

Filling The Gap For Respite & End Of Life Care For Children With Life-limiting Illnesses In Singapore: Our Journey As An Adult Hospice



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Introduction

Paediatric Palliative Care (PPC) is the active total care of the child's body, mind, and spirit with support for the family through to bereavement.¹ Children with life-limiting illnesses such as congenital/genetic, metabolic, oncological, and neurological conditions often have high and complex care needs, including dependence on healthcare technology.² Caring for these children has a profound impact on the physical and emotional well-being on families and informal caregivers.³ Before 2017, PPC services were provided by community day centres, hospitals, and homecare service within Singapore. There was no dedicated children's hospice providing respite and inpatient end-of-life care (EOL) for these children and their families. This led to the development of a PPC service within Assisi Hospice (AH).

Aim

We describe our journey as a predominantly adult hospice filling a healthcare system gap in providing respite and/or EOL care for children with life-limiting illnesses.

Development of the Assisi Hospice PPC service

The Care Facility Design: AH provides hospice services through 3 care settings: inpatient, homecare, and daycare. In January 2017, AH expanded to an 85-bedded inpatient hospice facility with provisions for caring for children with life-limiting conditions in a child-friendly environment. This included comfortable quiet spaces, a playroom, a sensory garden and a playground.

The Service provides inpatient care for children and young adults with life-limiting conditions, known to paediatric healthcare services within Singapore, aged up to 40 years, with estimated life prognoses not likely to reach adulthood. The inpatient hospice provided symptom management, end-of-life care and / or short-term respite care.

Six important service development areas were recognized and described below:

(1) PPC interdisciplinary team (IDT) includes physicians, nurses, social workers, clinical pastoral carer, physiotherapists, occupational therapists, art and music therapists, speech therapist and pharmacist. Nurses with paediatric care experiences, including a nurse clinician, were sought and employed to develop and support staff's education and training.

(2) Education and training of essential knowledge and skills for the IDT started 6 months prior to the start of the inpatient PPC service in 2016. When admissions started, IDT meetings, bedside teachings, pre-admission briefs, and case debrief sessions were held.⁴

To continue to guide education and training for staff, it was important to understand the demographics of the children (**Table 1**) and identify their care needs (**Table 2**). **Fig. 2** shows the percentages of the different level of care needs of the 64 admissions.

