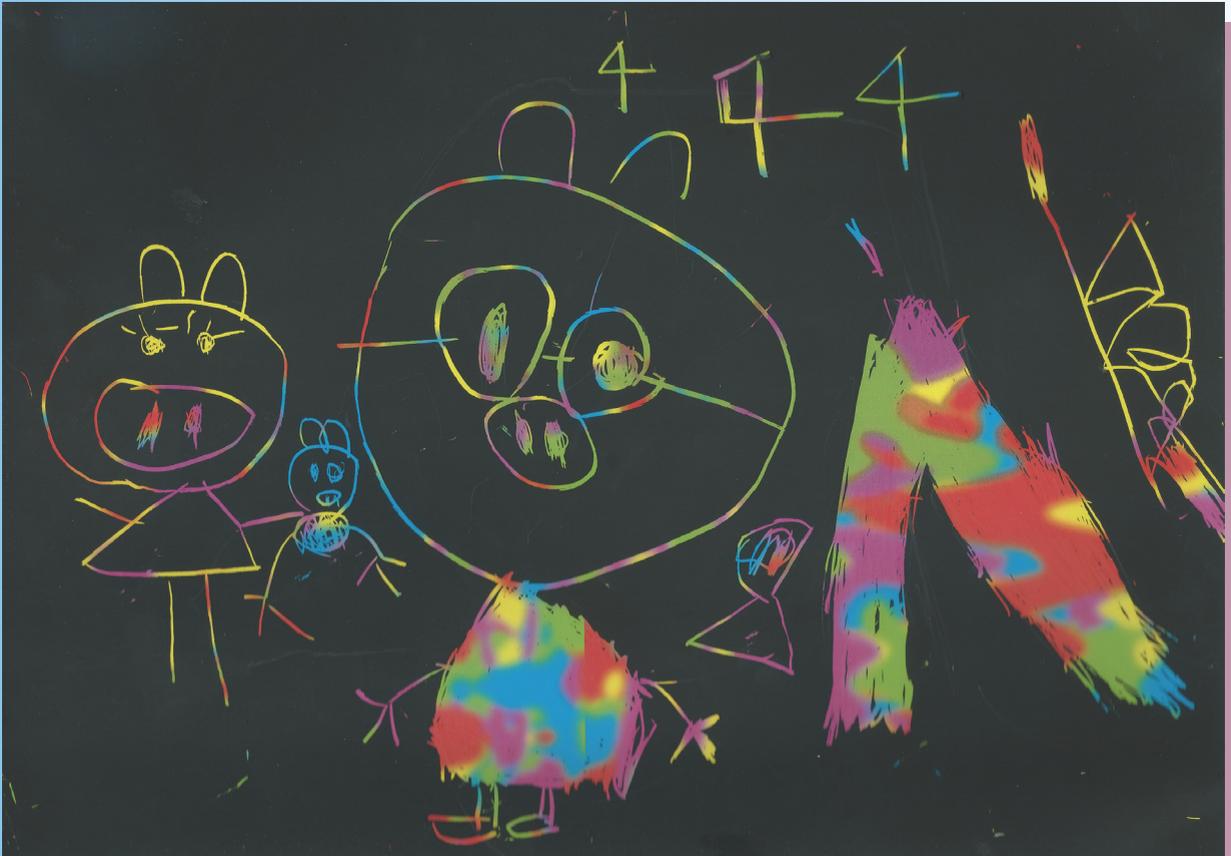


Volume 14  
No.1  
December 2013

# BRAINCHILD

The Official Publication of HKCNDP  
Special Issue on Neurodevelopmental Disabilities



香港兒童腦科及體智發展學會  
The Hong Kong Society of Child Neurology and  
Developmental Paediatrics





**The Hong Kong Society of  
Child Neurology and Developmental Paediatrics**  
**香港兒童腦科及體智發展學會**

**THE COUNCIL**

<b>President</b>	:	Dr. Chok Wan Chan
<b>Vice President</b>	:	Dr. Catherine CC Lam
<b>Honorary Secretary</b>	:	Dr. Stephenie KY Liu
<b>Honorary Treasurer</b>	:	Dr. Theresa YL Wong
<b>Council Members</b>	:	Dr. Mario WK Chak Dr. Tim KT Liu Dr. Kwing Wan Tsui Dr. Eric KC Yau Dr. Sam CM Yeung Dr. Florence MY Lee Dr. Jasper CP Chow (Co-opt)

**THE EDITORIAL BOARD OF BRAINCHILD**

<b>Editor-in-chief</b>	:	Dr. Chan Chok Wan
<b>Editorial Board</b>	:	Dr. Mario WK Chak Dr. Catherine CC Lam Dr. Tim KT Liu Dr. Yau Kin Cheong, Eric

---

Address : Room 3509, Bank of America Tower, 12 Harcourt Road, Central, Hong Kong  
Tel : (852) 2895 5211  
Fax : (852) 2577 1989 (Society Hon. Secretary Dr. K Y Liu)  
Email : enquiry@hkcndp.org  
Website : www.hkcndp.org

Printer : Printhouse Production Center Limited  
Flat A, 15/F, Gee Luen Hing Industrial Building, 2 Yip Fat Street,  
Wong Chuk Hang, Hong Kong

Copyright©2014. All rights reserved

The published materials represent the opinions of the authors and not necessarily that of the editors or the Society. The appearance of advertisement is not a warranty, endorsement or approval of the products. The Society disclaims responsibility for any injury to persons or property resulting from any ideas or products referred to in the articles or advertisement.



**The Hong Kong Society of  
Child Neurology and Developmental  
Paediatrics**

www.hkcondp.org

December 2013 Volume 14 No.1

**SPECIAL ISSUE ON NEURODEVELOPMENTAL DISABILITIES**

**CONTENTS**

**page**

<b>Message from the President</b> Dr. CHAN Chok Wan	1
<b>Comments from the Issue Editor: Care of Children with Neurodevelopmental Disabilities in Hong Kong</b> Ms. LEE Susanna	4
<b>Occupational Therapy in Neuro-developmental Perspective</b> Ms. FONG Sanne, Ms. CHENG Stella, Ms. CHIU Amy, Ms. CHUNG Vivian, Ms. NG Agnes, Mr. NG Marcus, Ms. POON Magdalene, Ms. TANG Minny, Ms. WU Anna	10
<b>Stretching and Physiotherapy</b> Dr. PIN Tamis	16
<b>Prevention of Pathological Fracture in Children with Severe Developmental Disabilities</b> Ms. LO Chui Han, Carol	19
<b>Gastrostomy Feeding in Children with Severe Developmental Disabilities</b> Ms. LO Chui Han, Carol	23
<b>Development of Patient Clothing for Paraplegic and Quadriplegic Paediatric Patients</b> Dr. CHAN Chee Kooi, Ms. KWOK Jenny, Dr. KAN Chi Wai, Dr. YU Chak Man, Ms. LEE Susanna, Ms. LO Carol	25
<b>Play has no boundaries</b> Ms. WONG Gloria	35
<b>Play • full of joy</b> Ms. WONG Iris	38
<b>“Today, I played with my little friend Didi.”</b> Ms. LAU Karen	39
<b>“Today, I played with my little friend Kiki.”</b> Ms. CHUI Tammy	40
<b>Love and Care Activated in 2011</b> Ms. WONG Gloria	41
<b>Paediatric Rehabilitation Service: Transition from Acute Care to Home or Community Care</b> Ms. LO Chui Han, Carol	44
<b>Child and adolescent psychiatric service: Aiming for more....</b> Ms. CHAN Kit Ping	47



# The Hong Kong Society of Child Neurology and Developmental Paediatrics

EDITOR'S NOTES for the December 2013 Issue

## Interdisciplinary Approach in the Care of Children with Neurodevelopment Disabilities

Dr. CHAN Chok Wan

This current issue of Brainchild published by The Hong Kong Society of Child Neurology and Developmental Paediatrics (HKCNDP) is devoted to Neurodevelopmental Disabilities as a report of the good works on the subject done by a group of multidisciplinary health care professionals in Hong Kong. It is capably edited by Miss Susanna Lee, an experienced nursing officer in Hong Kong.

This issue contains papers published by our society namely, Occupational Therapy in Neuro-developmental Perspective; Stretching and Physiotherapy; Prevention of Pathological Fracture in Children with Severe Developmental Disabilities; Gastrostomy Feeding in Children with Severe Developmental Disabilities; Development of Patient Clothing for Paraplegic and Quadriplegic Paediatric Patients; Play has no boundaries; Play full of joy; Love and Care Activated in 2011; Paediatric Rehabilitation Services: Transition from Acute Care to Home or Community Care; Child and Adolescent Psychiatric Service: Aiming for more....

Over the years, with the medical and technological advances and quality care, the numbers of infant and children survived from catastrophic medical events has been increased significantly. However, this also resulted in growing chances of the survivors living with a wide range of neurodevelopmental disabilities which might be chronic and even lifelong.

The goal of the caring process for children with neurodevelopmental disabilities aims to enable them to function at their maximum potential regardless of their degree of disabilities. Physical, emotional, social, cultural, educational, developmental and spiritual dimensions are all considered in the holistic approach of care to the children and family. To do this, interdisciplinary team approach is essential. The team usually encompasses doctors, nurses, patient and family, medical social worker, physiotherapist, occupational therapist, clinical psychologist, psychiatrist, speech therapist, pharmacist, play specialist, hospital school teacher, prosthesis and orthotic staff and supporting workers etc. The integration of expertise from individual discipline allows the team to analyze, synthesize and harmonize links between disciplines into a coordinated management to maximize individual's ability and achieve better quality of life. Intersectoral collaboration and transdisciplinary team approach are highly promoted.

The authors from the multidisciplinary health care team include doctors and nurse working in the Developmental Disabilities Unit (DDU) and Paediatric Rehabilitation

1

2

0

1

3

Unit (PRU), nurse working in the Child and Adolescent Psychiatric field, physiotherapist, occupational therapists, play specialists as well as Professors from Textile Department and Department of Rehabilitation Science of the Hong Kong Polytechnic University. Special thanks should be extended to the dedicated effort of all authors.

The articles illustrated the excellent local work of different disciplines in the care of children with developmental disabilities in various aspects aimed at improving the overall health outcomes of the children. The short briefs of the papers are listed as below:

“All clients shall lead their life of meaningful choice” is the vision of occupational therapist. Whatever the age of our clients, occupational therapy will facilitate them in adaption to their disease through the life span and overcome physical or other difficulties in order that they can function and participate in their everyday environment.

In addressing the underlying developmental impairments, intensive rehabilitation interventions were provided by physiotherapist. Muscle tightness and contracture are very common in children with neurodevelopmental disabilities. Passive stretching exercise was proven to be effective in promoting muscle extensibility and preserving joint flexibility. This led to a biomechanically workable body with better ambulatory ability, position and joint integrity of the children.

Children with neurodevelopmental disabilities often encounter feeding problems which affect their nutritional outcomes. They are also more prone to pathological fracture leading to physical impairment. Proactive measures have been made by nurses and the health care team with early risk identification and intervention. Early gastrostomy placement improved the nutritional status. The implementation of preventive measures also reduced the pathological fracture incident. The high quality care of the nurses and collaborative effort of the team contributed to the improvement in nutritional status, growth and development and physical wellbeing of the children.

As mentioned before, interdisciplinary approach in the care of children with neurodevelopmental disabilities is important. The effectiveness of team is largely dependent on how the professionals work with each other to meet the needs of their patients. Nurse, often being the team coordinator, demonstrated the critical role in the overall implementation and operation of the services such as in Paediatric Rehabilitation. She also helped in facilitating an effective transition of children from hospital to community care.

Although the clinical team is primarily focus on the medical treatment and rehabilitation intervention of the children, quality of life including promoting physical comfort, socialization and social wellbeing is pertinent and equally important for individuals with neurodevelopmental and related disabilities. The collaborative project between the health care team of Developmental Disabilities Unit, Caritas Medical Centre and the textile

department of the Hong Kong Polytechnic University in the development of the comfortable clothing specifically for the patient with severe developmental disabilities had highlighted the importance of basic physical comfort to these specific groups of patients in the improvement of their quality of life.

Play is important to all children. The play services and the outings provided by the play specialists enable the children to experience greater happiness, achieve personal satisfaction in social and emotional wellbeing, create friendships and develop the skills and competencies needed to become successful later at home, school and community.

In recent years, the number of children suffering from mental health problems are increasing even though the child and adolescent psychiatric services are ongoing expanding to meet the service needs. The statistic for Autistic Spectrum Disorders (ASD) and Attention Deficit Hyperactive Disorder (ADHD) were escalating. New clinics were set up and therapeutic environment was improving, specialized care programs were tailor made for patient with early psychosis, mood disorder and eating disorder cases. Though the workload is heavy and patient waiting time is long, the Psychiatric team still continues to explore ways to improve the quality care aiming at doing more and better for the children and adolescents.

The above papers showing the joint efforts of different disciplinary professional in order to provide quality care and optimal environment for children to maximize their potential, also to grow, learn and adapt into adulthood if possible; and be the useful members of our future community.

I wish you reading pleasure!



