

Original article

Three years' experience with the first pediatric hospice in Asia

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Abstract

Objective: Pediatric hospice has been the adoption of several service provision models in highly developed countries such as UK, Germany, Australia or Canada for a few decades, yet it has seldom been the case in the Asian Continent. This study aimed to evaluate the newest challenge for the children with Life-threatening illness (LTI) and described the characteristic of pediatric palliative care at the first pediatric hospice in Japan.

Methods: A retrospective review of all patients at our pediatric hospice in these three years was conducted. Of the 294 cases reviewed, 269 cases were eligible for analysis.

Results: We reviewed 269 patients admitted during the first three years. Most patients required intensive medical intervention. Patients were hospitalized in our pediatric hospice not only for end-of-life care (EOL), but also for respite care. Only 7% of the patients were with cancer. To support children and family to make the most of their time together, we provided a range of medical and recreational care. It is expected that the pediatric hospice will extend and establish cooperation with other hospitals or community services.

Conclusion: Three years' experience of pediatric palliative care at the first pediatric hospice in the Asian Continent is encouraging. Further experience and improved communication with other pediatric service providers as well as their education in palliative care will enhance the recognition of the capacity of our hospice and support the needs of more children. Furthermore, we would like to introduce the idea of pediatric hospice and spread it throughout the Asian Continent in the future.

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Keywords: Pediatric palliative care; End-of-life care; Pediatric hospice; Life-threatening illness; LTI

1. Introduction

In the 20th century, the remarkable success of high-technology care in hospitals changed the process of dying and enabled to prolong life expectancy. Against this backdrop, hospice and palliative care, which was focused initially upon adult, was developed since the

foundation of St. Christopher Hospice in 1960s [1]. Palliative care has been an increasingly important element of pediatric care for children with LTI, including incurable, terminal conditions since the foundation of Helen House by Sister Frances in 1980s [2,3]. WHO has been focusing on pediatric palliative care and developed the definition of palliative care for children [4]; Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care for children is as follows; Palliative care for children is the active total care of the child's

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body, mind and spirit, and also involves giving support to the family [1]. The principles apply to other pediatric chronic disorders. Sophisticated facility to care for severely mentally and physically disabled children “Shimada Ryouiku Center” established in 1961 for the first time in Japan. From then many similar facilities have been established all over Japan and have been taking most qualified care for these children for over 50 years. However pediatric hospice focused on taking active total care even when the children are confronting death. Such facilities that are coping with life-limiting condition and death of children had not existed in these decades in Japan and the Asian Continent.

2. Objectives

Pediatric hospice has been the adoption of several service provision models in high-income countries such as UK, Canada, Australia, Germany and so on for a few decades, yet there has been seldom experience in the Asian Continent. This study aimed to evaluate the newest challenge for the children with Life-threatening illness (LTI) and described the characteristic of pediatric palliative care at the first pediatric hospice in Osaka, Japan from November 2012 to October 2015.

3. Methods

Our pediatric hospice has been opened in Osaka in November 2012, for the first time in Japan and the Asian Continent. (Free-standing hospice facility consisting of adult hospice and pediatric hospice and stand near a general hospital with a pediatric department) (Fig. 1). This report documents the first three years’ experience of the first freestanding hospice to understand the precise characteristics of children and families enrolled and to establish baseline information for future perspectives in other Asian regions.

A retrospective review of all patient medical records at our facility from Nov. 2012 to Oct. 2015 was conducted. The following information for each patient was extracted: demographics; diagnoses; admissions/discharges; EOL care. Of the 294 cases reviewed, 269 cases were eligible for analysis (24 were never accepted onto program, and 1 duplicate entry) (Fig. 2). This study was approved by the ethical committee of Yodogawa Christian Hospital and we obtained comprehensive informed consent from patients/guardians.

4. Results

A total of 294 children were identified 25 cases were excluded, and 269 cases were analyzed.

250 children (92.9%) were with non-malignant conditions, mean age was 9.1 years old (median: 7.0 range: 0–43) (Fig. 3). Mean length of inpatient stay was 3.8 days



Fig. 1. Yellow Circle; Osaka prefecture; populations 8.8 million, population of children <20 years old 1.63million. (For interpretation of the references to colour in this figure legend, the reader is referred to the web version of this article.)

(median: 3, range: 1–36). Mean number of admission in these three years is 6.5 (median: 4; range: 1–36). Approximately 70% of the patients were admitted twice or more. 211 patients out of 250 live in Osaka prefecture. The non-malignant-patients belonged to various diagnostic groups (Table 1). Seventy-one cases (28.4%) used mechanical ventilator, 104 cases (41.6%) were with tracheostomy and 164 cases (65.6%) were with tube feeding (Fig. 4). Eleven cases out of 250 (4.4%) patients died in the three = year period out of hospice. Nine cases of 11 died in the hospital due to deterioration of their main disease (Cerebral Palsy 5, congenital anomaly 3, secondary 1). Two cases of 11 died due to sudden respiratory arrest at home and autopsy proved no intentional abuse (Cerebral Palsy 1, neuro-muscular 1).

Nineteen children (7.1%) are with malignant disease, median age on admission is 11.2 years old (range: 1–30) (Table 2). 19 patients with cancer, brain tumor was the majority (n = 13), followed by solid tumor (n = 5) and hematological malignancy (n = 1). Fourteen out of 19 (74%) patients died, 10 died at the hospice, 2 died at home, 2 died at other hospitals. Fifteen cases were hospitalized for respite care and 10 cases were hospitalized for EOL care. Six out of 10 cases were hospitalized at our hospice for respite care before that for EOL care. While, four cases were hospitalized for respite care before they died at home or other hospitals and five cases were hospitalized for respite care and still alive in Oct. 2015. Mean length of inpatient stay for EOL was 42.1 days (median: 13.5, range: 2–132). Mean length of inpatient stay for respite was 5.0 days (median: 4, range: 2–20) (Table 2).

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