

Paediatric Palliative care in Hong Kong

SPD3320 End of Life Issues

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Date of presentation: 10/4/2019

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Introduction

What is palliative care?

“an approach that improves the quality of life of patients (adults and children) and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, or spiritual” (World Health Organization, 2019).

Introduction

Paediatric palliative care

- Subject is children
- Shorter life
 - → more awareness needed
- Maximize their happiness



Introduction

How is it important?

- Leave with peace and joy
- No pain
- Improve the emotion of family members
- Claim and open mind





Background

Statistic

According to **Social Welfare Department**

- **Children Death Rate: 0.2** (2012 & 2013)
- **63.6%** natural factors & **36.4%** non-natural factors

Main Cause:

- Respiratory system Disease (22 cases)
- Certain Conditions Originating (20 cases)



Background

Palliative care

- Providing in 16 Hospital
- Aim: Provide Comprehensive Care
- Target: Terminal patients



Background

Paediatric palliative care

Provided in CCF:

4 Types of Children Need PPC

1: Life-Threatening

2: Premature Death

3: Gradually Deteriorate

4: Irreversible but non-progressive



Background

Services for children

- Counselling
- Psychotherapy & Assessment
- Supports
 - Financial + Educational + Social
- Half-way Homes
 - For convalescing Patients





Situation of paediatric palliative care in Hong Kong

1. No specialized expertise and training

Paediatric palliative care is not a specialty in health system

- No specialized doctors
- Related programme has yet to be developed
 - under the Hong Kong College of Paediatricians
- No coordinated training
 - nurses & health professionals in paediatric palliative care



1. No specialized expertise and training

Palliative care in HK may neglect the needs of children

- Uniqueness of care for children with illness
 - Learn to find out their discomfort
 - Medicine use for children is different to adult
 - e.g. Painkillers
- Specialized expertise and training in paediatric palliative care is needed



2. Lack of paediatric palliative care for non-cancer children

Providing of palliative care for children with cancer in Paediatric oncology department in public hospital

- Has not covered non-cancer children patients
- Neglect children who suffer from other condition
 - brain damage
 - metabolism problems
 - organ failures





2. Lack of paediatric palliative care for non-cancer children

Importance of paediatric palliative care for non-cancer children

- Death of children in HK
 - 70% are non-cancer
 - Demand is higher than cancer children
 - Condition of illness can sustain for few years
- Non-cancer children also need holistic palliative care

3. Lack of Education

Demand of palliative care

- Children < Adult and elder
 - Registered death in HK (2014): 45718
(children who aged < 18 : 256)
 - Less than 1% death are children
- People may neglect the importance of paediatric palliative care



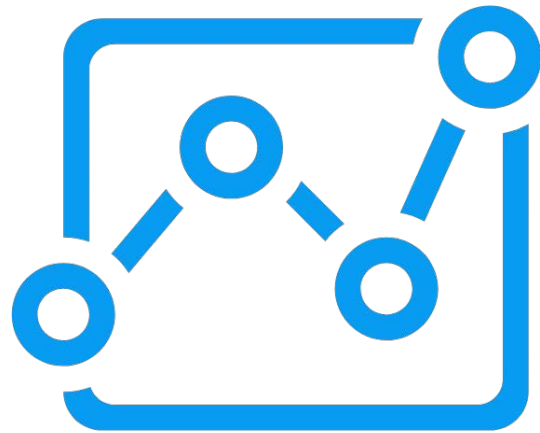
3. Lack of Education

- Insufficient information of paediatric palliative care to public
 - Also in palliative care
- Misunderstanding
 - palliative care and hospice care





Evaluation





Legal issues

Advance directive (AD)

- Patient's instruction document → Future treatment arrangements
- Mental Health Ordinance Cap. 136

Doctors have the right to provide treatment for
mental incapacity patients (best interest of the patient)



Legal issues

Do-Not-Attempt Cardiopulmonary Resuscitation (DNACPR)

- Do not perform CPR
- When life-sustaining treatment is ineffective

Fire Services Ordinance Cap. 95

- Guideline of “resuscitating or sustaining his life”
- Responsibility to perform CPR

Legal issues



Dying at home Coroners Ordinance Cap. 504

- Any death of a person (excluding a person who, before his death, was diagnosed as having a terminal illness) where no registered medical practitioner has attended the person during his last illness within 14 days prior to his death.
- A registered medical practitioner's medical certificate within 14 days
 - avoid criminal investigation
 - avoid autopsy