**Dr. CHAN Chok Wan**

Editor-in-chief, Brainchild, Official publication of HKCNDP  
President, the Hong Kong Society of Child Neurology & Developmental Paediatrics (HKCNDP)

3

2  
0  
1  
3

## Comments from the Issue Editor:

### Care of Children with Neurodevelopmental Disabilities in Hong Kong

Ms. LEE Susanna

*RN (HK, UK, Aust.), RM (HK, UK, Aust.), BBA, MN, FHKAN*

*President, Hong Kong Paediatric Nurses Association*

#### Neurodevelopmental Disabilities

Neurodevelopmental disabilities refer to a diverse group of chronic disorders that occur during the development process including conception, birth and growth which last often for life. The underlying basis for these disorders lies in fundamental deficits in the developing brain due to genetic, prenatal, perinatal, metabolic, and other factors. Major disabilities include intellectual disability, learning disabilities, communication disorders, autism spectrum disorders, cerebral palsy, and neural tube defects.

4

#### Escalating Service Demand

With the medical and technological advances and quality care nowadays, there has been an increase in the survival rate of the very preterm infant and children from catastrophic medical events. This resulted in growing nos. of survivors living with a wide range of neurodevelopmental disabilities and other developmental disabilities such as cerebral palsy, brain injury, genetic abnormalities etc. There are around 100 children with severe developmental disabilities currently reside in the Development Disabilities Unit (DDU) in Caritas Medical Centre whilst some still under the care in Paediatric Intensive Care Units (PICU) in different hospitals. At the same time, the nos. of children with rehabilitation potential demanding timely rehabilitation services also remarkably increased.

■

2

0

1

3

#### Limited Service Provision in Paediatric Rehabilitation

Extensive researches evidenced that early diagnosis and therapy intervention might improve the functional outcomes of the children. However, the access to paediatric rehabilitation services can sometimes be difficult. The Paediatric Rehabilitation Units which provide step down care and intensive rehabilitation services are limited. The waiting queue of the central allocation system for EETC, SCCC and ICCC placement for the early aged children with special needs is long. Children in early age with special needs may miss the golden time in receiving appropriate training and assessment which may affect their functional outcomes and future development.

#### From Multidisciplinary to Interdisciplinary Team Approach

Health-care delivery to children and adolescents with developmental disabilities requires participation and sharing of expertise of medical, social, and psychological disciplines. Traditionally multidisciplinary teams were led by a physician who makes the final decision

about the patient's care. Each team member only completes his/her specific tasks within the boundaries of his/her discipline. In recent years, the interdisciplinary team model is often adopted. Professionals will find themselves working with a number of other professionals on various "teams." These teams are usually composed of members from more than one discipline and working towards a common goal of providing comprehensive patient care depending on medical conditions. Members of clinical team often include: pediatrician, nurse, patient and family, orthopedic surgeon, neurologist, ophthalmologist, physiotherapist, occupational therapist, psychiatrist, dentist, dietician, medical social worker, clinical psychologist, pharmacist, prosthesis and orthotist, speech therapist, audiologist, pastoral care worker, Red Cross Hospital school teachers, play specialist/worker etc. Members in an interdisciplinary team share the responsibility for making the ultimate decision about patient's care. The assessment and the care plan reflect the integration of expertise from individual disciplines. Each member of the team shares his/her expertise with others through regular meetings, case conferences and reviews, and the team process is described as highly interactive which allows the team to analyze and synthesize views between disciplines into a coordinated management. This approach will be cost effective, better quality of care, reduced duplication but fill up the gaps in the delivery of health care.

5

### **The Important Role of Team Coordinator**

The goal of the rehabilitation process for children aims to enable them to function at their maximum potential regardless of their degree of disabilities. Physical, emotional, social, cultural, educational, developmental and spiritual dimensions are all considered in the holistic approach of care. The effectiveness of team is largely dependent on how the professionals work with each other to meet the needs of their patients. The coordinator of the team plays critical role in the overall implementation and operation of the services. Nurse, the person who takes care of the child most of the time and as the key contact person of the patient, family and the working team is the most suitable person to take up the role of team coordinator, the duties may include:

- ❖ Coordinate case screening on admission, pre-discharge planning and interdisciplinary case review
- ❖ Work closely with the family and community
- ❖ Coordinate and facilitate the transition of rehabilitation services from acute care to step down care and then to home/community, bringing together the expertise of different health professionals
- ❖ Coordinate and facilitate the transition from child oriented to adult oriented health care system.
- ❖ Schedule patient appointments and clinic sessions.
- ❖ Maintain and implement program/institutional policy and procedures
- ❖ Schedule and facilitate team meeting
- ❖ Ensure appropriate medical information and past reports are available prior to patient visit
- ❖ Facilitate referral process

2  
0  
1  
3

- ❖ Obtain, organize, and distribute the final written reports to appropriate practitioners and agencies
- ❖ Educate and empower patient, carer and family by running education class and regular parent meetings.

The coordinator of the team plays critical role in the overall implementation and smooth operation of the services.

## Quality of Life

All along method such as Capacity Profile (CAP) has been used to assess the additional care needs of these children at an early age and to gain insight in the future care needs of these children is essential to parents for planning individual care, to physicians for installing adequate and time medical interventions and to society for optimal decisions regarding resources policies and quality assurance.

Quality of life is pertinent and important for individuals with neurodevelopmental and related disabilities. As most of the patients cannot communicate well, includes both parents and caregivers in the care decisions may better address the conceptualization of quality of life for these patients.

Models of quality of life for this population reflect lifespan challenges for achieving personal satisfaction in the following areas: (1) physical well-being or functional status, (2) material well-being (3) social and emotional well-being, and (4) developmental abilities.

### Physical well-being and Material well-being

Most of the individual with neurodevelopmental disabilities are either partially dependent with limited mobility or totally dependent who are bed-ridden. Some of them are vision and/or hearing impaired and on nasogastric tube feeding, tracheostomy etc. Therefore, to promote physical well-being, besides providing appropriate medical treatment and rehabilitation intervention, ensuring basic daily physical comfort is equally important e.g. comfortable clothing and bedding, positioning, good personal hygiene care etc.

### Social and Emotional well-being and Developmental Abilities

Socialization and social well-being are the key aspects of general Quality of Life. Depending on individual's ability, engaging the children in play, arts, music and exercise; participation in social activities e.g. outings, festive party, religious activities can allow them to experience greater happiness and enjoyment in life. It helps the children to achieve personal satisfaction, developing competencies; achieving mental and physical health; understanding their own strengths and abilities; and creating friendships and relationships. It is by participating that the children and adolescents learn about the expectations of society, and develop the skills needed to become useful later at home, school and community.

## **Transition from Child Oriented to Adult Oriented Health Care Setting**

With the advances in medical sciences, more children with neurodevelopmental disabilities now grow and become adults. They may need to transit from child oriented to adult oriented health care system. The adolescent who get used to the protective paediatric environment have to face the challenges of establishing a new relationship with the new physician and staff, and adjust himself/herself into the new environment. They also have to face the future life including medical care, education, vocation, daily living and activity, financial and employment. Therefore transition is not only an event but a process that takes place over time. Ideal care before the transition is to promote independence and self-sufficiency of the patients as later the decision making will be shifted to the young adults. A well planned transition should assess the readiness of the adolescent and the family and facilitate the medical care in the adult-oriented setting. The family must be involved in the decision process. A pre-transit orientation visit to the adult setting with the patient, family and staff will enable psychological readiness. Clinical handover with comprehensive case summary together with video which records the patient's special characteristics and behavior will help the staff in the adult setting to understand more about the care of the patient, hence minimize patient's frustration in the new environment. Good transition process to adult-oriented care fosters the adolescent with a hope for the future and enhances his/her sense of personal responsibility and control. The transition process may also facilitate treatment adherence and continuity of care.

7

## **Discharge from Rehabilitation Care to Home or Community Care**

To enable a successful transition of Child with neurodevelopmental disabilities from hospital to the community, discharge planning for the individual is important, the interdisciplinary team tailors made the program for the children to maximize patient's functional level, provide education and empowerment program for the parent/carer to care the children at home, co-ordinate appropriate resources e.g. NGO in the community and ensure the children can access to the community support in medical, social and education system.

2  
0  
1  
3

## **Conclusion**

With the advances of medical science and quality care today, the survival rate of the children is increasing. This resulted in growing nos. of survivors living with a wide range of developmental disabilities. As such, the demand for rehabilitation and infirmary services is continually escalated. More resources should be put to increase services provision for these groups of children.

Optimal health care for children with Neurodevelopmental Disabilities should consider a holistic approach to the child and his/her family. Interdisciplinary team approach is widely promoted. The approach was proven to be cost-effective, better quality and reduction in errors and duplication in service delivery. The team coordinator, often the nurse, contribute to the effectiveness in the overall operations of the services.

In the care of children with special health care needs, besides providing medical and rehabilitation interventions, addressing their quality of life in the areas of physical, social and emotional wellbeing are also important such as comfortable clothing, good daily hygiene, communication, plays, outings, festive gathering, entertainment and exercises.

Nowadays, more children with neurodevelopmental disabilities will grow into adults who may need to transit from child oriented to adult oriented health care system. A well planned transition should assess the readiness of the adolescent and the family and facilitates medical care in the adult-oriented setting. Good transition process will minimize frustration of the adolescent and family, foster a hope in the future and enhance his/her sense of personal responsibility and control. It also facilitates treatment adherence and continuity of care.

For children who has the potential to discharge home/community from hospital, discharge planning should start early. Before discharge, the team should provide all relevant information and find suitable resources for the patient and family and ensure that they are able to access to comprehensive medical, educational and social care services.

8

## **The Way Forward**

### **Medical Home**

■

2

0

1

3

With increasing health care costs, technology, survivorship, specialization and fragmentation of care in the community, the “Medical Home” model is becoming more popular in the profession. Every child deserves a Medical Home is one of the American Academy of Pediatrics (AAP) essential child health outcomes for the 21st Century. To enable a successful transition of Child with neurodevelopmental disabilities from hospital to the community, “Medical Home” concept should be promoted. Medical Home is not a building, house, or hospital, but rather an approach to providing comprehensive primary care. A “Medical Home” is defined as primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. In a medical home, a pediatric clinician works in partnership with the family/patient to assure that all of the medical and non-medical needs of the patient are met. Through this partnership, the pediatric clinician can help the family/patient access and coordinate specialty care, educational services, out-of-home care, family support, and other public and private community services that are important to the overall health of the child/youth and family.

### **References**

- Patel, D.R., Greydanus, D.E., Omar, H.A, and Merrick, J., editors. *Neurodevelopmental Disabilities - Clinical Care for Children and Young Adults*. NY: Springer; 2011.
- World Health Organization. (2007). *The International classification of functioning disability and health-child and youth version*. Geneva: WHO.
- Choi, B.C.K., Pak, A.W.P. (2006). Multidisciplinarity, interdisciplinarity and transdisciplinarity in health research, services, education and policy: 1. Definitions, objectives and evidence of effectiveness. *Clin Invest Med.*, 29(6), 351-64.
- Pratt, H.D., Rickerts, V.I. (2004). Concepts of multidisciplinary versus interdisciplinary approaches to team work. *Soc Adolesc Med Newsl.*, 14(3), 4, 7.

- Schofield, R.F., Amodeo, M. (1999). Interdisciplinary teams in health care and human services settings: are they effective? *Health Soc Work*; 24, 210-19.
- McCallin, A. (2001). Interdisciplinary practice. A matter of teamwork: an integrated literature review. *J Clin Nurs.*, 10, 419-28.
- Meester-Delver, A., Beelen, A., Hennekam, R., Nollet, F., & Hadders-Algra, M. (2007). The Capacity Profile: a method to classify additional care needs in children with neurodevelopmental disabilities. *Dev Med Child Neurol*, 49, 355-60.
- Voll, R. (2001). Aspects of quality of life of chronically ill and handicapped children and adolescents in outpatient and inpatient rehabilitation. *International Journal of Rehabilitation Research*, 24, 43-49.
- Dahan-Oliel, N., Shikako-Thomas, K., Majnemer, A. (2012). Quality of life and leisure participation in children with neurodevelopmental disabilities: a thematic analysis of the literature. *Qual Life Res*, 21, 427-439.
- Sia, C., Tonniges, T.F., Osterhus, E., & Taba, S. (2004). History of the Medical Home Concept, *Official Journal of The American Academy of Pediatrics*, 113, 1473-1478.  
<http://www.pediatrics.org/cgi/content/full/113/5/S1/1473>

## Occupational Therapy in Neuro-developmental Perspective

Ms. FONG Sanne, Ms. CHENG Stella, Ms. CHIU Amy, Ms. CHUNG Vivian, Ms. NG Agnes, Mr. NG Marcus, Ms. POON Magdalene, Ms. TANG Minny, Ms. WU Anna

*“All our clients shall lead their life of meaningful choice”* is the vision of occupational therapy (OT). We empower our clients to return to their valued life roles at home, work and leisure by making the best use of their functional capabilities.

Majority of the occupational therapists apply the *model of human occupation* (MOHO). This articulates concepts that guide OT practice. Human occupation is defined as the doing of work, play, or activities of daily living within a temporal, physical, and sociocultural context that characterizes much of human life. Volition, habituation, and performance capacity are integrated parts of each person, operating seamlessly, forming a coherent whole. With reference to the environment, each contributes different but complementary functions to what we do and how we experience our doing. The vision of MOHO is occupation-focused, client-centred, holistic, evidence-based, and complementary to practice based on other occupational therapy models and interdisciplinary theories.

