

RESEARCH ARTICLE

Planning the Discharge from Paediatric Intensive Care of a Child with Complex Care Needs

Authors:

1. Maeve McAllister, Specialist Registrar in Paediatric Intensive Care Medicine
2. Diarmaid Semple, Senior Clinical Pharmacist
3. Martina Healy, Consultant in Paediatric Intensive Care Medicine
4. Suzanne Crowe, Consultant in Paediatric Intensive Care Medicine

Affiliation

Paediatric Intensive Care, Children's Health Ireland, Crumlin, Dublin 12, Ireland.

Corresponding Author:

Dr. Suzanne Crowe

Consultant in Paediatric Intensive Care, CHI at Crumlin.

Email: Suzanne.crowe@olchc.ie

Phone: +353868328930

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Abstract:

Many children admitted to the Paediatric Intensive Care for management of serious illness recover quickly. This is reflected in a mean length of stay is <5 days for many tertiary level critical care units. A small proportion of infants and children require a prolonged paediatric intensive care stay, due to the severity of their illness, complexity of medical and nursing care required, and presence of underlying co-morbidity. This cohort of patients have particular needs when being discharged to ward level care, and onwards to home. This paper reviews the complex care that patients may require in the first days and weeks following discharge from paediatric intensive care. Supported by available published literature, the authors outline the key relevant themes, and make recommendations on how transition to the ward may be facilitated.

Introduction:

A small proportion of patients have a length of stay of greater than 30 days in PICU (1). The specialty of paediatric intensive care medicine treats children from birth to the age of fifteen years, with a wide range of diagnoses. In such a heterogeneous population, there are many reasons for prolonged admission in critical care.

Complex care needs can arise after a prolonged critical care stay due to the admission pathology, complications arising from treatment for the admitting illness, morbidity secondary to ICU supportive therapies, and the post-intensive care syndrome. The need for complex care can lead to adverse psychological, emotional and developmental consequences for the child and family unit. We bring together the key concepts that should be considered when managing the medical and nursing care of children who have had a prolonged intensive care admission.

Key Points:

1. A greater proportion of children survive to discharge from PICU. A small number of children who have had a prolonged PICU admission may have significant morbidity and medical issues requiring further management.
2. Planned transition to the ward from PICU benefits from multidisciplinary involvement to anticipate challenges and intervene early.
3. Communication between PICU team members, patient and their family, and ward staff is a vital part of maintaining trust in planned discharge to the ward.

Factors Influencing the Discharge of a Child with Complex Care Needs:

1.1 Comprehensive handover of the patient's background, pre-admission status, Intensive Care course and current issues is vitally important to establishing ongoing care on the ward. Communication lapses at this point in care are common, and may erode rapport and trust between the child's family and the ward team assuming care (2). Multidisciplinary team meetings in advance of anticipated discharge can give all team members an opportunity to ask questions, voice concerns and flag issues that could be optimised before discharge (3). Discharge of complex patients well-known to the PICU team should be planned for periods when the ward is well-staffed and briefed, ideally between 10am-4pm, Monday – Friday. A phased discharge may be considered, where the patient goes to the ward for several hours each day, returning to PICU at night. This is a simple measure which can highlight issues that need redress before completing discharge, and increase parental and ward staff confidence in caring for the child outside PICU.

1.2 After a prolonged PICU admission, there may be significant ongoing medical issues, some of which place large demands on nursing and allied supports (4). Central or peripheral neurological / neuromuscular impairment due to brain injury, seizures or myopathy can require intensive rehabilitation. Some infants and children may have a relatively new tracheostomy and / or ventilator support (5). Continuous positive pressure (CPAP)

or biphasic positive pressure (BIPAP) can be continued at ward level using a portable ventilator. Education and support of staff looking after patients with a surgical airway and a ventilator is required. Patients with impaired cardiac function need close monitoring and medical management to prevent decline into symptomatic cardiac failure. Understanding parental expectations of further intervention and recovery is important at this juncture.

1.3 Clarification of resuscitation status and / or commencement of palliative medical management should take place before discharge to the ward (6). Decisions made with the patient and their family about planned direction of care must be documented and communicated to healthcare teams assuming care of the child.

1.4 Infants and children who have recovered from critical illness often remain on multiple medications, some of which will need to be continued and monitored, and others which need to be gradually weaned. Examples of common classes of medication on discharge from PICU are in Table 1. Emphasis should be placed upon phased reduction and cessation of

medications which have the potential to produce withdrawal symptoms. These symptoms can be pronounced and distressing for children who have been prescribed sedating or analgesic medication over a prolonged duration of time (7). Sudden cessation may precipitate acute withdrawal and necessitate re-admission to the high dependency or paediatric intensive care unit for management (8). A plan to wean medication may be commenced before discharge and individualised with the use of a clinical scoring tool such as the SOFIA score (9, 10). Other medications require a more tailored approach, depending on the reasons for commencement, target levels and potential duration of therapy (11). Transitions of in-patient care are recognised as an independent risk factor for medication reconciliation errors (12). A structured medication reconciliation process that involves a clinical pharmacist is one strategy that can improve communication of medication use and decrease medication reconciliation errors on discharge from the PICU (13).