Fig. 2: Level of care needs percentages

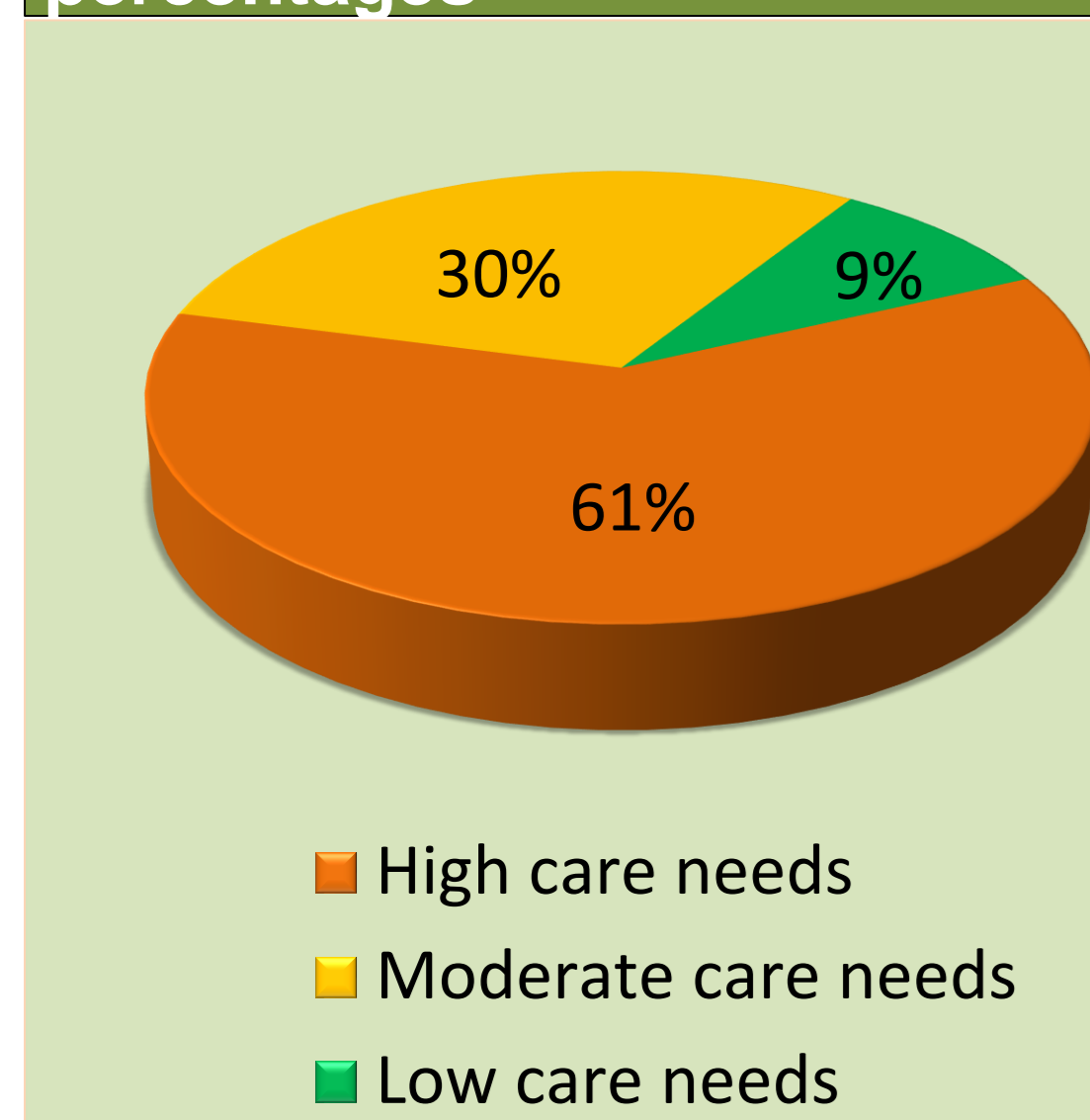


Table 1: Demographics of 32 unique children admitted from January 2017 to June 2021

		No. of patients	%
No of patients with repeated admissions		16	50
Age (years)	Range	1-38	
	Mean	12	
Gender	Male	16	50
	Female	16	50
Ethnic Group	Chinese	14	44
	Malay	16	50
	Indian	2	6
Diagnostic Category	Cancer	1	3
	Neurological including cerebral palsy	16	50
	Congenital/Genetic	12	38
	Metabolic	3	9
Prognosis	> 1 year	26	81
	4-6 months	1	3
	< 3 months	5	16
Reason for admission	Respite	59	92
	End-of-life	5	8
Length of stay (days)	Average	18	
	Range	1-133	
Ventilator status	Not on Ventilator	22	69
	Invasive Ventilator	5	16
	Non-invasive Ventilator	5	16
Resuscitation status	Active	26	81
	Do not resuscitate order	6	19

Table 2: Level of care needs

Care needs level	Nursing procedures	Neurological issues	Behavioural issues	Remarks
Low	1. Bolus enteral feeding 2. OP/NP suctioning: 2-3 times /day 3. ADL dependent, Bed and WC bound	Mild	Mild	e.g. Oral feeding once a day
Moderate	1. Enteral feeding: Bolus/continuous feeding 2. O2 therapy 3. SaO2 monitoring 4. Tracheostomy without ventilator 5. Nocturnal NIV 6. OP/NP suctioning: > 3 times /day 7. ADL dependent, Bed and WC bound	Moderate	Moderate	e.g. Schedule daily routine with social worker / allied health
High	1. Enteral feeding: Bolus/continuous feeding 2. Tracheostomy with invasive ventilation 3. 24/7 continuous NIV 4. SaO2 monitoring with/without O2 therapy 5. OP/NP suctioning >3times/day 6. ADL dependent, Bed and WC bound	Severe	Severe	e.g. - Schedule daily routine with social worker / allied health - Toilet training - Frequent venting and gastric decompression