Occupational therapists work with babies and very young children, as well as school aged children and teens, but of course the 'tasks' that a baby has to perform are very different from the leisure and work tasks that a teen needs to participate in. Whatever the age of our clients, occupational therapy will facilitate them in *adaption to their diseases through the life span* and overcome physical or other difficulties, in order that they can function and participate in their everyday environment.

Children with neurodevelopmental disabilities belong to a broad and heterogeneous group. There is a spectrum of developmental consequences associated with neurological insults during childhood, ranging from mild to profound cognitive, sensory, motor, behavioral and/or emotional impairments. Cases referred for occupational therapy include epilepsy, cerebral palsy, mental retardation, disorders of attention and hyperactivity, specific learning disabilities, communication disorders, autism, sensory disturbances and orthopedic conditions such as spina bifida. Furthermore, other brain-based conditions such as traumatic brain injury, brain tumors, low birth weight, hydrocephalus, meningitis need sophisticated planning of intervention of the neurobehavioral consequences.

The purpose of occupational therapy is to help the child achieve or maintain their maximum level of independence and to develop practical life skills so that the child can participate to his/her full potential in the home, classroom and community environment. This occurs in partnership with the child's family or teacher within the child's home or school community.

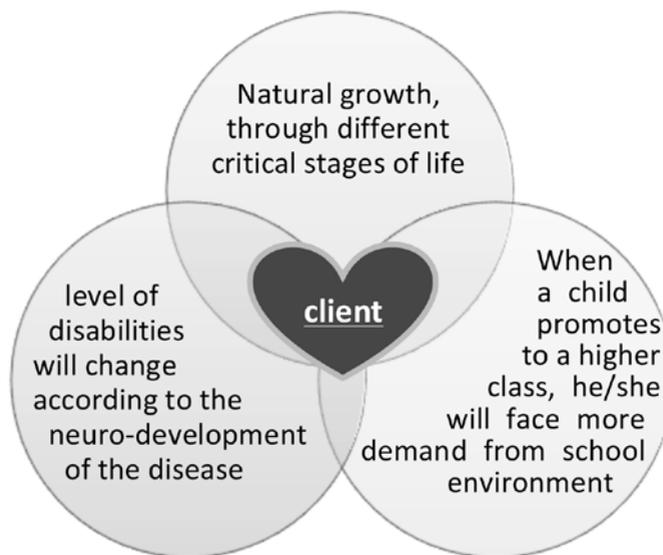
Paediatric OT service settings include hospital, special school system, home-based, private practice and special child care centres. When a client is going to school, he/ she will face a lot of challenges due to the natural growth (table 1), developmental disability related barriers, and the continuous increasing academic demand. Occupational therapists will address the neurological organization, processing skills, and developmental deficits. We concern if he/she can cope with the following life skills independently.

### **Self-care**

- eating, buying snacks, hand hygiene and managing toilet

### **Academic demand**

- copying, visual arts, use of stationeries like rulers and scissors, computer use, memory and attention



11

2  
0  
1  
3

### **Social life in school**

- group activities during recesses; participation in extra-curricular activities, group discussion and physical education

All the above domains demand integration of visual acuity, eye-hand coordination, visual-perception, appropriate cognition and communication skills. For clients suffered neuro-developmental diseases, they need facing the challenges of natural growth and overcome the turbulence in different critical stages in life. Furthermore, these diseases will bring additional issues along with the development. The bidirectional influence of disease on peer relationships and the influence of peers on children's and adolescents' adaptation to diseases is also a concern. Last but not least, when one gets higher academic achievement, there will be further demand from the school environment. They are interlinked with each other.

<i>preschool</i>	<b>Life skills training to improve learning ability</b>
<i>kindergarten</i>	All around life skills training and adaptation to the environment
<i>Primary school</i>	<ul style="list-style-type: none"> <li>* Independent in self-care</li> <li>* Adjust to change of class</li> <li>* More conceptual knowledge to learn</li> <li>* Needs guidance of learning strategies</li> </ul>
<i>Secondary school</i>	<ul style="list-style-type: none"> <li>* A remarkable change in autonomy</li> <li>* Adapt to changes in puberty</li> <li>* Face challenges of academic demand such as risk in handling equipment in laboratories, practical skills, group projects</li> <li>* Helping clients to recognize themselves, personality and interests, find right direction of life, and generate a continuous life plan</li> <li>* Career plan and learn proper work attitude, different skills in money management, stress management and team spirit.</li> </ul>
<i>College life</i>	<ul style="list-style-type: none"> <li>* Full autonomy of self, the environment demands more sophisticated facilities in daily college life</li> <li>* Clients may need environmental modification to handle college life independently</li> </ul>

12

■

2  
0  
1  
3

Occupational therapists are responsible for carefully selecting and applying *frame of reference* in practice. Neurodevelopmental treatment approach and sensory integration, visual information analysis, biomechanical and psychosocial frame of reference are commonly applied in clients with neuro-developmental diseases.

### ***Neuro Developmental treatment frame of reference (NDT)***

NDT is a sensorimotor approach for **neuromuscular disorders**. Sensory motor techniques are applied to remediate the developmental sequelae of dysfunctions. These intervention techniques are designed to enhance the quality of the client's motor performance within the context of the functional environment, by improving a child's postural control. The aim is for the child to achieve mastery in selected developmentally appropriate areas of play, self-care, and ultimately beginning school skills. The use of this frame of reference requires a focus on active participation in goal-directed activities. ***Optimum achievement is possible when individual treatment is combined with activities at home and in school.***

### ***Sensory Integration (SI) frame of reference***

SI is the ***process of organizing sensory information*** in the brain to make an adaptive response. An adaptive response occurs when a person successfully meets an environmental challenge. In short, function and skill are based on sensory system integration. The SI frame of reference is applied when sensory system processing deficits make it difficult for a child to produce an appropriate adaptive response. From neurobiological processes point of view (Bundy, Lane, Murray, 2002, p.5 & 14), behavior is linked to neurological processes. When one taking in sensation from own body and environment, integrating and organizing the sensory information (sensory inputs) at brain stem level efficiently, and

then making an adaptive response to meet the demands of a desired task. Each adaptive response creates a sensory feedback that leads to further integration of sensations. This results in a more organized state of the brain which is important for learning and adaptive behavior. In developed countries, many children who have handwriting problems, praxis problems, or behavior problems that are related to sensory system modulation problem will need intervention of OT with SI approach.

### ***Frame of reference for visual perception (VP)***

Application of visual information analysis refers to the function/ dysfunction continua, which include visual attention, visual memory and visual discrimination skills. This behaviour observed clinically may indicate that the child is having ***difficulty processing visual information***. With this frame of reference based on the teaching/ learning process, therapist plays a major role in providing ***environmental strategies*** and ***teaching/ learning strategies*** so the child is able to analyze and understand visual information.

### ***Biomechanical frame of reference***

This applies to cases of ***neuromuscular dysfunction***, who cannot maintain posture through automatic muscle activity, to substitute for the lack of postural control. The use of external positioning equipment may enhance central stability of a child so as to enable him/her to engage in functional skills.

13

### ***Psychosocial frame of reference***

This serves as a framework for occupational therapy practice in paediatric psychosocial settings. Temperament, attachment, peer interactions, play, the ability to cope, and environmental interactions are the central issues in the development of good mental health and in the functional interventions that deal with pediatric psychosocial disorders. All the facets are interconnected in a growing child and that facilitate or hinder overall developmental progress reciprocally.

2  
0  
1  
3

**Legitimate tools of paediatric occupational therapy** used in bringing about change:

#### **Conscious use of self**

The therapist use of his or herself as an agent to establish a positive therapeutic relationship with the clients and effect change within the therapeutic process.

#### **Nonhuman environment**

Everything that the child comes in contact with, including the community, school, and home as well as pets, objects, play things, technology, and transitional objects but have meaning for the child.

#### **Purposeful activities**

Graded activities that is meaningful to a child, in group or individual.

## ***Service Provision***

Thorough **developmental assessment** is essential before provision of treatment. That includes clinical observation and implementation of standardized tests.

**Developmental skills** (including cognitive, motor & play development). We specialize in the developmental, neurological and behavioural assessment of babies and young children.

**Motor skills and co-ordination** where there are concerns about general coordination in relation to function such as learning to ride a bike, performance in P.E., sitting posture in the classroom; and in particular relation to functional tasks such as handwriting, using knife and fork, managing scissors etc.

**Self-care and functional skills** such as feeding, dressing or toileting and the need for special seating.

**Visual perception skills** (in relation to handwriting & other functional tasks).

**Handwriting** including pencil grip, stroke force and strategies in copying tasks.

**Environmental barriers** that limit active participation of an individual.

14

■

2  
0  
1  
3

The ultimate goal of **intervention** is to improve a child's occupational performance as observed through his/her ability to participate in daily life activities, including social participation with family, peers and others. Occupational therapists help patients build skills to perform daily activities, such as playing, dressing or participating in school activities. We help patients to become more independent by focusing on strengthening their muscles and integrating their senses in a way that maximizes their abilities. Therapy may be individualized or in groups such as handwriting groups, social skills training groups etc. Home and school programmes may also be provided. Consultation and training are provided for teachers and parents as appropriate.

Sometimes, arrangement for the provision of special equipment to enhance independent living is essential.

**Wheelchairs in adjunct with special seating features** that address growth, correction and/or accommodation of deformities and pressure relieving purpose;

**Equipment** such as CCTV to facilitate clients with low vision to learn in classroom; portable oxygen therapy for outdoor activities; functional equipment for school and home such as special chairs

**Adaptive aids and gadgets** for activities of daily living, such as handwriting, bathing and toilet aids.

It is believed that people who have disabilities deserve a lifetime of excellent health care—from birth through adulthood. Occupational Lifestyle Redesign Programme is effective in helping the adolescents with chronic illness to gear towards a productive adulthood. We observe, evaluate and facilitate our clients to participate in and contribute to their society within cultural, social and economic context. For some clients, comprehensive rehabilitation

is needed. Use of advance technology and proper environmental modification are more cost-effective in helping this group of clients. Although this is a continuous changing arena, we are committed to keep updated with advancement of modalities and collaborate with other professions to find best options of service for our clients within limited resources.

### ***Challenges ahead***

As there are more cases with neurodevelopmental diseases that are eligible to receive inclusive education in mainstream schools, the Authority should consider a thorough policy to encourage and support clients, family members and school teachers. The policy should mandate school-based rehabilitation when the clients are in need.

### **References**

1. Conceptual Foundations of Occupational Therapy (1992) Kielhofner, F.A. Davis Company, Philadelphia
2. Frames of Reference for Pediatric Occupational Therapy (2<sup>nd</sup> ed), 1999, Kramer & Hinojosa, Lippincott Williams & Wilkins
3. Health & Wellness Fact Sheets - Addressing Sensory Integration Across the Lifespan Through Occupational Therapy, American Occupational Therapy Association. <http://www.aota.org/en/About-Occupational-Therapy/Professionals/HW.aspx>
4. Model of Human Occupation: theory and application (4<sup>th</sup> ed) (2008), Kilhofner, Lippincott Williams & Wilkins
5. Occupational Therapy service in Gillette Children's Specialty Healthcare, USA
6. Paediatric occupational therapy service of Australian Government, Department of Social Services
7. Sensory Integration - fact sheet, 2011, Specialty Group in Paediatric OT Service, Hong Kong Occupational Therapy Association.
8. Treating Neurodevelopmental Disabilities: Clinical Research & Practice (2006) Farmer et al, The Guilford Press

15

2  
0  
1  
3

## Stretching and Physiotherapy

Dr. PIN Tamis

*Assistant Professor, Department of Rehabilitation Sciences, Hong Kong Polytechnic University*

Muscle tightness or contractures are commonly seen in children with neuro-developmental disabilities such as cerebral palsy (CP), spinal bifida or muscular dystrophy (1). Although at present, the mechanism of muscle hypoextensibility, especially in conditions with spasticity, remains unknown (2), stretching is one of the Physiotherapy intervention frequently applied to combat this problem (3). The rationale is based on the assumption that stretching can increase muscle extensibility and preserve joint range of movements (4, 5). In a long term, adequate muscle extensibility and joint flexibility may lead to a biomechanically workable body for better ambulatory ability, positioning and joint integrity and may delay orthopaedic intervention (6). Stretching is commonly conducted in the following ways (7):

- manually by the therapist or the client, and
- positioning by external devices such as splints, casts, tilt-table, seating equipment etc.

16

The first category, manual stretching or commonly called passive stretching, is by holding the joint to the achievable end range of movement manually for a set amount of time and then releasing it. The duration of the stretch is usually for a short time limit as expressed in seconds or minutes. The other category of stretching involves sustained stretches by holding the targeted joint to the achievable end range of movement by mechanical means such as orthoses, casting, standing frames or positioning equipment, which would be sustained for minutes, or up to hours.

2  
0  
1  
3

In our systematic review on the effectiveness of passive stretching in children with spastic CP (8), we concluded that the current level of evidence to support the effectiveness of passive stretching in children with spastic CP remains weak. The main limitations are inadequate rigorousness of research designs and the small number of participants involved. There are a few conclusions drawn from the existing evidence:

- The dosage and methods of stretching programmes vary greatly in the literature. Stretching for 30 minutes is the most commonly chosen duration, which might be based on previous animal studies.
- There appears to be some evidence favouring passive stretching in increasing range of movements and decreasing spasticity in children with CP although the effect size remained small.
- There is some evidence to indicate that sustained stretching is preferable to manual stretching in improving range of movement and reducing spasticity in targeted joints and muscles in studies of children with spasticity.

