

Needs of paediatric patients with life-limiting disease: abridged secondary publication

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KEY MESSAGES

1. Children with life-limiting diseases, their parents, and healthcare professionals all identified needs related to understanding the disease, living with the disease, and coordination and continuity of care.
2. There is a need for greater parental engagement in care planning and management, with support from healthcare professionals.
3. Paediatric palliative care facilitates holistic care for children with limited lifespans and should be introduced after the diagnosis is confirmed.
4. A nurse case manager on the paediatric palliative care team can facilitate continuity of care and interdisciplinary communication.

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Introduction

Children with life-limiting diseases and their families face numerous challenges. Such children continue to grow and have developmental needs, along with healthcare and social needs. Caring for children with life-limiting diseases is a lifelong project for parents, who may experience fatigue because their time and space are fully engaged in managing the child's condition. Sometimes the spousal relationship is affected by the tension and disruption of normal family life.

Continuity of care is desirable, with coordination extending from hospital to home. Early and regular communication between parents and healthcare providers is essential for determining treatment options. Children with life-limiting diseases benefit from a palliative approach that advocates holistic care supported by an interdisciplinary team. The initiation of paediatric palliative care (PPC) is recommended after a diagnosis of life-limiting disease is confirmed.¹ The demand for PPC is increasing worldwide, but access to this service is limited. Currently, there are no data regarding the number of sick children requiring PPC in Hong Kong. The concept of palliative care is underdeveloped among paediatric patients, compared with adult patients. The Hospital Authority has established a strategic service framework for palliative care to support all patients with life-limiting conditions.

This study explored the perceived needs of paediatric patients with life-limiting diseases and opinions regarding PPC from the perspectives of affected children, parents, and healthcare providers.

Methods

Children aged 8 to 19 years with life-limiting diseases, as categorised by the Association for Children's Palliative Care Services,¹ who were not receiving active treatment, along with their families and healthcare providers, were recruited from five regional hospitals in Hong Kong between August 2019 and October 2021 for in-depth semi-structured interviews. All interviews were transcribed verbatim, and qualitative content analysis was independently performed by two researchers to explore similarities and variations in the perceived care needs of the three groups of participants. The agreement was 62.6% initially and reached 88.7% after repeated discussions until consensus.

Results

In total, 65 individuals (25 children, 25 parents, and 15 healthcare providers) in 25 cases were interviewed. Their mean ages were 13.5, 45.4, and 47.7 years, respectively. There were 44.0% female children, 68.0% mothers, and 46.7% female healthcare providers. According to the Association

for Children’s Palliative Care Services, 8.0%, 24.0%, 28.0%, and 40.0% of the children’s diseases were categorised as I, II, III, and IV, respectively (Table).

In total, 3784 units of needs of children with life-limiting diseases in three categories were analysed (Fig). Of these, 51.8% were from parents, 24.7% were from healthcare professionals, and 23.5% were from children. The category ‘information and understanding about the disease’ comprised 27.4% of the units in two subcategories: ‘information and communication process’ and ‘understanding of child’s condition and treatment process’. The category ‘living with the disease’ comprised 55.8% of the units in three subcategories: ‘living with physical

concerns’, ‘living with non-physical concerns’, and ‘perspectives of life’. The category ‘care support and palliative care’ comprised 16.8% of the units in two subcategories: ‘continuity and coordination’ and ‘understanding of palliative care’.

In the category of ‘information and understanding about the disease’, doctors were identified as the primary source of information, although parents and children were able to search for information online. Patient groups were helpful in providing access to community resources. Healthcare professionals mainly provided medical information related to their own specialties; parents and children reported that this information was

TABLE. Characteristics of participants

	Children (n=25)*	Parents (n=25)*	Healthcare providers (n=15)*
Age, y	13.5±3.4	45.4±7.1	47.7±6.6
Sex			
Female	11 (44.0)	17 (68.0)	7 (46.7)
Male	14 (56.0)	8 (32.0)	8 (53.3)
Education			
Primary	9 (36.0)	2 (8.0)	-
Secondary	16 (64.0)	15 (60.0)	-
Tertiary or above	0	8 (32.0)	-
Association for Children’s Palliative Care category			
I (curative treatment may be feasible but can fail)	2 (8.0)	-	-
II (long periods of intensive treatment needed to prolong life and allow normal activities)	6 (24.0)	-	-
III (progressive conditions without curative treatment options and treatment is exclusively palliative)	7 (28.0)	-	-
IV (irreversible but non-progressive, causing severe disability leading to health complications and premature death)	10 (40.0)	-	-
Marital status			
Single	-	0	-
Married	-	20 (80.0)	-
Widowed	-	3 (12.0)	-
Divorced	-	2 (8.0)	-
Employment			
Full-time	-	7 (28.0)	-
Part-time	-	3 (12.0)	-
None	-	15 (60.0)	-
Housing type			
Public	-	17 (68.0)	-
Private	-	8 (32.0)	-
Occupation			
Physician	-	-	13 (86.7)
Nurse	-	-	2 (15.3)
Experience in paediatric specialty, y	-	-	21.9±5.5 (7-31)

