Paediatric Palliative Care in a Nutshell

Role of Occupational Therapy for transition care of patients:
- from hospital to home
- living in community
- from adolescent to young adult

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26th October 2019
Adapted from Professor CK Li’s lecture notes
Scope of Services

Occupational Therapy

- ADL & IADL
- Oro-motor & feeding skills
- Developmental
- Fine motor skills
- Handwriting skills
- Cognitive & perceptual
- Pre-vocational

- Infant Stimulation Programme
- Occupational Lifestyle Redesign Programme

- Sensory Integration therapy
- Horticultural therapy
- Prescription of assistive devices to enhance daily functions
- Prescription of pressure relieving devices to prevent pressure sore and/or ulcer

- Seating assessment and seating accessories prescription
- Scar management and pressure therapy
- Splintage for protection / enhancing functional movement / neuro-recovery
  - Neurorehabilitation
  - Palliative care
  - Therapeutic play

- Home / school / on-job site visit and environmental modification
- Screening and referral of special services for adolescents (e.g. work assessment and training, driving assessment, referral for sexual rehabilitation)
Occupational Therapy for PPC

Acute side & Late effects during & after invasive treatment

Disability, lower QOL & function
(ADL, School / Work & Leisure)

Rehabilitation
Occupational Therapy for PPC

Domain of Concern

ADL (e.g. Feeding)

Development

Study / Work

Leisure
OT: Scope of Services

- Cognitive
- Fine motor
- ADL
- Environmental Modification
- OT PPC
- Aids
- Seating

OT Services
- Splint
- Pressure Therapy
- Infant stimulation
- Pre-vocation
- Developmental training
- Sensory Integration
ADL & IADL Assessment & Training

- ADL: Dressing, Grooming, Feeding, Bed mobility etc.
- IADL: Transportation, Money management etc.
- purposeful simulated ADL & IADL training

Cognitive Assessment & Training

- Memory
- Visuo-motor Construction
- Praxis
- Cognitive & executive function
- Visual Perception
- Spatial Perception
- Thinking Operations
- Orientation
Fine Motor & Handwriting Assessment & Training

- Fine Motor Precision
- Fine Motor Integration
- Manual Dexterity
- Handwriting Speed
- Handwriting Legibility
- Special Examination Arrangement in school
Prescription of Assistive Devices

- Shower chair
- Button hook
- Adapted chopsticks
- Adapted pen grip
- Adapted nail cutter
- Special feeding utensils
- Book holder

ADL

Study / Work
Prescription of Assistive Devices -2

- Heel protector
- Pillow
- Soft collar
- Air Mattress
- Corset

Proper Position, Pain & Pressure relief, facilitate functional ADL

Return to home with oxygen therapy
Seating Assessment & Prescription

Assessment

Pressure Mapping

Prescription & Training

Calf support

Head support

Monitoring & maintenance

Safety belt

Back & Lateral support

Cushion

Head, Trunk & Pressure Ax

Pressure Mapping
Home / School / On-job site visit & Recommendation for Environmental modification
Key message: Team Collaboration is essential to provide Quality Service

Children are best assessed and treated by multidisciplinary team

?? Pre-intervention documentation
When?

How to facilitate transition from among hospitals??

When & Where to start??
Consideration of OT Intervention for Teenager

- Hand function training
- ADL training
- Home environment exploration for safe & independent living, assistive devices prescription and advice
- Carer education
- Special seating devices prescription by multi-disciplinary seating team
- **Special Examination Accommodation** recommended
- **Transition** from hospital to hospital for step down rehabilitation

**Reflection**

- Prepare for HKDSE
- Step down training in regional hospital
- Facilitate return to home
Release of results of the 2018 HKDSE
About 57,650 candidates will receive their results notices on 11 July. Please refer to press release for the overall results.

Under New Academic Structure (NAS), all students are expected to complete three years of junior secondary education followed by three years of senior secondary education. Upon completion of this six-year secondary education, students will take the Hong Kong Diploma of Secondary Education Examination (HKDSE), which aims to measure the attainment of students. The HKDSE was administered for the first time in 2012 as presented by schools.

Most school candidates may take four core subjects (Chinese Language, English Language, Mathematics and Liberal Studies), plus two to three elective subjects from Category A Senior Secondary subjects, Category B Applied Learning subjects or Category C Other Language subjects in the HKDSE.