Since the publication of our systematic review, it has been argued that clinicians should not 'throw the baby out with the bath water', i.e. totally abandon stretching programme due to weak research evidence (9). Instead, while waiting for more rigorous research studies in

this area, clinicians should rely on their clinical expertise to individualise the Physiotherapy intervention, including stretching programme, to their clients based on accurate assessment findings and specific treatment goals (10).

For children with higher level of mobility or GMFCS levels I to III, sustained passive stretching, if used solely on its own, should be targeted for specific goals. This includes increase the range of ankle dorsiflexion to a plantigrade position so as to tolerate the ankle-foot orthosis for longer duration without skin breakdown or increased heel strike during walking after Botulinum toxins. Injection is an example of this kind. Or else, stretching should be more 'active' (9), in which the child moves the joint to the end range as allowed in some functional activities, e.g. stretching hamstrings when practicing sitting to standing. The active stretching is based on the principle of normal muscle physiology i.e. when an agonist contracts, the antagonist will relax and be stretched. In this way, not only will the antagonist be stretched, the agonist will be simultaneously strengthened with repeated contractions. Strengthening exercises have been proven to be an effective intervention for children with neurodevelopmental disabilities (12). Besides, as soon as the children are physically able, they should be educated to perform the stretches on their own as part of their daily routines like brushing their teeth or putting clothes on. For those children with good cognitive ability, physiotherapists may try to apply techniques from proprioceptive neuromuscular facilitation such as hold-relax, contract-relax and stretch relax (9). Furthermore, instead of focusing on maintaining the joint range of movements at the impairment or body function level, physiotherapists should emphasize on maintaining flexibility and encourage children with developmental disabilities to explore and develop various movement repertoire and experiences at the level of activity or participation (14). Children with movement disorders should be encouraged to participate in fun activities, such as Yoga, "Tai Chi", horse-riding or sports for the disabled just like their peers, in which children would be active participant in the exercise programmes that encourage flexibility and fitness, rather than recipients of passive stretching (14). Children should actively move through the gained range of movements after stretching, otherwise the movement range gained may not be maintained for a long period of time.

For children with limited mobility or GMFCS levels IV and V1, sustained passive stretching with external devices such as orthoses, standing frames, seat inserts in wheelchairs or night-time positioning in beds would be recommended to maximize the effects of stretching on the extensibility of both muscle fibres and connective tissues (9). Regular change of positions such as getting out of the wheelchair to lying in prone on the floor or over a wedge during lunch time are alternatives to passive stretching. Whenever possible, this group of children should be encouraged to move the joint through the gained range of movements after passive stretching with active or assisted active movements, such as in a hydrotherapy pool or assisted transfers.

It is obviously unethical to carry out high quality randomised controlled trials to prove the effectiveness of passive stretching in children with neuro-developmental disabilities by

withholding any kinds of stretching in the control group. It is also difficult to tease out any components of stretching antagonists when working on the agonists in any kinds of exercise programmes in both participant and control groups in well-designed controlled trials. Hence, with their expertise knowledge in movement analysis, exercise physiology and good goal-setting with the children and their families, physiotherapists should find innovative ways and utilize community resources to promote life-long exercise programmes or recreational activities to maintain muscle extensibility and joint flexibility for children with neuro-developmental disabilities.

## References

1. Tecklin JS, editor. Pediatric Physical Therapy. 4<sup>th</sup> ed. Baltimore: Lippincott Williams & Wilkins; 2008.
2. de Bruin M, Smeulders MJC, Kreulen M. Why is joint range of motion limited in patients with cerebral palsy? Journal of Hand Surgery. 2012;38E(1):8-13.
3. Burns Y. Principle of Physiotherapy Management. In: Burns YR, MacDonald J, editors. Physiotherapy and the Growing Child. London: WB Saunders; 1996. p. 123-30.
4. Farmer SE, James M. Contractures in orthopaedics and neurological conditions: a review of causes and treatment. Disabil Rehabil. 2001;23(13):549-58.
5. Massagli TL. Spasticity and its management in children. Phys Med Rehabil Clin N Am. 1991;2(4):867-89.
6. Gage JR, Schwartz MH, Koop SE, Novacheck TF, editors. The Identification and Treatment of Gait Problems in Cerebral Palsy. 2nd ed. London: Mac Keith Press; 2009.
7. Gracies J-M. Pathophysiology of impairment in patients with spasticity and use of stretch as a treatment of spastic hypertonia. Phys Med Rehabil Clin N Am. 2001;12(4):747-68.
8. Pin T, Dyke P, Chan M. The effectiveness of passive stretching in children with cerebral palsy. Dev Med Child Neurol. 2006;48(10):855-62.
9. Gorter JW, Becher J, Oosterom I, Pin T, Dyke P, Chan M, et al. 'To stretch or not to stretch in children with cerebral palsy'. Dev Med Child Neurol. 2007;49(10):797-800; author reply 799.
10. Sackett DL, Richardson WS, Rosenberg W, Haynes RB. Evidence-based medicine: how to practice and teach EBM. New York: Churchill Livingstone; 1997.
11. Palisano RJ, Rosenbaum P, Walter S, Russell D, Wood E, Galuppi B. Development and reliability of a system to classify gross motor function in children with cerebral palsy. Dev Med Child Neurol. 1997;39:214-23.
12. Dodd KJ, Taylor NF. A systematic review of the effectiveness of strength-training programs for people with cerebral palsy. Arch Phys Med Rehabil. 2002;83:1157-64.
13. World Health Organisation. International Classification of Functioning and Health. Geneva 2001.
14. Wiart L, Darrah J, Kembhavi G. Stretching with children with cerebral palsy: what do we know and where are we going? Pediatr Phys Ther. 2008;20(2):173-8.

## Editorial's comment

*This article stimulated our thoughts and review on the effective ways on the stretching. Both "Passive" stretching and "Active" stretching and functional activities are equally important to maintain muscle extensibility and joint flexibility*

# Prevention of Pathological Fracture in Children with Severe Developmental Disabilities

Ms. LO Chui Han, Carol

RN (Gen), BN, MSc (Rehab)

Ward Manager, Developmental Disabilities Unit, Department of Paediatrics and Adolescent Medicine, Caritas Medical Centre, Hong Kong

## Introduction

Pathological fracture is a common problem of children with cerebral palsy especially if they are non-ambulatory. Sturn, et al. (1993) found that up to 20% of children with cerebral palsy may have a femur fracture during their developmental period. Another study by Lohiya, et al. (1999) showed that 5.3-13.2% of institutionalized children with cerebral palsies had history of femur fracture. The fracture rate was significantly higher in residents with epilepsy, older age, male gender, white race, independent ambulation, osteoporosis, and residence in intermediate care units.

## Major risk factors

A retrospective case control study on “Risk Factors for Pathological Long Bone Fractures in Non-ambulatory Cerebral Palsy Children” had been carried out by our Paediatric team in 2002. The result showed that the predictive risks factors of fracture were low B.M.I., significant contracture of extremities and prolonged immobilization. This suggested that prolonged postoperative immobilization was an important independent risk factor for fracture, after adjustment for the nature of operation, ambulatory status, and preoperative nutritional status. Pathological fracture of long bones in non-ambulatory children with cerebral palsy was common. Causes were multifactorial including nutrition, contractures, non-ambulation, lack of weight-bearing exercise, etc. Over 80% of pathological fractures happened in femur.

The result of the study by our Paediatric team in 2002 showed that among the population of 235 children, 47% of them had a weight below 5th percentile which contributed one of the significant risk factors of malnutrition. Another major factor found was prolonged immobilization especially after orthopaedic surgeries. Both studies by Sturn, et al. (1993) and Stasikelis, et al. (1999) showed about one third of non-ambulatory children with cerebral palsies developed femur fractures within a few months after hip osteotomies. The presence of severe spasticity with fixed contracture over extremities increased the difficulty in positioning and handling, thus further increased the risk of fracture during multiple daily activities.

## Implementation of Continuous Quality Improvement (CQI) Program

Since we have noticed there was an increasing trend of fractures in 2003 - 2004 (Table 1) from 2 - 6 incidents per year in the years between 1992 and 2002 to 9 incidents in the years 2003 and 2004, a CQI program was implemented to prevent pathological fracture.

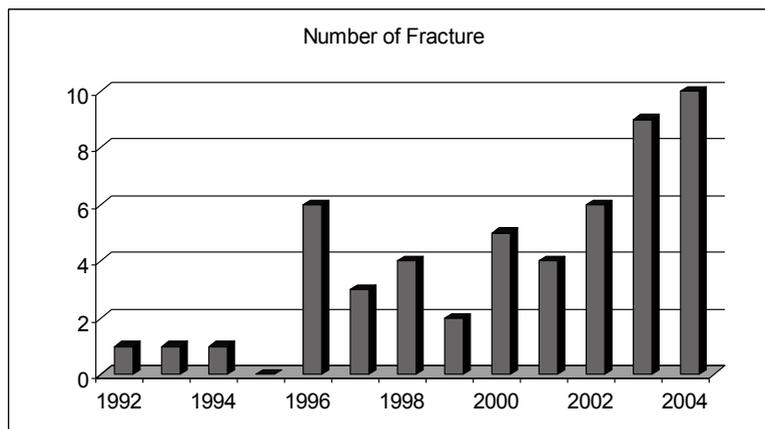


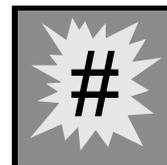
Table 1: Fracture rate from 1992 to 2004

### 1. To identify children with high risk of fracture

All children were assessed by the multidisciplinary team to see if they presented with one or more of the risk factors for fracture, such as:

- a. History of previous fracture
- b. Presence of spasticity with significant contractures and deformities
- c. Long lever arm
- d. Low weight-for height ratio

They were given a special label in red colour on the information sheet at bedside for special awareness. Special nursing would be considered for caring those children, such as shower in a bath trolley; carried out nursing care by two workers; handled with extra care, etc. All children were reassessed every half-yearly for modification of care if needed.



### 2. Revision of nursing activities

Revised the daily nursing activities and tried to reduce some unnecessary handling. We discussed with School to postpone the school time by 15 to 30 minutes to avoid staff worked in hurry. We also reinforced some existing nursing care procedures so as to eliminate the risk of causing fracture, e.g. technique of changing napkin and changing clothing for children with severe spasticity.

### 3. Revision of manual handling technique

The physiotherapists were invited to have a joined program for prevention of fracture. We worked together to produce a video for demonstrating the proper handling technique. We arranged training workshop on back care and manual handling. An internal audit was conducted to ensure every staff was familiar with the correct way of lifting so as to protect both the children and the staff. We also organized regular refresher courses and audits to keep our workers reminded about the proper handling technique.

20

2  
0  
1  
3

**4. Revision of diet**

All the children were referred to dietitian for evaluation if dietary supplement of Calcium and vitamin D should be required and the recommended amount according to their age and types of diet.

**5. Encourage children to have sun-bathing program**

We discussed with School for the possibility of increasing outdoor activities to let our children have more chance for sun-bathing. Hopefully, it could help in synthesis of Vitamin D and keep the long bone in a more healthy state.

**Outcome and Evaluation**

After implementation of the above measures, the number of fracture incidents dropped to 2 in 2006. This showed that increased awareness of carers, proper manual handling technique, appropriate dietary supplement and adequate sun-bathing could effectively reduce the incident of pathological fracture in children with severe developmental disabilities. Unfortunately, there was an increased in incidence of fracture noted in 2007. We immediately worked with our health care partners Lok Yan School to standardize manual handling technique, conducted training workshops to reinforce proper handling technique and spot audits. The effect was sustainable with - 1 to 3 incidents per year in the subsequent years

21

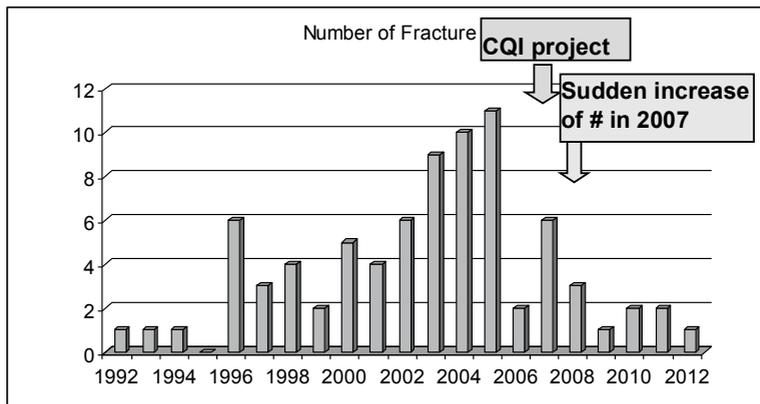


Table 2: Fracture rate from 1992 to 2012

**Conclusion**

There were so many factors contributing to pathological fracture, such as intrinsic factors of the children themselves including severe spasticity with contractures or deformities; osteoporosis due lacking of weight-bearing exercise; prolonged immobilization, malnutrition, etc. We could try to eliminate those risk factors by measures like early management of spasticity; encourage weight-bearing exercise as tolerated and early nutritional management. On the hand, we reassessed the children regularly to identify presence of risk factors leading to pathological fracture and provided eye-catching symbols to increase the awareness of carers. They would take special precautions according to the instructions during daily caring activities. The staffs were also educated to pay special attention on any abnormality detected

2  
0  
1  
3

and seek for medical treatment promptly. By implementing the above actions, the rate of fracture maintained at 1 – 2 incidents per year since 2008 and even Nil in 2013. We should thank all the staff working in DDU for their effort on preventing fracture in our high risk population.

