Compassionate Extubation at Home (CEAH) in Paediatric Palliative Care: A Case Series

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Background

- **Compassionate extubation** is defined as the cessation of mechanical ventilation in patients with irreversible and untreatable conditions, where the suffering associated with futile prolongation of the death process outweighs the benefits for the patient.[1]
- When a child's life is being sustained by artificial ventilation in an ICU, the option for palliative extubation at home is usually possible, but all too often, it may not be offered as professionals **may not realise this option exists.**[2]

Background

- Compassionate extubation at home (CEAH) offers an approach for children to pass away peacefully within the familiar surroundings of their homes.[3]
- Parents have described these experiences as **positive, deeply meaningful** and **providing a sense of control and comfort** to themselves and other family members.[4]
- Despite growing interest in offering CEAH as a feasible option, there are few published studies involving children on this subject.[5]

Aim

To investigate the characteristics of compassionate extubation at home (CEAH) in paediatric patients supported by a paediatric palliative home care service

Methods

- Retrospective case series review
- **Inclusion criteria**
  - Paediatric patients (<21 years old)
  - Underwent CEAH between Jan 2019 and Dec 2023
  - Supported by paediatric palliative home care service in Singapore
- **Data collection**
  - Data from medical records extracted e.g. patient demographics, diagnosis, relevant information prior to, during and after the CEAH
  - Email survey to multi-disciplinary providers about their experiences
- **Data analysis**
  - Descriptive statistics performed to collate and summarize data

Methods

- Star PALS (Paediatric Advanced Life support)
  - Sole PPC home care provider in Singapore
  - 12 multi-disciplinary health care workers
  - ~80 patients, 2000 home visits/year
  - Referrals from 2 paediatric hospitals

Results

Patient and family demographics

	A	B	C	D	E
Age	18days	11months	1yr5months	6years	20years
Gender	F	F	F	M	F
Diagnosis	Congenital hepatic haemangioma	Congenital myopathy	Neuro-degenerative disorder	Spontaneous Intra-cranial haemorrhage	Diffuse midline glioma
Race	Chinese	Malay	Chinese	Malay	Chinese
Religion	Christian	Muslim	Buddhist	Muslim	Christian

Preparation phase

	A	B	C	D	E
Inpatient palliative care team	Yes	No	Yes	Yes	Yes
Duration btw activation to home (days)	1	10	3	1	1
No. of meetings between SP & family	1	3	0	1	0
Mode of communication	Virtual consultation	Hospital visits	-	Hybrid	-