Ethical issues

- Autonomy → intention, understanding and cannot be controlled
- A child makes choice depends on developmental level & life experience
- If child who has already no conscious and without further chance to discuss the treatment
- The infant had suffered a life-threatening illness difficult for parents to choose palliative care or life sustaining → atment

Professional issues



- Continuing education of palliative care have better conception and operation than general nurses (White et al., 2014)
- Symptom and pain management, communication skills
- HK medical students not required to take relevant courses



Suggestions





Suggestions

Provide Paediatric Palliative Care Service to Non-Cancer Children Patients

- Neurological disease
- Cardiac disease
- Genetic disease

Setting up palliative care team

- Develop service guide
- Provide advice / counselling services to patient & family
- Coordinate with patients' school → support staff & caregiver

Suggestions

Education & Promotion in Paediatric Palliative Care

Bangladesh: Paediatric Cancer Care Service

- Raising awareness + Education

Hong Kong Government

- Philosophy and practice of paediatric palliative care
- Effective communication with families
- Posters, pocket-reference cards & handouts



Suggestions

Training workshop

Pain management & palliative care

- Assess pain in children
- Pain alleviation
- Use related therapies appropriately

Communicate with patient & families

- Prognosis
- Relapse
- End of life





Oversea examples



Australia

Paediatric palliative care:

Widely distributed

- Western Australia
- Queensland
- Victoria
- New South Wales
- Australian Capital Territory
- South Australia



Western Australia-Perth Children's Hospital

- Medical treatment and care
 - Aged 0-16
- Inpatient, outpatient and day-stay care services
- Helicopter service
 - Transportation for emergency cases
- Education towards
 - Families, health professionals and the community



Well-developed transportation system



Educational work towards child have life limiting conditions



Queensland-Queensland Children's Hospital

Services provided at

- Home
- Children's hospital
- Local hospital
- Hospice

Telephone call and video conference

- Consulting from medical team immediately

✓ **Alternative way for patients and families in seeking medical assistance**

✓ **Diversified service (Location)**





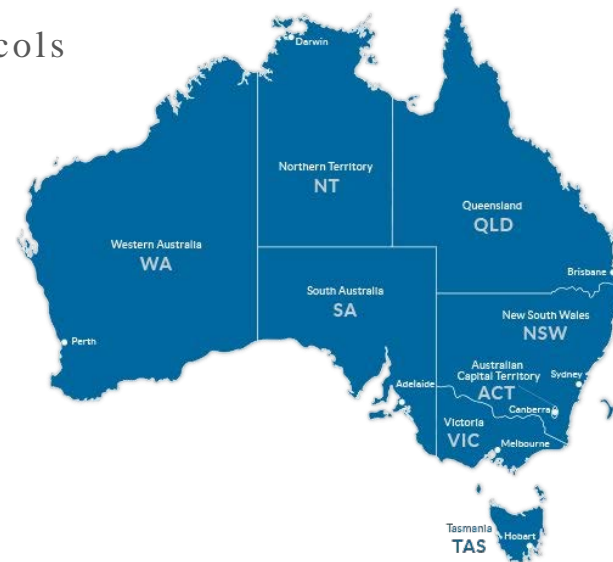
Australia-Government regulation

Western Australia:

- Creation of national standard, guidelines and protocols
- Improve service quality
- Collection of clinical data

Victoria:

- Suggestion in developing statewide policy
 - ◆ Public health
 - ◆ Children care services
 - ◆ Community care provider



Canada-Government regulation

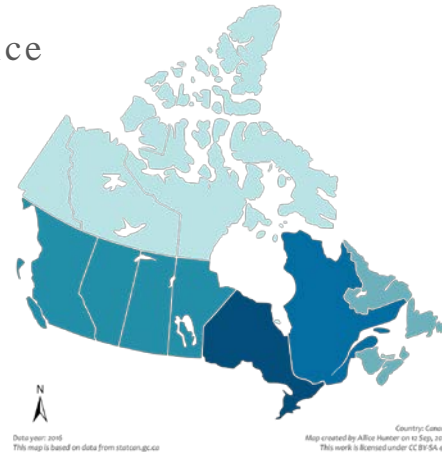
Canadian Hospice Palliative Care Association:

Setting up

- Paediatric palliative care guiding principles and Norms of practice
 - Child and family care
 - The process of providing care
 - Programs support functions
 - Resources

✓ **Provide standard practice for medical specialist**

✓ **Enhance current paediatric palliative care service quality**





Conclusion



Conclusion

End of life

- Last period of a life
- Full of pain and sadness
- Children have a difficulty when facing death

Paediatric palliative care

- Indispensable for the support
- Maximize happiness and enrich their short life
- A room of improvement





Q & A





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