## References

1. Lohiya GS, Crinella FM, Tan-Figueroa L, Caries S, Lohiya S. (1999). *Fracture Epidemiology and Control in a Developmental Center*. Western Journal of Medicine: 170(4), pp 203-9.
2. Keck E, Gollnick B, Reinhardt D, Karch D, Peerenboom H, Krüskemper HL. (1982). *Calcium metabolism and vitamin D metabolite levels in children receiving anticonvulsant drugs*. European Journal of Pediatric: 139, pp52-5.
3. King W, Levin R, Schmidt R, Oestreich A, Heubi JE. (2003). *Prevalence of reduced bone mass in children and adults with spastic quadriplegia*. Developmental Medicine & Child Neurology:45, pp12-6.
4. Samson-Fang L, Fung E, Stallings VA. (2002). *Relationship of nutritional status to health and societal participation in children with cerebral palsy*. Journal of Paediatric: 141, pp 637-43.
5. Stasikelis PJ, Lee DD, Sullivan CM. (1999). *Complications of osteotomies in severe cerebral palsy*. Journal of Pediatric Orthopaedic: 19, pp207-10.
6. Sturn PF, Alman BA, Christie BL. (1993). *Femur fractures in institutionalized patients after hip spica immobilization*. Journal of Pediatric Orthopaedic:13, pp246-8.
7. Wilmshurst S, Ward K, Adams JE, Langton CM, Mughal MZ. (1996). *Mobility status and bone density in cerebral palsy*. Archives of Disease Childhood: 75, pp164-5.

22

## Editorial's comment

Pathological long bone fracture is a common problem of children with cerebral palsy due to severe contracture, osteoporosis, immobilization, malnutrition. Early identification of the risk factors with proactive treatment and careful manual handling by all carers greatly reduced the rate of fracture.

■  
2  
0  
1  
3

## **Gastrostomy Feeding in Children with Severe Developmental Disabilities**

Ms. LO Chui Han, Carol

RN (Gen), BN, MSc (Rehab)

Ward Manager, Developmental Disabilities Unit, Department of Paediatrics and Adolescent Medicine, Caritas Medical Centre, Hong Kong

Giving birth to a baby should be a gladsome event to a family. But if parents have a child with severe neurological impairment, this might create lots of caring problems. Difficulty in eating and swallowing was one of the most common problems in children with severe neurological impairment leading to under nutrition and growth failure.

Feeding was a complex task requiring significant neuromuscular coordination. Children with severe neurological impairment might have difficulties in this complex coordination leading to poor feeding or even aspiration of bolus. Prolonged inadequate nutrition may result in poor growth and development, prolonged tissue repair and deprived immune function. It might also decrease muscle strength, resulting in ineffectiveness of cough and a predisposition to aspiration pneumonia. Other adverse effects of chronic under nutrition included susceptibility to the development of pressure sores, delayed wound healing, decrease in cerebral function with possible exacerbation of existing neurological impairment, increased irritability and decreased motivation, energy and attention span for rehabilitation, and bone demineralization and fracture.

Common manifestations of feeding difficulties included drooling, persistent vomiting, choking during feeding and prolonged feeding time. Prolonged feeding time would cause frustration to both the parents and children. Some of the children also presented with oromotor dysfunction such as poor lip seal, inability to swallow, delayed swallowing reflex, pharyngeal incoordination, incoordination of tongue and swallowing muscles, gastroesophageal reflux etc.

Early identification of feeding problems for early nutritional intervention might improve the nutritional state of the children, leading to enhanced growth and development. We should refer the child to undergo investigation such as video fluoroscopy study, to confirm if the children could swallow safely without aspiration and recommend the most suitable texture for safe oral feeding. If oral feeding was proved to be unsafe, nasogastric tube could be used for short term alimentation of nutrition for children who could not receive adequate intake orally. However, as this poses the risk of tube displacement and aspiration, it should not be considered for long term use.

Percutaneous Endoscopic Gastrostomy (PEG) was a simple procedure for children requiring long-term enteral feeding. Qualitative research studies by Yamashiro et al. (1996) and Cook et al. (2005) had shown that gastrostomy feeding reduced stress in dealing with

patients with feeding difficulties. It improved health status and thus bettered the quality of life for both the patients and the caregivers.

One of the most common complications of a gastrostomy was formation of granuloma (an overgrowth of the granulating tissue around the stoma). It could be treated by application of local antifungal treatment or cauterization with silver nitrate pencil. Other minor complications included post-operative wound infection, leakage, ulceration and tube dislodgement, which could be prevented by proper stoma care and choosing of appropriate devices.

Gastrostomy feeding reduced the feeding time and was considered to be a safer mode of feeding in children with oromotor dysfunction, thus reducing the frustration of parents in nourishing children with feeding problems and improving quality of life of both the children and the parents.

## References

- 24 Cook S, Hooper V, Nasser R (2005). Effect of gastrostomy on growth in children with neurodevelopmental disabilities. *Canadian Journal of Dietetic Practice & Research*, 66(1):19-24.
- Sullivan PB, Juszcak E, Bachlet AME, et al (2004). Impact of gastrostomy tube feeding on the quality of life of carers of children with cerebral palsy. *Developmental Medicine & Child Neurology*, 46:796-800.
- 2 Sullivan PB, Juszcak E, Lambert B, Rose M, Ford-Adams ME (2005). Gastrostomy tube feeding in children with cerebral palsy: a prospective longitudinal study. *Developmental Medicine & Child Neurology*, 47(2):77-85.
- 0 Sullivan PB, Juszcak E, Lambert B, Rose M, Ford-Adams ME (2002). Impact of feeding problems on nutritional intake and growth: Oxford Feeding Study II. *Developmental Medicine & Child Neurology*, 44(7):461-467.
- 1 Sullivan PB, Lambert B, Rose M, et al (2000). Prevalence and severity of feeding and nutritional problems in children with neurological impairments: Oxford Feeding Study. *Developmental Medicine & Child Neurology*, 42(10):674-680.
- 3 Sullivan PB, Morrice JS, Vernon-Roberts A, et al (2006). Does gastrostomy tube feeding in children with cerebral palsy increase the risk of respiratory morbidity? *Arch DisChild*, 91:478-482.
- Yamashire K, Nakada Y, Takasu N, et al (1996). Percutaneous endoscopic gastrostomy in patients with swallowing difficulties – home care and long term result. *Japanese Journal of Geriatrics*, 33(9):662-668.

## Editorial's comment

*Marked feeding disorders and risk of malnutrition in children with severe developmental disabilities are common problems. Though healthcare professionals advised earlier gastrostomy tube placement, a delay in acceptance of the procedure by parent is often encountered. In general, the parent often found difficult to accept the hole in the tummy for feeding and tended to refuse the treatment. Nevertheless, healthcare professionals should provide past evidences to parent showing the positive nutritional outcome such as improvement in growth rate i.e. a positive trend in body weight and height after gastrostomy tube feeding. Most parents would agree to earlier gastrostomy tube feeding had they acknowledge its benefit and ultimately satisfied with the children overall improvement such as less risk of choking, less frequent respiratory infections and feeling of improved nutritional status.*

# Development of Patient Clothing for Paraplegic and Quadriplegic Paediatric Patients

Dr. CHAN Chee Kooi, Ms. KWOK Jenny, Dr. KAN Chi Wai

*Institute of Textiles and Clothing, The Hong Kong Polytechnic University*

Dr. YU Chak Man, Ms. LEE Susanna, Ms. LO Carol

*Department of Paediatrics and Adolescent Medicine- Developmental Disabilities Unit, Caritas Medical Centre, Hong Kong*

**Abstract:** *The paraplegic and quadriplegic patients have very delicate and sensitive skin which is vulnerable to skin impairment resulting in redness, skin breaks and infection. They also have some adverse characteristics such as spastic, persistent drooling of saliva, sweaty and heavy secretions from tracheostomy. The purpose of this collaborative research project was to investigate the special clothing needs for this group of patients in paediatric hospital; to develop the textile material suitable for these patients; to promote comfort and improve the quality of life for these patients with special health care needs. The design process was developed based on the principles of product development to meet the special clothing needs during hospitalization. The new materials were developed through the experimentation of varying combinations of different materials such as raw materials, yarns and fabric weave constructions. A series of experiments were carried out to investigate the physical and comfort properties. Results indicated the new patient clothing material not only performed better than the existing one in terms of physical properties but also comfort properties.*

25

**Keywords:** *Patient clothing, paraplegic and quadriplegic patients, paediatric hospital, product development, comfort and quality of life*

2  
0  
1  
3

## Introduction

Maynard et al. defined quadriplegia as impairment or loss of motor and/ or sensory function in the cervical segments of the spinal cord due to damage of neural elements within the spinal canal [1]. Paraplegia was defined as complete paralysis of both limbs [2]. Most of the children with severe mental and physical handicapped who resided in Developmental Disabilities Unit in Caritas Medical Centre are paraplegic and quadriplegic with significant associated medical conditions. They have very sensitive and fragile skin which is vulnerable to skin impairment resulting in redness, skin breaks and infection. They have some adverse characteristics such as spastic, persistent drooling of saliva and profuse sweating. They may have eczema at their back due to the poor wickability of the existing clothing, especially for the young patients who sweat heavily. Their clothing can cling to their bodies due to the perspiration which makes them feel very uncomfortable. In addition, all patients wear diapers and they may feel great discomfort if there is urine leakage from diapers. As these patients are all bed ridden, comfortable clothing and bedding to them are certainly important in improving their quality of life [6].

According to Edvardsson, the patient clothing enabled the feelings of being comfortable and practical [3]. The clothing for patients used in Hong Kong is washed and dried at high temperature everyday. Therefore, the textile material used for patient clothing should meet the stringent washing condition. However, there are no specific requirements for the textile materials used in the paediatric hospital and no patient clothing designed for their special needs.

A collaborative research project that included the Developmental Disabilities Unit (DDU) of Department of Paediatrics and Adolescent Medicine of Caritas Medical Centre, the Institute of Textiles and Clothing of the Hong Kong Polytechnic University and Hong Kong Research Institution of Textiles and Apparel (HKRITA) was conducted from Mar 2009 to May 2010. The project was funded by the Innovative and Technology Fund (HKRITA) with the objective to investigate the special clothing needs for the paraplegic and quadriplegic patients; to develop a new textile material that can meet the stringent sanitary, comfort and care requirement for the patients with special health care needs; and to promote comfort and improve the quality of life of the paraplegic and quadriplegic patients.

26

## Research methodology

The project was an in situ user trial project which conducted in DDU. The DDU patients were the study subjects to look into the outcome and benefit of the developed textile material after the application of the new textile product. All paraplegic and quadriplegic patients in DDU with special characteristics such as spastic, heavy salivation, profuse sweating and fragile skin were recruited. Written consents from parents/authorized guardians were obtained. Patients in serious illness, serious skin problem and with no written consent from parents/authorized guardians were excluded. A total of 10 subjects were included in this study. The subjects in the control group were the same subjects in the intervention group. Prior to the user trial study, opinions were collected from DDU ward staff and parents through survey on their requirement of ideal clothing for these children in DDU. During the 12 weeks of user trial period, through observation in different time intervals, the designated ward staff helped to collect feedback for analysis. The effectiveness of the newly developed textile materials was evidenced by comparing the outcome of two sets of data i.e. wearing current clothing and clothing from the newly developed textile.

The principles of product development were applied to the present case study of developing patient clothing for paraplegic and quadriplegic patients in paediatric hospital. In details, the research methodology consists of nine steps: (1) identification of problem area, (2) problem analysis, (3) formulation of objective and project, (4) formulation of the demands of the user, (5) data processing and analysis, (6) specification of the use-demands and transformation for these into technical terms, (7) development of ideas and technical solution, (8) evaluation, modification and selection of prototype and (9) evaluation of the final solution in relation to the objectives [4]. Table 1 reveals the frame structure of the design process of the patient clothing.

2  
0  
1  
3

**Table 1:** Patient clothing design process

Stage	Operational
1. Identification of problem area	Medical and nursing staff experienced problems with the performance of the patient clothing.
2. Problem analysis	Literature research related to paraplegic and quadriplegic paediatric patients and the clothing material. Survey conducted with feedback collected from medical and nursing staff working in DDU and patients' parents so as to identify the importance of the patients' characteristics and the weakness of the existing patient clothing. Hospital visits for observation.
3. Formulation of objective and project	Development of the clothing material which was suitable for paraplegic and quadriplegic patients in paediatric hospitals. Promoting comfort and improve the quality of life of patients
4. Formulation of the demands of the user	Based on stage 2.
5. Data processing and analysis	Based on stage 2.
6. Specification of the user- demands and transformation of these into technical terms	Specifications matrix based on results from stage 2 were developed.
7. Development of ideas and technical solution	Development of new clothing materials based on results from stage 6 through the experimentation of using different materials by varying the raw materials, yarns and fabric weave constructions.
8. Evaluation, modification and selection of prototype	Fabric performance testing was carried out. Reiteration of stages as needed to obtain satisfactory performance of the patient clothing.
9. Evaluation of the final solution in relation to the objectives.	User trial survey and observation study was conducted in DDU with feedback collected from ward staff of DDU.