Table 1: Common Prescribed Medications in Child recently discharged from PICU

Medication	Monitoring	Clinical Assessment Tool
Opiates e.g. morphine sulphate	No	SOFIA score, COMFORT score
Sedatives e.g. lorazepam	No	SOFIA score, RAMSAY sedation score
Anticonvulsants e.g. phenobarbitone	Phenobarbitone serum level	RAMSAY sedation score
Anticoagulation e.g. tinzaparin	Factor Xa serum level	
Antibiotics e.g. vancomycin	Vancomycin serum level	
Immunomodulators e.g. prednisolone, sirolimus	No	No
Cardiac medications e.g. ACE inhibitors, anti-arrhythmics	Flecainide serum level	
Nebulised medications e.g. salbutamol, 3% saline	No	No
Chemotherapeutic agents e.g. methotrexate, etoposide	White cell, red cell and platelet count	No
Electrolyte supplements e.g. magnesium, potassium	Serum level	No

1.5 Medical technology is currently used to continue cardiovascular and respiratory support outside of the critical care environment (14). Discharge to the ward with medical technology e.g. portable ventilators, infusion pumps, feeding pumps and monitoring software, adds complexity to care. It may require increased equipment provision, healthcare staff training and allocation to provide a safe environment. e.g. ventilation, infusion pumps, feeding pumps, monitoring software (15). There is considerable interest in the development of increased portability and wearable technology, which may be

adapted for use in the home environment (16). Discharge to home with medical technology support requires dedicated home care nursing staff and separate funding (17)

1.6 Although the child may have recovered sufficiently to be safely managed on the ward, their ongoing medical management may mean that further or follow-up investigations and interventions are indicated, e.g. magnetic resonance imaging of brain or percutaneous gastrostomy feeding tube insertion. The indication and timing of investigations and interventions needs to be effectively

communicated to the team receiving medical care.

1.7 Referral to allied health care professionals such as a clinical dietician, occupational health therapist or neurodevelopmental physiotherapist will usually occur as part of routine practice in the intensive care unit. The involvement of all team members enhances care of children with a broad range of medical challenges (18), and a regular forum to hear the perspective of all team members may improve team effectiveness and morale (19). Physicians must ensure that this multidisciplinary input continues when the child is discharged to the ward.

1.8 Psychosocial issues may arise during a child's prolonged PICU stay. Anxiety, behavioural disorders, nightmares, and insomnia occur in intensive care patients (20, 21). Patients require assessment for delirium when in PICU, as symptoms of hyperactivity may be interpreted as behavioural disorder. Parents can experience high levels of stress when their child is critically ill (22) and posttraumatic stress is also recognised amongst this group. Early referral to a clinical psychologist and signposting to support services is key in addressing potential problems early (22). As the child is transitioned to the ward, parental anxiety may increase. This is a common phenomenon and can be addressed with family involvement in decision-making, formal support and a PICU liaison nurse (23).

1.9 Post-intensive care syndrome is defined as a new and deteriorating disorder in the cognitive, mental, and physical health

status experienced after discharge (24). Although well described in adults (25), less is known about its incidence and features in children (26). Nevertheless, each of these potential outcomes should be anticipated and addressed as the child progresses through their PICU journey.

1.10 Multidisciplinary teams delivering community care to paediatric patients require information and guidance following discharge home of a patient who has been in PICU for several weeks or months. This is especially vital if the child is dependent on medical technology or specialised services such as home nursing (27). Written communication of medication to be continued, and follow-up investigations, interventions or hospital visits should be sent to the child's family doctor and community nurse in advance of their arrival home. Telemedicine may be helpful in coordinating planned discharge to the community of complex patients (28).

1.11 The presence of a specific liaison nurse or transition programme can facilitate transition to the regular ward (29) (30). One aim of such a programme is to reduce the chance of potential deterioration on the ward and necessity for re-admission to PICU. Common reasons for re-admission to PICU are summarised in Table 2. Understanding the common themes facilitates focus during the planning for discharge phase (31). This data is particularly important to examine as readmission episodes have been recognised to have a longer length of stay and higher mortality compared with index admissions (32).

Table 2: Common Reasons for Re-Admission to the PICU following Discharge to Ward

Reason for Re-Admission	Additional factors
Infection	Wound infection, Central venous access related
Respiratory failure	Retained secretions, poor cough
Cardiac failure	Changes in enteral intake or diuretic may contribute
Nursing care exceeds ward nursing ratio	Requirement for frequent suctioning, positioning, multiple intravenous medications
Relapse of medical issue	Mucositis, typhlitis post-chemotherapy
Acute symptoms from withdrawal of analgesics or sedatives	Distressing symptoms increase physiological demands and contribute to patient and parental concerns

1.12 It is important to audit outcomes after prolonged PICU stay (33). Data from patient admission and intensive care course is usually collected and compared with standardised mortality ratio for benchmarking and peer review. Re-admission, particularly when unplanned, is an important quality indicator. Audit data routinely extracted should include re-admission rate, reasons for re-admission and course thereafter. Some aspects of care may prove to be amenable to a quality initiative e.g. re-admission due to withdrawal symptoms.

1.13 The concept of a PICU follow up clinic is has been garnering increasing interest. This may take place in person or via telephone consultation, with the objective of identifying and addressing ongoing issues amongst PICU survivors. Some centres provide ad hoc outpatient review after critical care admission, but there is conflicting data with regard to outcome 12 months after discharge (34-36).

Discussion and Conclusions:

Children who have had prolonged critical illness often have a variety of ongoing, complex needs upon discharge.

They may experience issues related to medications, functional impairment, or psychological distress. We have discussed these potential care needs, and how they may be managed safely in the ward setting.

All involved clinicians have a responsibility to ensure a smooth transition, initially to ward level care, and then to home. This requires meticulous planning and clear communication amongst hospital doctors, allied health professionals and community teams. It is essential to involve and support the parents in this process.

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