Note: OP: Oropharyngeal; NP: Nasopharyngeal; ADL: Activities of Daily Living; WC: Wheelchair; NIV: Non-invasive Ventilator

Ten of the 32 unique admissions (31%) were children on respiratory ventilators. All children admitted had advance care plans (ACP) and care preferences discussed and documented. 26 (81%) of these children had plans for active resuscitations. (Table 1). The complex needs of these children reinforced the value of collaborative practice and training with primary healthcare teams.

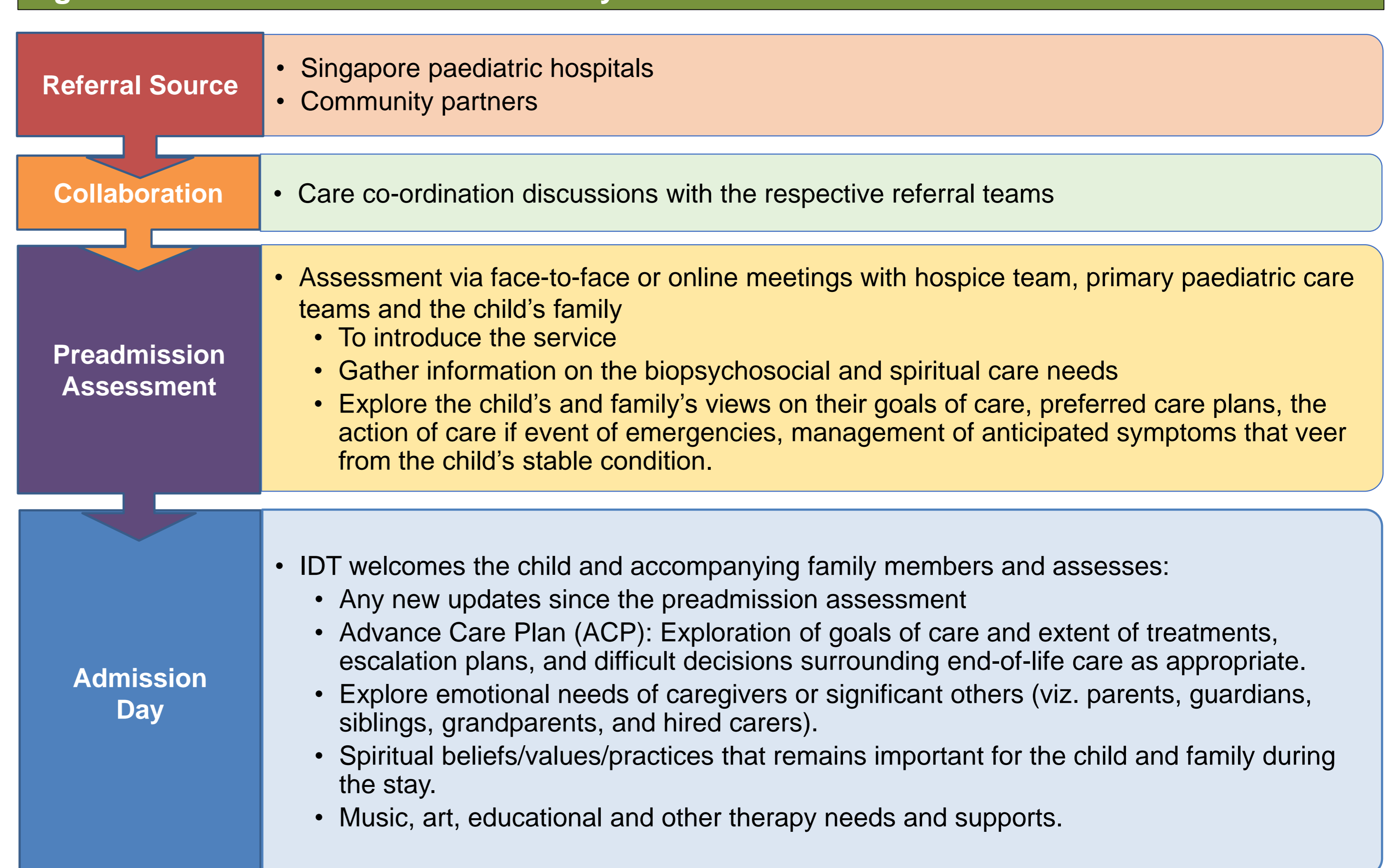
(3) Collaboration with hospitals, homecare and support services through cross-learning and interdisciplinary care coordination