27

2  
0  
1  
3

## Questionnaire

In order to understand the special needs of clothing for these young patients, hospital visits and observations were carried out to study their daily activities and the daily routine work of nursing staff in the wards of the Developmental Disability Unit, Caritas Medical Centre, Hong Kong. The hospital environment and clothing handling procedures were also investigated and observed during the hospital visits.

A set of questionnaire was designed to obtain more information on the importance of young patients' characteristics affecting the clothing and the associated problems in terms of comfort of the clothing used in the hospital. The survey was conducted in the hospital with 92 respondents including 90 medical, nursing and supporting staff as well as 2 patients' parents.

## **Fabric performance testing**

A series of tests including the comfort properties, moisture management properties and durability were conducted to investigate the performance of the existing and the newly developed patient clothing.

### **Comfort properties**

Kawabata Fabric Evaluation System for Fabric (KES-F) was conducted to evaluate the fabric objective hand value of the patient clothing materials. Total hand value and hand value were calculated according to the tensile, shearing, bending, compression and surface properties [5]. A total of three specimens of the existing and the newly developed clothing materials were prepared for each property testing.

28

### **Moisture management properties**

#### **Water absorbency**

The time for the water absorbency of fabrics was measured and tested by the burette according to AATCC TM 79-2007. A total of five specimens of the existing and the newly developed clothing materials were prepared for the test.

2  
0  
1  
3

#### **Wickability**

The wicking property of fabrics was evaluated by suspending a strip of rectangular specimen having a size of 150 mm x 50 mm vertically with its lower edge immersed in a reservoir of distilled water. The height of rise by water in a given time, i.e. 1 minute, 3 minutes and 5 minutes was measured as the wicking behavior of specimen. A total of three specimens of the existing and the newly developed clothing materials were prepared for the test.

#### **Water vapour permeability**

The water vapour permeability of fabrics was investigated by the turntable based on BS 7209:1990. A total of three specimens of the existing and the newly developed clothing materials were prepared for the test.

### **Durability**

#### **Dimensional change**

The dimensional change of fabrics was evaluated by ISO 5077 with prior treatments of three washing cycles using programme 1A and the drying process E were conducted by ISO 6330 using the James H. Heal & Co. Ltd. washing machine and Whirlpool tumble dryer.

## Tensile strength

The tensile strength properties were measured using the Instron Tensile Tester 4411 according to ISO 13934-1. Ten specimens of the existing and the newly developed clothing materials were prepared for testing, five for warp direction and the other five for weft direction.

## Tearing strength

The tearing strength of test specimens was evaluated by using the Elmatear, digital tear tester according to the ASTM D1424-09. Ten specimens of the existing and the newly developed clothing materials were prepared for testing, five in warp direction (for tearing across the weft) and five in weft direction (for tearing across the warp).

## Results and discussion

### Questionnaire

Ratings 1, 2, 3, 4 and 5 represent the least important, less important, neutral, important and the most important respectively. Figure 1 shows the mean ratings for each patient's characteristic affecting the desire of the existing clothing. Serious salivating does affect the desire of the existing clothing most adversely while eczema is the least important factor. However, all the patients' characteristics have an average rating higher than 3.5, suggesting that all these characteristics are the special needs of the young patients and should be taken into consideration when developing new material for clothing. Therefore, the results indicate that good moisture management and comfort are the basic requirements for the young patient clothing.

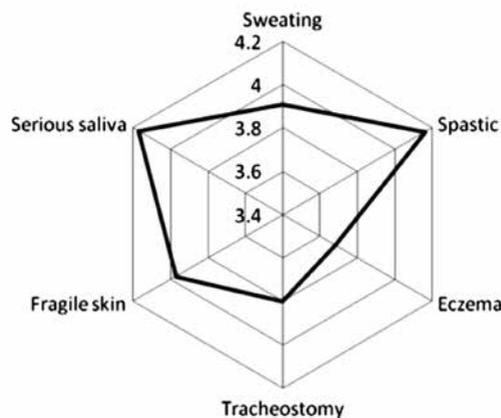


Figure 1: Importance of young patients' characteristics affecting the performance of the clothing

Ratings 1, 2, 3, 4 and 5 illustrate the level of satisfaction of respondents representing strongly disagree, disagree, neutral, agree and strongly agree respectively. Eight attributes including softness, smoothness, comfort, fineness, un-prickle, breathability, quick dry and warmth are indicated in the range of "neutral to disagree" on the comfort of the existing clothing material, suggesting the comfort property perceived by the medical and nursing staff and parents is below their expectation. In other words, all these eight attributes are important for the young patients and should be improved when developing new material for the patient clothing.

## Fabric performance testing

### Comfort properties

Both of the hand values of the smoothness, fullness and softness of the newly developed clothing were higher than the existing clothing according to Figure 2. Overall, the findings reflected the fact that the handle of the newly developed clothing was better than the existing clothing.

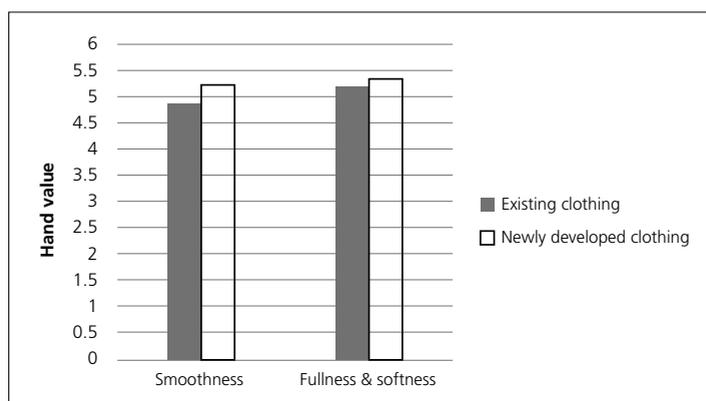


Figure 2: Hand value of the existing clothing and the newly developed clothing

30

### Moisture management properties

Moisture management property is important for the patient clothing according to the questionnaire results and hospital observations. Since the young patients usually have eczema with the problems of salivating and sweating, thus the fabric designed for the patient clothing should absorb sweat or saliva quickly in order to prevent skin irritation caused by sweat and saliva. In addition, all the young patients need to wear disposable diapers in the paediatric unit. In case of any leakage of urine occurs, good absorbency of the clothing fabric is essential.

### Water absorbency

During the test, a drop of water fell on the fabric and the time for absorbency was measured. The experimental results showed that the newly developed patient clothing absorbed the water immediately while the existing patient clothing absorbed it after 60 s. This confirmed that the newly developed patient clothing had remarkably good water absorbency.

### Wickability

Table 2 showed that the existing clothing does not absorb water in 1 minute, 3 minutes and 5 minutes for both the warp and weft directions while the newly developed clothing has a good wicking effect. In general, a higher water rise means that the fabric absorbs more water.

2  
0  
1  
3

**Table 2:** Wickability of the existing clothing and the newly developed clothing

Test		Sample					
		The existing patient clothing			The newly developed clothing		
Wickability	Warp (cm)	1 min	3 min	5 min	1 min	3 min	5 min
		0	0	0	4.0	6.6	8.3
	Weft (cm)	1 min	3 min	5 min	1 min	3 min	5 min
		0	0	0	4.1	6.5	8.2

**Water vapour permeability**

Good water vapour permeability for the patient clothing is preferable. If the insensible perspiration cannot escape, a build up of vapour will occur near the body, making the body feel clammy and resulting in discomfort. The experimental results indicated that both of the existing clothing (99.9%) and the newly developed clothing (100.3%) had good water vapor permeability.

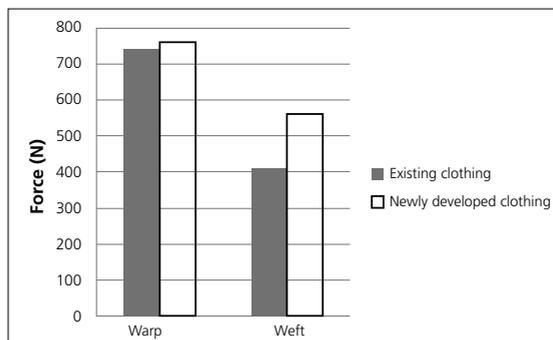
**Durability**

**Dimensional change**

Since the patient clothing is washed and dried at high temperature everyday, thus the dimensional change to washing and drying becomes important. The existing clothing had 5.1% shrinkage for the warp direction and 0.1% growth for the weft direction while the newly developed clothing only had 2.0% shrinkage in the warp direction with no significant change in the weft direction. It was clear that the newly developed clothing performed a better dimensional stability to washing and drying than the existing one.

**Tensile strength**

As there is a stretching force applied to the patient clothing during dressing and undressing, thus it is important for the fabrics to pose sufficient strength in the warp and weft directions. Figure 3 shows that the tensile strength in the warp direction is higher than that in the weft direction for both of the existing clothing and the newly developed because of a higher density in the warp direction. However, the findings indicate that the tensile strength in warp and weft directions of the newly developed clothing is higher than the existing clothing.



**Figure 3:** Tensile strength

## Tearing strength

Some young patients unknowingly and uncontrollably tear their clothes with their hands according to the hospital visits and observations. Therefore, the patient clothing should withstand the tearing force exerted by the patients. As the findings in Figure 4 show that the tearing strength of the newly developed clothing is remarkably higher than the existing clothing for both of the warp and weft directions.

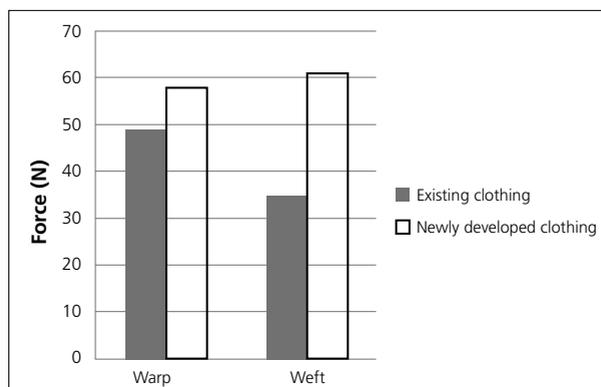


Figure 4: Tearing strength

## User trial result

After 12 weeks trial use of the new products, a questionnaire with 11 point scale with score assignment from 5 to -5 representing the performance of the current patient clothing and the new patient clothing were used to compare the performance of the newly developed patient clothing with the current hospital patient clothing in terms of comfort sensation and overall performance. A total of 37 staff working in DDU of CMC took part in this user trial survey. The results were shown as in Figure 5.

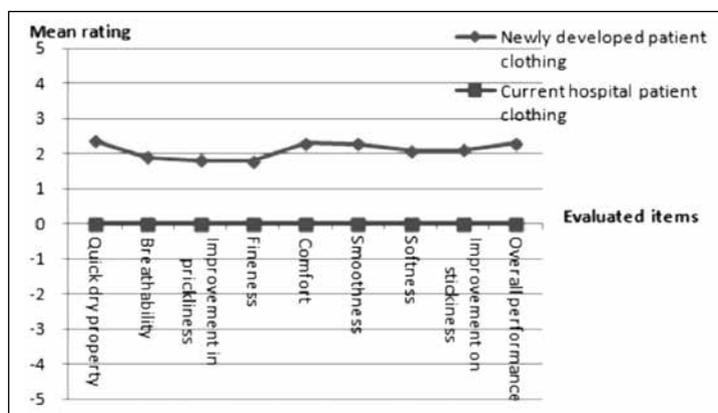


Figure 5: Questionnaire results of comparisons between the newly developed patient clothing and the current hospital patient clothing

The positive mean ratings of the newly developed patient clothing were obtained from both the comfort sensation and the quick dry property with a mean score of 2.35, breathability with a mean score of 1.89, improvement on prickliness with a mean score of 1.81, fineness with a mean score of 1.78, comfort with a mean score of 2.30, smoothness with

a mean score of 2.27, softness with a mean score of 2.08, improvement in stickiness with a mean score of 2.11 and the overall performance with a mean score of 2.30.

The user trial survey concluded that the performance of the newly developed patient clothing was improved when compared with the current one. The newly developed clothing had improvement in the quick dry property, breathability, prickliness, fineness, comfort, smoothness, softness, stickiness and the overall performance.

The user trial survey was further followed by an observation study by 2 designated nurses. The same subjects wore the clothing provided by the hospital on the 1st day and clothing from newly developed textile materials on the 2nd day. In these 2 successive days, the temperature and humidity level were controlled and recorded, the subjects were closely observed by 2 nurses at 3 hourly intervals i.e. at 0 hour, 3 hour, 6 hour, 9 hour and 12 hour for skin condition and physical comfort with record. The results observed from the subjects between the new developed clothing and the current clothing were compared. It was shown that that clothing from the newly developed textile yielded better performance.