Preparation phase - Conversations

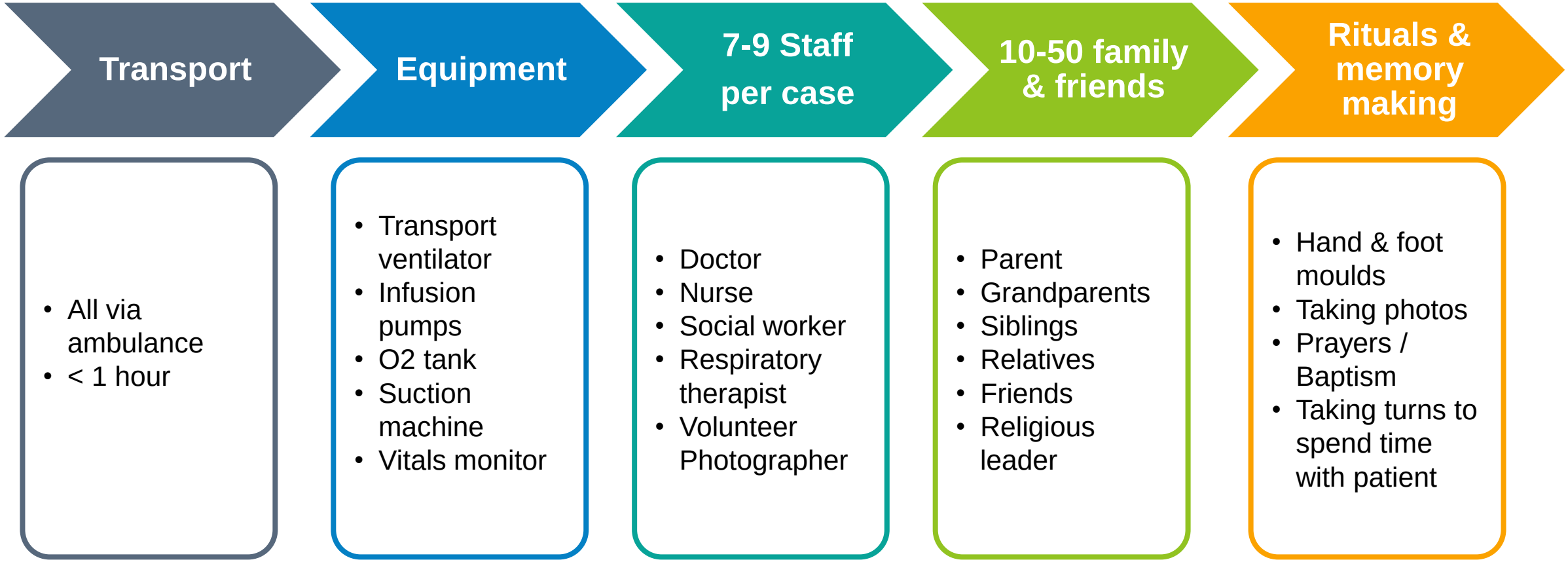
Family

- “What will happen after the tube is pulled out?”
- ”How soon will he pass on after the tube is removed?”
- Timing of extubation due to religious reasons
- Mutual concern for each other’s well-being

Health care team

- Assessment of family’s understanding
- Practical aspects
- Anticipated symptoms and symptom management
- Cultural & religious customs
- Dedication to patient’s comfort

Execution phase



Execution phase

Symptoms	Medications	Time from extubation to death	Last office	Total time at home
• Most comfortable • Respiratory symptoms	• Morphine • Midazolam • Anti-secretory agents • Inotropes	• Immediate to 10 hours	• Certification of death • Removal of tubes and lines • Cleaning & dressing the body	• 1 to 6 hours • 3 visits extending beyond office hours

Follow up phase

- Bereavement visits
  - 2-3 weeks after child's death
  - Comfort box
  - Ongoing bereavement support
  - Invitation to memorial service
- Team debriefs
  - Within 1-2 weeks of death
  - 1 joint team debrief btw SP and hospital

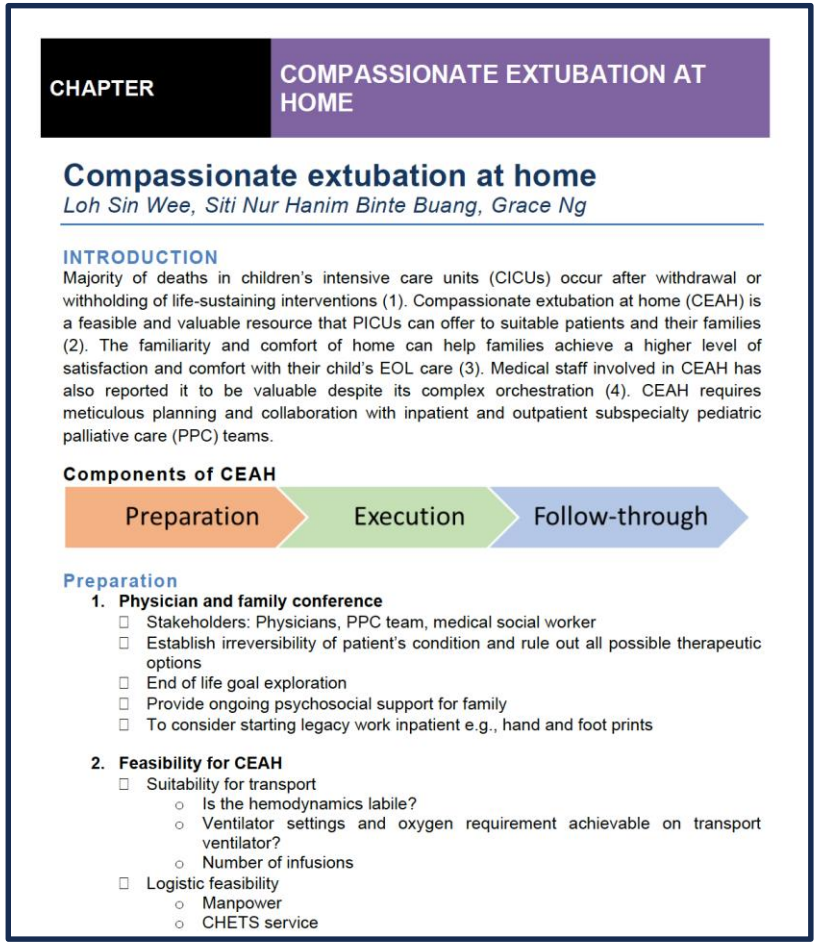
Professional provider reflections

- Challenges
  - Short activation time was stressful
  - Emotional & moral distress
  - Sudden changes to what was planned
- Supportive factors
  - Effective communication
  - Close collaboration of the multi-disciplinary team
  - Increased experience led to increased confidence
- Overall satisfaction

