and to provide them with support during the decision-making process [59].

The donation process requires a significant work from the PICU team. They must engage with local or national organ donation coordinators and facilitate relevant investigations. The benefits of organ donation include improved quality of life for the recipient and potential beneficial effects on the bereavement process of the parents [60].

10. The multidisciplinary team

Palliative care in PICU is delivered by a multidisciplinary team in an effort to provide a holistic approach to address the needs of the child and their family. In addition to PICU medical and nursing staff, the team ideally includes the following staff members:

- *Physiotherapy:*
The physiotherapist facilitates interventions such as therapeutic massage, passive movements and positioning. They provide education for the family and carers regarding patient transfers and respiratory care.
- *Psychology:*
A clinical psychologist can assess and assist in the management of emotional or behavioural disturbances in the child.
- *Complementary therapist:*
Therapies such as, aromatherapy, massage, music and reflexology may improve the patient's quality of life or psychological wellbeing [61].
- *Pastoral care:*
Involvement of the local pastoral care team can provide spiritual and religious support for family and staff caring for a child with life-limiting or terminal illness. Some families may wish to have their own faith leader present on PICU.
- *Social workers:*
Medical social workers are key support for the parents. They will assist the family with planning, finances and minimising the impact on the patient's siblings. Some parents have difficulty accepting the need for palliative care for their child [36] and social work can refer them for specific psychological or bereavement support.

As aforementioned, routine meetings between the family and the interdisciplinary team should provide the family with consistent communication about the child's clinical condition and agree upon treatment goals. All team members are provided with an opportunity to discuss the patient and support the medical team and family with difficult decision-making.

11. Audit, quality assurance and follow-up

A focus on audit and quality improvement is key to the delivery of high-quality palliative care in PICU. There are many evidence-based guidelines [62] which specify standards for provision of a comprehensive paediatric palliative care service. Undertaking audit against such guidelines is essential to gauge whether care is adequate and also provides the impetus to develop local quality improvement plans.

Another simple means of assessing a unit's performance is to conduct surveys amongst both the PICU staff and parents. This will identify areas that need to be improved upon and inform local research.

It is important that the institution recognises the need to educate care providers regarding palliative care practices. Education may take place in the form of multidisciplinary teaching sessions, provision of online resources or provision of funding for staff to gain additional qualifications such as a diploma or masters in palliative care.

Development of an integrated care pathway for palliative care in PICU will provide guidance for staff. All members of the multidisciplinary team should have input in the creation of such a document. It should function as a guide in the delivery of palliative care but recognise the importance of individual patient needs.

As aforementioned, in our institution we meet with bereaved parents in the months following a child's death. We also have an ethical duty to support our staff who can be left with a profound emotional impact from caring for a dying child. A helpful means of debriefing is the 'Schwartz Round', where the multidisciplinary team can discuss the emotional impact of their work [63]. This enables staff to support each other and can strengthen relationships within the team.

12. Conclusions

Palliative care in PICU can be a complex process. Paediatric patients may require palliative care for a variety of reasons and interventions should be tailored to each specific patient. The goals of care are to enhance quality of life and relieve suffering of patients and their families.

Ideally the patient, family and multidisciplinary team will form a shared plan to guide their palliative care journey. Regular family conferences should take place to continue this collaborative process and build relationships between the family and caregivers.

Processes such as redirection of care, withdrawal of life-sustaining therapies and organ donation should be approached by the team with sensitivity and compassion.

As not all children will have an advance care plan, the PICU team need to be equipped to deliver end of life care and guidance should be in place to facilitate this. Regular audit of outcomes should guide quality improvement in palliative care practices in the PICU.

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Conflict of interest

The authors declare no conflict of interest.

Abbreviations

PICU	Paediatric Intensive Care Unit
CBT	Cognitive Behavioural Therapy
ACP	Advance Care Plan
ECLS	Extra Corporeal Life Support
ECMO	Extra Corporeal Membrane Oxygenation

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