## Conclusion

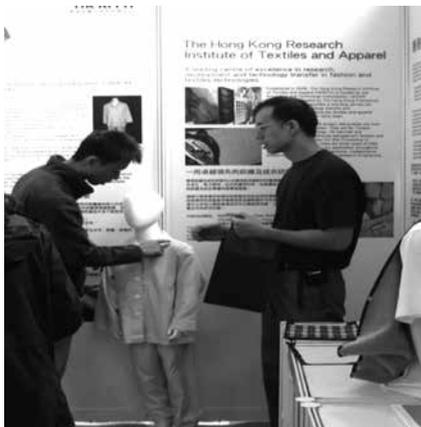
The principles of product development were applied to the development of patient clothing for paraplegic and quadriplegic patients in paediatric hospitals. The importance of the patients' characteristics was identified for the patient clothing used for these young patients via hospital visits, observations and survey. The results indicated that serious salivating was the most important factor, which should be considered when designing a new patient clothing material. These results also suggested that there was a strong need to design and develop innovative clothing to improve the performance of the clothing used for paraplegic and quadriplegic patients in paediatric hospitals, especially in view of comfort, moisture management properties and durability. Hence, a new clothing material was developed and evaluated by a series of experiments. The experimental results indicated that the newly developed clothing had enhanced the functional performance of comfort, moisture management properties as well as durability. The method of the principles of product development has proved to be applicable in the development of the patient clothing material whereas the functional properties are of vital importance.

*Acknowledgement: Hong Kong Research Institute of Textiles and Apparel (HKRITA) of the Innovation and Technology Fund, Government of the Hong Kong Special Administrative Region, Ref. No.-ITP/038/08TP*

## References

1. Maynard, FM et al: International standards for neurological and functional classification of spinal cord injury, *Spinal Cord*, Vol. (35) No. 5, pp. 266-274, ISSN 1362 - 4393/97
2. Capildeo, R and Maxwell, A (Eds.). *Paraplegia*, Macmillan Press, ISBN 0333347277, London, (1984)
3. Edvardsson, D: Balancing between being a person and being a patient – A qualitative study of wearing patient clothing, *International Journal of Nursing Studies*, Vol. (46) No.1, pp. 4-11, ISSN 0020-7489

4. Rosenblad-Wallin, E.: User-oriented product development applied to functional clothing design, *Applied Ergonomics*, Vol. (16) No. 4, pp.279-287, ISSN 10.1016/0003-6870(85)90092-4
5. Kawabata S and Niwa M: High quality fabrics for garments, *International Journal of Clothing Science and Technology*, Vol. (6) No. 5, pp. 20-25, ISSN 0955-6222
6. Voll, R. (2001). Aspects of quality of life of chronically ill and handicapped children and adolescents in outpatient and inpatient rehabilitation. *International Journal of Rehabilitation Research*.



34

2  
0  
1  
3

## **Editorial's comment**

Quality of life is pertinent and important for individuals with neurodevelopmental and related disabilities. Most of the individuals with neurodevelopmental disabilities are either partially dependent with limited mobility and weakness or totally dependent and bed-ridden. Some of them are vision and/or hearing impaired, having difficulty in swallowing and on nasogastric tube feeding, and/or having difficulty in breathing with tracheostomy. Therefore, in promoting physical well-being and quality of life for the children with severe developmental disabilities, apart from providing appropriate medical treatment and rehabilitation intervention, ensuring their basic daily physical comfort is vitally important e.g. providing comfortable clothing and bedding, positioning, soothing environment with music, good personal hygiene etc.

As most of these patients have difficulty in expressing their feeling, a holistic approach that includes both individual and parental or caregiver perceptions better addressed the conceptualization of quality of life for these patients.

The research study showed that ideal textile material for making clothing for the patients with special needs was successfully identified. The newly developed clothes resulted in improving physical comfort and quality of life for this specific group of patients. We hope that new funding can be injected to continue the supply of the newly developed clothes for these patients.

## Play has no boundaries

Ms. WONG Gloria

*Hospital Play Specialist, Playright Children's Play Association*

*At Playright we constantly proclaim the right of all children to play, and we regularly back our concern by drawing attention to the provisions of the United Nations Convention on the Rights of the Child, which speaks of the right of all children, whatever their circumstances, to enjoy leisure time, to take part in age appropriate play and to engage freely in cultural and artistic activities.*

*Nowhere is the failure to live up to the demands of this convention more painfully apparent than in hospitals that make no special provision for the play and leisure needs of children in their wards and in out-patient clinics. And when a child in hospital is not only sick, but also developmentally challenged physically or mentally, the effects of such deprivation can be magnified beyond belief.*

*Playright's professional hospital play service seeks to address this problem by providing play activities for as many of these children as it can. In 2008, thanks to support from Operation Santa Claus, we were able to widen our efforts to include the Developmental Disabilities Unit (DDU) in Caritas Medical Centre. One of our trained hospital play specialists, Gloria Wong, here shares with you how she and her colleagues have since then been helping children—and young teenagers too—overcome their often very challenging developmental disabilities.*



35

2  
0  
1  
3

“Play has no boundaries and it’s an amazingly varied activity.,” says Gloria. “While it can take on many different forms and trigger boundless flights of the imagination, it can readily serve children’s most fundamental needs in even its simplest guises.

”In my job as a play specialist,” she continues, “I now often work with children who live with developmental disabilities. Although their physical and mental limitations may seem to stand in the way, I still have to design and encourage play which will support self-expression. One valuable road to such play opportunities is through the children’s five senses, so I regularly seek to stimulate my patients through what they see, what they hear and what they can touch.”

“When I let them work with a non-breakable mirror, for example, they are delighted to see themselves and their surroundings reflected. Their eyes really shine with excitement. We also use water based paints, posting the artwork on the walls of the unit for everyone to share and admire. I would really love to show you some photos of these activities, but you will understand that we operate under a strict privacy code that limits what we can reasonably

ask children and their families to reveal. But if supporters or friends of Playright ever get the chance to visit them in person, I hope they will take it up, because it's immediately evident how much joy the children experience—and also how much joy we hospital play specialists ourselves feel when we play with them.”

“Music is a universal language, as working with these children shows. When children cannot talk or see, music provides important sound contrasts for them to enjoy, such as sound and silence, fast and slow pulses, and high and low pitches. This in turn encourages them to express their understanding and their feelings even if their facial expressions have thus far been limited. I adore conducting bedside talent shows, singing and playing instruments myself and inviting the children to join in. Many of my patients are teenagers, so I often use pop songs to echo their special needs and feelings.”

“When I play an instrument, the sounds that my patients hear or the vibrations that they feel stimulate them directly and also open up the world of the imagination. The waves of sound that I can create with my drumming can become for them the sea itself or the effect of wind on grass.”

“I also have ready a wide array of differently textured sensory balls and massagers to stimulate the sense of touch. This is particularly valuable where my patients' physical movements have had to be limited to prevent them from damaging themselves, or where there are blood circulation problems in their hands or feet.”

“Children who are not thus challenged will often beg to be taken out at the weekend. The children I work with often have no way of asking, however, although they have the same needs and desires. Since I have been working with them, Playright has successfully sought sponsorship for two outings - the first to a lunar New Year market followed by “yum cha”, and the second a trip to the countryside. I can still see the looks and gestures of excitement, especially from children confined to a wheelchair.”



“When we visited the lunar New Year stalls, we played a shopping game, with each of us planning what to buy to decorate our upcoming Rainbow House together. For some of them this was probably the first time they had used real currency to play. Afterwards, the “yum

*cha*” gave them a chance to taste something quite different from hospital canteen food—here yet another sense was involved. Some of the children gobbled their food down, while others hesitated, maybe because they were still getting used to new tastes and textures!”

“Our carefully planned countryside trip away from the hospital took place on a pleasant autumn evening and it involved family members as well as young patients. I had chosen different activities for them including playing musical instruments, singing, handcrafting with natural materials, enjoying grass and flowers, and blowing bubbles—a rare chance for them to get close to nature with their families. Their parents were really grateful that we had handled transport and helper arrangements so efficiently. This made an otherwise impossible outing a vivid reality—and a precious memory.”

“As you can imagine, playing with children who live with developmental disabilities can be hard work for us play specialists,” concludes Gloria, “but it is truly meaningful and we are amply rewarded by the amazing responses we get from the children and teenagers that we are committed to helping as part of Playright’s mission. This work must continue—and it will do so given the support of the community!”

## Play • full of joy

Ms. WONG Iris

*Hospital Play Specialist*

*Playright Children's Play Association*

Since some of our play specialists have not yet had the opportunity to work in the Development Disabilities Unit at Caritas Medical Centre, we arranged a special play session for them there in order to familiarize them with the skills needed to work effectively with physically or mentally challenged children. They are very happy to share their experiences with you!



38

“At first I wasn't sure if Lily really wanted to play. But her excitement was obvious when she excitedly explored and finally clung to the colour lamp I showed her, and I could see that she really wanted and loved to play.”

■

2  
0  
1  
3

“We often suppose that children who are mentally challenged have difficulties in expressing their needs, desires and emotions directly. But a little more thought and close observation shows that the real difficulty often lies not in their own capabilities but in the limited understanding that others have of them. In fact, if we are willing to spend more time and attention to get to know these children, such difficulties really fade away. Look at their happy faces as they play and you will soon understand what I mean!”

## “Today, I played with my little friend Didi.”

Ms. LAU Karen

*Hospital Play Specialist, Playright Children’s Play Association*



“We started with different musical instruments, each of which he patiently tried to play. He was particularly attentive when I used a keyboard. Each time I played a new note, he clapped and laughed. He soon realized that the notes were controlled by my fingers and he moved my hands to produce different notes.”

“When I played mirrors with him, he smiled into the mirror and touched his own reflection. Whenever he saw me in the mirror, he laughed out loud. He soon had me making all sorts of faces to entertain him.”

“This all gave me a fresh understanding of what play specialists can achieve with developmentally challenged children. These children appeared to lead a limited life but we can readily introduce new stimuli to encourage play. I believe that the pleasure that they get from play can gradually translate into a sense of the love and care that people have for them.”

## “Today, I played with my little friend Kiki.”

Ms. CHUI Tammy

*Hospital Play Specialist, Playright Children’s Play Association*



40

■

“When Kiki and I made handicrafts together, I helped her choose different colours for face, hair and clothes. Whenever I held up the colours she had chosen, she responded with a bright smile. We carried on working together and she finished a self-portrait. When I asked her “Does that look like you?”, she only stared at her work without a smile. But when the ward assistant added ‘Actually, it looks like her favourite singer!’, she instantly burst out laughing. Who would dare claim that Kiki is isolated from the world? I stuck the picture up next to her bed so she could enjoy it all the time. Seeing her so look so happy and satisfied really brightened my day.”

2  
0  
1  
3

## Love and Care Activated in 2011

Ms. WONG Gloria

*Hospital Play Specialist, Playright Children's Play Association*

Most children just cry and cry when they are sick and have to stay in hospital. But can you imagine the feelings of child patients who have to go through numerous treatments, operations and examinations, such as those children with severe physical needs often requiring long-term hospitalization. They just lie in bed for the majority of each day, and their feelings are just beyond words. Who cares about their needs for social interaction, development and play?

Hospital play specialists do. Thanks to the support of the Melco Group and Partnership Fund, we carried out the programme of "Goodwill Action by Hospital Play Services" from 1 January to 31 December 2011 in hospitals, hoping to provide therapeutic games for child patients requiring special attention through the goodwill contacts of hospital play specialists, medical staffs and volunteers. To be specific, we organized volunteers to visit and play games with long-term hospitalized children. Through training support, we encouraged medical staff to conduct distraction games so as to help child patients receive examinations and treatments in a more relaxed environment.

This one-year programme was in the charge of two hospital play specialists. Being one of them with the important task, I am thankful for all those unforgettable experiences. One year was not too long or short, but it was enough for me to make friends with hundreds of children in the Paediatric Developmental Disabilities Unit of Caritas Medical Centre. And I can still recall those innocent faces of lovely children, beautiful boys and girls.

Although most children lay in bed all day and seemed to be indifferent at first sight, I still managed to get along with them with care and patience. Some were passionate enough to give me the "signature" smile whenever I called out their names. Others were cool outside but warm inside. They were easy to get familiar with and they just could not hold their laughter when I told them funny things. There were also the shy ones, who needed more time to "warm-up". You have to pay great attention in order to notice their short-lived smile. Then there were the very serious children, who pulled a long face all the time. Even all my "tricks" were not enough to make them smile. But it was already satisfactory to see the slightest changes in their response such as heavier breath or rotating eyes.



41

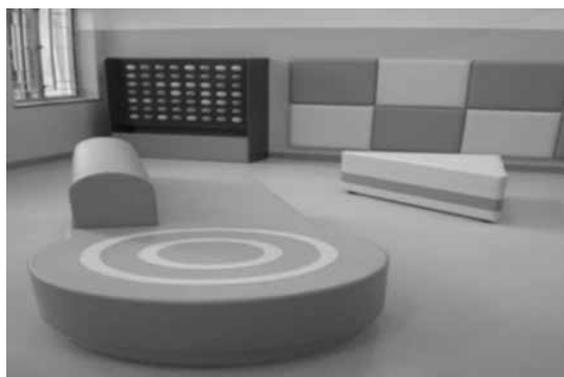
2  
0  
1  
3

The said "tricks" refer to sensory stimulations to the child patients in terms of visual, auditory, tactile, olfactory and taste, in addition to the sixth sense of aesthetic feeling. Hospital play specialists brought different play experiences to the child patients based on their individual needs and abilities. Those able to play instruments could enjoy the fun of music making (and here we would like to thank the medical staff and the neighbours for their tolerance); those hoping for a surprise could explore the gadgets from the "treasure bag" of the play specialists. When conditions permitted, we also took the child patients out of the ward for some quality time in the Rainbow House (a play room) or outdoors, for handicraft with fallen leaves, or for make-up and photo taking. It was really fun!