"I wasn't sure if it was ok for me to cry…" – Junior doctor

"I felt satisfied that I could capture the moments for the family, so that in the future the family can look back at the photos and videos and remember the times together." – Volunteer photographer

CEAH workflow



CHAPTER | COMPASSIONATE EXTUBATION AT HOME

Compassionate extubation at home

Loh Sin Wee, Siti Nur Hanim Binte Buang, Grace Ng

INTRODUCTION

Majority of deaths in children's intensive care units (CICUs) occur after withdrawal or withholding of life-sustaining interventions (1). Compassionate extubation at home (CEAH) is a feasible and valuable resource that PICUs can offer to suitable patients and their families (2). The familiarity and comfort of home can help families achieve a higher level of satisfaction and comfort with their child's EOL care (3). Medical staff involved in CEAH has also reported it to be valuable despite its complex orchestration (4). CEAH requires meticulous planning and collaboration with inpatient and outpatient subspecialty pediatric palliative care (PPC) teams.

Components of CEAH

Preparation → Execution → Follow-through

Preparation

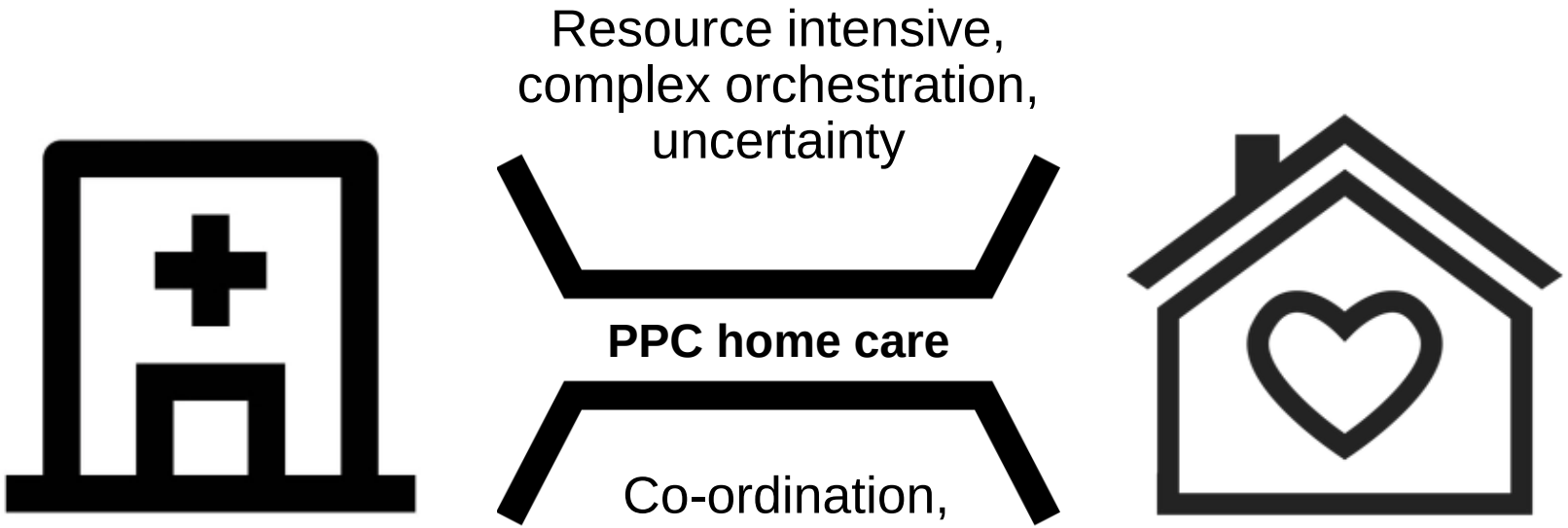
1. **Physician and family conference**
   - Stakeholders: Physicians, PPC team, medical social worker
   - Establish irreversibility of patient's condition and rule out all possible therapeutic options
   - End of life goal exploration
   - Provide ongoing psychosocial support for family
   - To consider starting legacy work inpatient e.g., hand and foot prints

2. **Feasibility for CEAH**
   - Suitability for transport
     - Is the hemodynamics labile?
     - Ventilator settings and oxygen requirement achievable on transport ventilator?
     - Number of infusions
   - Logistic feasibility
     - Manpower
     - CHETS service

- Key considerations:
  - Information sharing with families
  - Importance of activating the SP team as soon as possible
  - A checklist of necessary equipment and medications to prepare
  - Planning for the staffing and allocation of roles

Summary

Compassionate Extubation at Home



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Thank you!

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“Thank you for fulfilling our wish to let K pass away at home in the presence of her extended family & for allowing her to be comfortable in her final moments. We are incredibly grateful and no words can fully express our gratitude to you and your team!” – Bereaved family