helped staff learn and care for the children and families. Attachments and visits to local and international children's hospitals, hospices, and palliative homecare services, conferences and workshops e.g., home ventilation and Paediatrics Education in Palliative and End-of-Life Care (EPEC) were opportunities for networking and staff training in paediatric clinical assessments and care, including communication skills, gastrostomy feeding, tracheostomy and ventilatory care. Staff gathered knowledge and guidance on PPC service development. Shared online resources, case-based discussions, bedside teaching and combined lectures were held between AH and a local children's hospital and/or paediatric palliative homecare IDTs. Such opportunities allowed care collaboration between hospice team and primary shared care teams. AH conducted service roadshows to build networks with clinical staff at the children's hospitals and to create awareness of the hospice's PPC inpatient service. Service brochures were developed and shared with referral teams and made available for interested families.

(4) A systematic holistic interdisciplinary assessment of care needs

was incorporated into the admission workflow. (Fig. 3) The children with complex and high care needs necessitate a well-coordinated care among the multiple professionals involved in each child's care and their families. The care model used a patient-family centred approach that provided medical and nursing care, including flexible feeding and bath schedules. Music, art, play, and physical therapy were used to engage and explore concerns with the children and their siblings. Psycho-emotional and spiritual supports for caregivers or significant others (e.g., siblings, grandparents) were made available.

Fig. 3 Workflow: From referral to the day of admission



(5) Delivering a safe and responsive care is a valued goal of the service. Advance care planning explored difficult decisions and individualised care plans surrounding treatments like recurrent infections, seizure managements, behavioural management, resuscitation care, end-of-life care issues and other care preferences.

Having skills to recognising a sick child, understanding the differences in age-relevant observation charts and having awareness of the child's usual baseline condition and vitals were important factors that help staff determine appropriate escalation for emergencies as required. A protocol modelled after the Paediatric Early Warning System (PEWS) was modified to suit our patients' profiles. This protocol aimed: (a) to help staff recognise a sick child; (b) to alert, guide and empower staff to identify trends in a child's condition; (c) to address clinical care issues that may arise; and (d) to communicate and promote timely escalations of concerns and reviews.

(6) Service feedback through caregiver satisfaction survey forms were gathered from each admission stay to help improve the services. Of the 64 admissions, 27(43%) responded satisfaction survey forms were received. The caregivers' satisfaction surveys showed that 96% of respondents were satisfied with the support and services provided and all the 27 respondents said they would recommend the service.

Discussion

Recognising the need of an inpatient hospice service for children with life-limiting conditions, Assisi Hospice developed the PPC service. A small portion of the children were admitted for end-of-life care. Majority of these children had complex care needs requiring respite. Our approach was family-centred as the lives of our paediatric patients were deeply amalgamated with their families. Caring for the child also meant caring for the exhausted caregiver. As a predominantly adult hospice and a low volume of paediatric cases, education and training remained important aspects to support our PPC learning needs to enhance and maintain knowledge and skills. De-briefing sessions were important for staff to attend to their emotional stressors which commonly surfaced in the process of witnessing suffering during caring for children at the end of life and a space for reflection and development in self-awareness and self-care strategies.

Conclusion

The years ahead remains formative as we continue to serve children with life-limiting illnesses and their families, and to support staff's wellbeing, educational and training needs. Bereavement care is an area for future service development.

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