* Data are presented as mean±standard deviation, mean±standard deviation (range), or No. (%) of participants

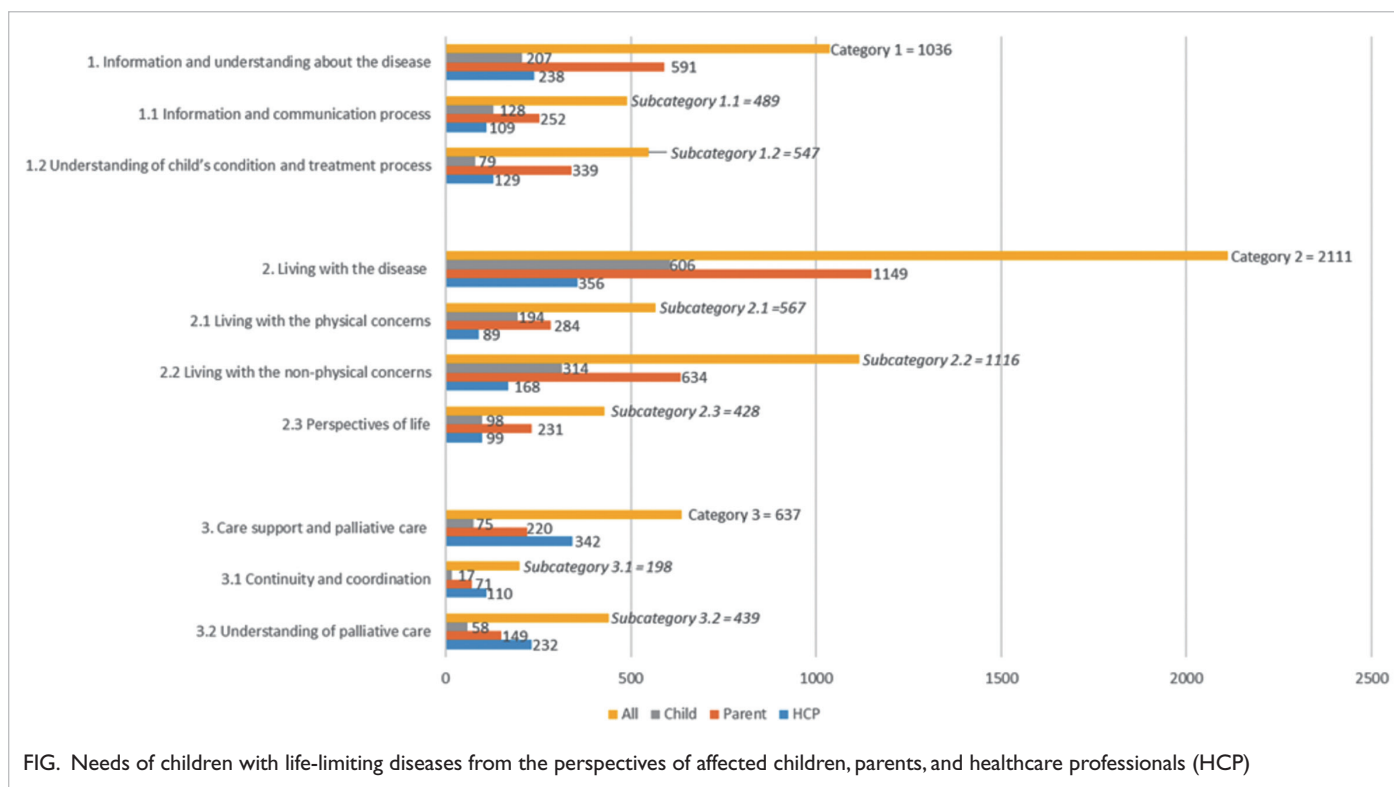


FIG. Needs of children with life-limiting diseases from the perspectives of affected children, parents, and healthcare professionals (HCP)

fragmented. Doctors acknowledged that they had minimal time available for patients and children during clinic consultations. Nurses often assumed the role of providing more detailed explanations; they acted as facilitators and agents of communication between patients/caregivers and doctors. The diagnosis stage could be a long process, followed by multiple treatments and repeated surgeries when the diagnosis was confirmed. In addition to Western medicine, alternative therapies were also regarded as care options.