In line with international standards and to ensure the transparency and explicitness of the results, HKDSE Category A adopts Standards-referenced Reporting of assessment results. Candidates’ achievement under this category is reported against a set of standards divided into five levels (levels 1 to 5), with 5 being the highest. Candidates with the best performance in each level are awarded a 5*, and the second best is awarded a 5.
Copying Speed Test for Hong Kong Secondary Students (CST-HK)

- Copy Chinese & English passage, 15 minutes each
- Must be conducted by certified OT
- Cut-off point: - 1.3 S.D.

Interpretation

Handwriting speed
- Chinese: number of characters per minute
- English: number of words per minute

Performance level
Clinical observation
How to Consider Special Arrangement (SEA)?

FULL JUSTIFICATION IS ESSENTIAL
Occupational Lifestyle Redesign Certificate Course for Adolescent Clients with Chronic Illness

School to Work Transition

- Develop a vocational identity
- Solidify a career pathway
- Enhance coping with disability
- Maximize Occupational performance

WILL WAYs
Distribution with nature of disease out of the 87 trainees

- Renal: 14%
- Orthopaedic: 14%
- NM Disease: 20%
- Head Injury: 19%
- NM, HI, Orth: 53%
- Medical: 8%
- Oncology: 8%
- Psychiatry: 8%
- Surgical: 3%
- IEM: 3%
- Deaf: 3%
After complete OLSR Certificate Course

**How about them?**
- Environmental barrier?
- Self-efficacy?
- Ready for transition?
- Employment network?

![Pie chart showing percentages: 59% get a job, 38% further study, 3% unemployed/pending for further study](chart)

**Opportunity**
Shape and manipulate the **ENVIRONMENT** for AdoSCN to experiment and create another way to practise **LIFE**
Ample of choices throughout life

**Conclusion:**
Occupational Lifestyle Redesign Programme was successful in guiding 62% the adolescents with physical handicap and chronic illness to be productive and independent adults.
Greenhouse in HKCH
Activities from horticulture therapy
• Maximize the utilities of Green House
• Regular programme / activities to welcome both in- and out- patients
• a productive place for the sick children & adolescent
• A nice place to explore

The environment ...
Work closely with PPC team

Engage in meaningful activities ~

for patients and the families
Positioning for purposeful activities
2015 Quality of Death Index—Overall scores

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The 2015 Quality of Death Index Ranking palliative care across the world

A report by The Economist Intelligence Unit

Commissioned by LIEN foundation
Palliative Care vs Hospice Care

**Palliative Care**
- No life expectancy limit
- Covered under traditional medical insurance or Medicare
- More aggressive treatment of symptoms without compromising quality of life
- Quality of Life: Emotional, Physical, & Spiritual Support

**Hospice Care**
- Life expectancy of 6 months or less
- Covered under Medicare
- Pain management to allow patient to die with dignity
- fowieng@hospicecare.org.hk

**Palliative Care vs Hospice Care**
Palliative care is aimed at anyone who has been diagnosed with a life-threatening illness.

Hospice care is mostly aimed at patients who have been diagnosed with a terminal illness.

Palliative care helps maintain quality of life and reduce illness symptoms – and recent findings suggest that cancer patients who receive palliative care alongside standard treatments can live longer.

Hospice care is aimed at providing patients with a dignified, pain-free death – in the U.S., hospice care is mostly meant to be administered inside the patient’s home, while in Russia, the concept of hospice care is just beginning to gain ground.

Source: The Mayo Clinic (mayoclinic.com) and OncologyNurseAdvisor.com

Palliative Care vs Hospice Care
The role of Occupational Therapy in Palliative Care

American Occupational Therapy Association

- **Activities of Daily Living (ADL)**
  - dressing, bathing and showering, functional mobility

- **Instrumental activities of daily living (IADLs)**
  - Meal preparation, Home management, health management, religious or spiritual activities

- **Rest and sleep**
  - Assess sleeping habits, provide relaxation techniques and positioning to increase comfort, improve ability to rests, and reduce skin breakdown from pressure

- **Leisure participation**
  - Identify and facilitate ways to participate in enjoyable leisure and community activities
  - Coping strategies

- **Psychosocial / behavioral health**
RESPECT