The category of 'living with the disease' showed that children had both physical and non-physical concerns. Parents played a key role in supporting their children during daily living. Healthcare professionals supported parents in managing symptoms by arranging specialised equipment and teaching home-based nursing care. Caregivers, particularly mothers, had health issues themselves due to these heavy responsibilities. In some instances, spousal relationship was affected. Numerous emotional and psychological responses were identified in the subcategory 'living with non-physical concerns'. Parents and children both reported encountering social stigma. Children coped with psychosocial challenges by engaging in their favourite activities, with support from their parents. Although doctors noticed these psychosocial issues, they acknowledged lacking time to address such

issues; nurses helped to fill this gap. In addition to hospital support, social and community support (ie, sponsorship for devices and activities) were also important. Children and their parents demonstrated realistic acceptance of the situation; children continued to plan their education and career.

The category of 'care support and palliative care' revealed concerns about continuity and coordination of care; healthcare professionals primarily focused on physical conditions. Healthcare professionals, children, and parents all noted that better coordination among specialties and better continuity of care were desirable. All three groups regarded palliative care as a more holistic approach to address their needs; they agreed that a nurse case manager could help coordinate interdisciplinary services and enhance continuity of care. Parents emphasised the need for early initiation of palliative care because of their children's limited lifespans, and healthcare professionals concurred.

Discussion

Children with life-limiting diseases and their parents experience complex challenges. There is an urgent need for better coordination and facilitation of care. Parents play an important role in caring for their children. Palliative care facilitates holistic care supported by a multidisciplinary team, thereby

optimising quality of life for both children and parents.

Children with life-limiting diseases go through several phases in their disease trajectory, from diagnosis to treatment, living with the disease with episodes of life-threatening events, and finally reaching the end-of-life phase.² Living with the disease involves functional limitations, constant interventions, and frequent surgeries that elicit fear and worry. Positive thinking, family support, and peer support are important, as are patient groups and community resources.

Parents often act as surrogate decision-makers, whereas children are passive recipients.³ The parents in this study exhibited great resilience, but the demands on their well-being raised concerns. Changes in employment status and quality of life were reported by these parents. Such changes could lead to poor family functioning² and an increased caregiver burden. However, informal caregivers often are not engaged as key care planning partners in collaboration with healthcare professionals.⁴ There is an urgent need to involve caregivers as essential members of the care team.⁴

The formation of a true partnership requires healthcare professionals to adapt to reciprocal information exchange and involve families as co-creators in care planning and coordination processes. Additionally, informal caregivers require training to enhance their knowledge and skills in home care provision and resilience, thereby protecting themselves from adverse effects on physical and mental health. Palliative care advocates holistic care and coordination and continuity of care supported by an interdisciplinary team.¹

The palliative care approach aims to improve quality of life for individuals with life-threatening illnesses through early identification and management of problems in a holistic manner that involves coordinated multidisciplinary efforts. Engaging a key worker as a single point of contact to assist with care coordination is recommended. A narrative review suggested that nurses are the most appropriate individuals to assume such a role.⁵ Participants who had experience with a nurse case manager confirmed that the service was beneficial. Early integration of PPC can support children with life-limiting diseases and their families in making sound and realistic decisions; symptom management can be enhanced by better care coordination. The Strategic Service Framework for palliative care, introduced to Hong Kong in 2017, has helped to promote PPC; however, the service remains underdeveloped. This framework guides the development of palliative care and services; it aims

to support patients with life-limiting conditions by addressing their physical, psychological, and spiritual needs and improving their quality of life. Unlike adult palliative care services, PPC services are underdeveloped and carried out in an unstructured manner. Some hospitals do not have designated PPC teams. For example, two of the five study hospitals had a designated PPC team; the other hospitals provided PPC services in addition to their routine services.

Conclusion

This study highlighted the need for greater parental engagement in care planning and management for children with life-limiting diseases. Our findings can help inform healthcare policymakers and providers in the establishment of a PPC model.

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Disclosure

The results of this research have been previously published in:

1. Wong FKY, Ho, JMC, Lai TC, et al. Importance of parental involvement in paediatric palliative care in Hong Kong: qualitative case study. *Arch Dis Child* 2024;109:130-7.

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