42

2  
0  
1  
3



Apart from promoting the interactive communication between child patients and play specialists, the programme also successfully introduced the new element of enthusiastic volunteers. In addition to financial support, the Melco Group encouraged its employees and their friends and relatives to visit child patients and to have fun with the children in hospitals and outdoors in the capacity of "Playful Big Brothers and Sisters". I remembered that during the Dragon Boat Festival, the "Playful Big Brothers and Sisters" told the child patients about the origin of the festival and simulated dragon boat racing with musical instruments. For those who were mouth fed, they got a taste of the glutinous rice dumplings, for those who were tube fed, they could at least smell and touch the dumplings to get some festive mood from it. I also remembered how we had our flag raising ceremony, and to have a true-or- false competition by raising flags to indicate right from wrong answers about Hong Kong on the anniversary of the return of Hong Kong to China on 1st July. During the hot season, we played with sand and ate popsicles, enjoying the fun of "Summer ShaLaLa". The most exciting and memorable event for the children was the first outdoor day camp, of course. The "Playful

Big Brothers and Sisters" carefully pushed the wheelchairs around so that the children could fully enjoy the scenery of the campsite. It was subsequently followed by exciting competitive games and natural hand-paintings. Both the volunteers and the children were enthusiastic in the process and greatly enjoyed themselves.

Seeing the smiles of the volunteers, I believe memories full of happiness and satisfaction are already stored in the minds of the "Playful Big Brothers and Sisters"! Although the programme was completed by the end of December 2011, as hospital play specialists, we are most happy to see that love and care have been activated, with actions taken to care about child patients with special needs and long-term hospitalization. Even more excitingly, volunteers of the Melco Group promised to continue their visits to the child patients in hospitals on a regular basis as "Playful Big Brothers and Sisters". Love and care will go on!

## Paediatric Rehabilitation Service: Transition from Acute Care to Home or Community Care

Ms. LO Chui Han, Carol

RN (Gen), BN, MSc (Rehab)

Ward Manager, Developmental Disabilities Unit, Department of Paediatrics and Adolescent Medicine, Caritas Medical Centre, Hong Kong

### Introduction

Children after acute insult or illness affecting their neurological system may require a long period for rehabilitation before going back to the community. Patients and their families encounter lots of stress and problems in accepting and helping the patients to live with the disabilities. The Paediatric Rehabilitation Unit (PRU) of Caritas Medical Centre was established in October 2007 with the aim to provide holistic step-down service to patients after major surgeries or required neurological rehabilitation. The PRU received cases from other acute hospitals after stabilization of acute conditions. During the transition period, we tailored rehabilitation program by our multidisciplinary team to maximize patient's functional level, provide holistic care to empower carers, assist the patients and their families to adapt living with the disabilities, arrange and co-ordinate appropriate resources in the community to facilitate care at home after discharge such as modification of the home environment according to their needs.

### Review of service

During the review period from Oct 2007 to Feb 2011, there were 205 admissions receiving different services. The data were further divided into two categories for analysis: Long-stay - for patients admitted to our unit for more than one week; Short-stay - for patients admitted not more than 7 days.

For the long-stay group, we have 37 patients admitted in the reviewed period. Sixty-five percent was male and 35% was female patients with mean age 8.80 years (ranged from 1 to 21 years). The average length of stay was 133.41 days (range from 8 days to 15 months). Over 50% of patients had cerebral palsy, 14% with various types of syndromes, 8% with brain tumours, others included post infection or malformations of the central nervous system, post traumatic brain injuries, etc (Chart 1). Sixty-four percent of patients were admitted for neurological rehabilitation and 25% required intensive rehabilitation program after major orthopaedic or neurological surgeries. The remaining included those under the nutritional rehabilitation program and carer empowerment program (Chart 2).

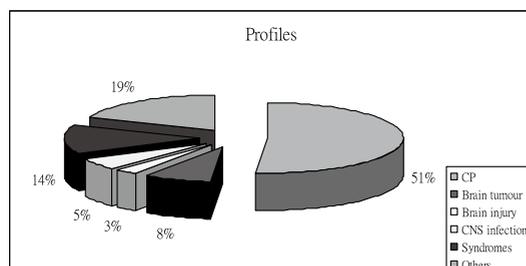


Chart 1

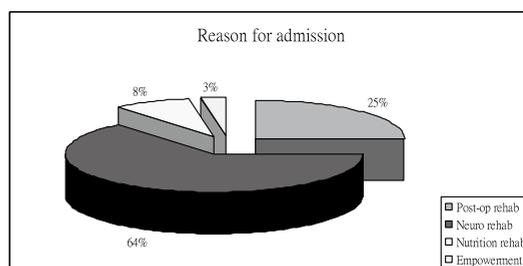


Chart 2

Ongoing reviews and assessments by the multidisciplinary team were carried out throughout the admission period. Discharge planning was well-discussed along with the input from the patients and their families. About 58% of patients were discharged home with regular follow-up for continuous assessment; 21% were discharged to Developmental Disabilities Unit due to unstable medical condition and required long-term medical care after monitoring for few months; 15% were discharged to special child care centers or special school in the community for more structural training since their conditions were stable. Six percent eventually died due to relapse of the brain tumours and sudden deterioration of conditions (Chart 3).

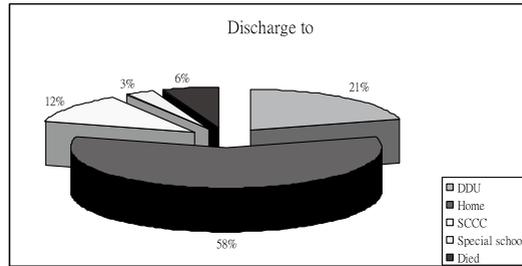


Chart 3

Patients who had received rehabilitation program showed improvement in various aspects: over 75% of patients improved in their muscles strength and about 56% patients improved in their range of movement (Chart 4).

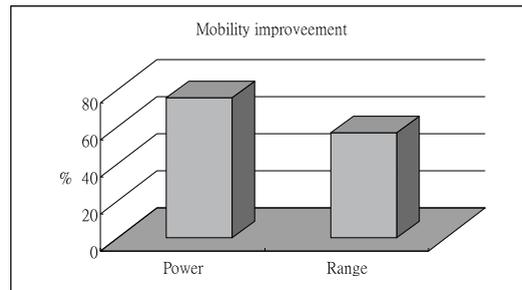


Chart 4

For the short- stay group, among the 168 patients, 54% were female whereas 46% were male. The mean age was 12.31 years (ranged from 3 – 20 years), and the average length of stay was 1.65 days (ranged from 1 to 7 days). Majority were admitted for different investigations or procedures such as Phenol or Botox injection for spasticity management; oral gastroendoscopy and 24 hours oesophageal pH monitoring; intravenous Pamidronate infusion therapy for strengthening the long bone. Twelve percent of patients received step-down care immediately after gastrostomy surgeries before going back to the original institutes (Chart 5).

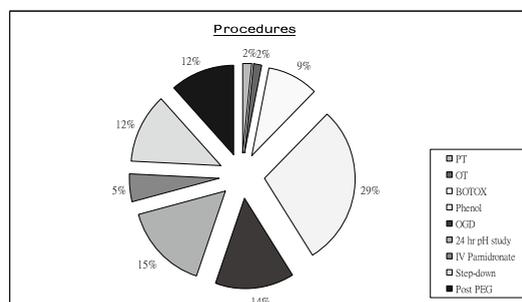


Chart 5

There were also 199 ambulatory day admissions for multidisciplinary assessment, investigations or other simple interventions, and there were 56.3% male and 43.7% female. There were a total of 1408 day admissions for regular physiotherapy and occupational therapy within the investigation period. Among them, 49.4% was male and 50.6% was female.

## **Conclusion**

The Paediatric Rehabilitation Unit (PRU) provided holistic care bridging between acute service and community or home care. During admission, we trained up the kids in order to maximize their abilities; liaised with the external community resources; empowered the parents/carers to facilitate home/community care; and relief the workload of the acute services. Majority of patients, including long-stay, short-stay and ambulatory cases, improved in their self-care abilities, muscles strength and range of movement, as well as their ambulatory state. We provided ongoing assessment by our multidisciplinary team after discharge for monitoring the progress.

## ***Editorial's comment***

46 *Interdisciplinary approach in the care of children with neurodevelopmental disabilities is important. The effectiveness of team is largely dependent on how the professionals work with each other to meet the needs of their patients. Nurse, often being the team coordinator, demonstrated the critical role in the overall implementation and operation of the services such as in Paediatric Rehabilitation and facilitating an effective transition of children from hospital to community care.*

## **Child and adolescent psychiatric service: Aiming for more....**

Ms. CHAN Kit Ping

RN (Psychiatry)

*Advance Practice Nurse, Yaumatei Child Psychiatric Clinic*

There has been a huge change of the child and adolescent psychiatric services in Hong Kong (HK) over the past 30 years.

Thirty years ago, the child and adolescent psychiatric services in HK was still in a very small scale and exploring stage. The psychiatric child clinics which situated in Hong Kong Island were mainly for neuro-developmental disorders e.g. Autistic Spectrum Disorder (ASD). Over the years, similar child clinics were progressively set up to treat young people with various kinds of psychiatric problems. Children with ASD and/or Attention Deficit Hyperactive Disorder (ADHD) were seen in the day hospitals whereas young people with acute or complex psychiatric problems were treated as in-patients. However, the environment is still suboptimal and the services provided are inadequate. For instance, in Kowloon West Cluster, the child clinic was attached to the adult out-patient department and the service was only provided once per week. The children had to mix with the adult psychiatric patients in the same clinic that was far from the standard of achieving therapeutic environment for those children and their carers.

In order to improve the child and adolescent services, well organized child and adolescent psychiatric clinics were set up with specific purposive built environment to meet the needs of child and adolescent clients. Since 1990 well trained child and adolescent psychiatric teams had been established in different areas of HK. Recently there are in total 5 child and adolescent psychiatric teams in different clusters under management by HAHO serving all children and adolescents who have mental health problems in HK.

Nowadays, the scope of service of child and adolescent psychiatric teams has been expanded extensively to include out-patient, day hospital and in-patient ward services for young people with various kind of mental problems. Majority of the children and adolescents are receiving specific psychiatric services in the out-patients department and day hospital. Among all of them, 40% of children with ASD and 40% of children with ADHD are being treated. There are different specifically tailored programs provided in the child centre. However, the services provided still could not meet the increasing demand due to increase in recognition of mental health problems and the growing complexity of problems among the young people. For example, in Yaumatei Child Psychiatric Clinic, there is 60% increase in SOPD new referrals from 2009 to 2012, 102% increase in SOPD new cases from 2009 to 2012 and the waiting time for SOPD new case is around 20 months. Besides, there is 109% increase in day hospital psychosocial treatment referral from 2011 to 2013. The waiting time for day hospital is also long and resources for psychosocial treatment are insufficient. Though

many initiatives aiming at reducing the SOPD new case waiting time have been carried out and yet the long waiting lists still persist. Research evidences showed that early intervention was important. However, timely treatment still cannot be offered to this target group of ASD and ADHD patients despite the support program for additional resources in year 2011. The long waiting queue quickly recurs as demands are greatly over the resources supplied. Moreover, there is limited manpower to provide professional care to facilitate the transition of the adolescent to adulthood.

Nowadays, more improved programs for ASD and ADHD including acute psychiatric problems and specialized care programs for early psychosis, mood disorder, and eating disorder in young people have been implemented. The care programs for engaging and supporting carers and family members have become increasingly important during the treatment regime. The involvement of community stakeholders as partnership to carry out more preventive measures is essential in providing a comprehensive care to clients and their families. We are continuing to strengthen the framework of mental health service delivery to enforce all the primary, secondary and tertiary tiered model of care and to explore ways to improve the core quality care aiming at doing more and better for our children and adolescents. Although child and adolescent psychiatric service is facing different challenges always, various innovative strategies and new approaches are under planning or being tried. We hope that more effective and excellent service could be provided to enhance better health for our children

48

■

2  
0  
1  
3

## ***Editorial's comment***

*The child and adolescent psychiatric services in Hong Kong have been expanding tremendously in the past 30 years. The services are exceling with wider coverage, more family focus and community involvement. Specific programs are well designed to meet individual special health care needs of the child and adolescent.*

*To ensure the children receive the timely treatment, early identification of the illness and intervention are very important, however, the long waiting queue of SOPD and the central allocation system for EETC, SCCC and ICCS placement form a bottleneck that the children in early age with special needs e.g. ASD, ADHD will miss the golden age to receive appropriate and timely treatment. This may affect their functional outcomes and future development.*

The printing of this issue of Brainchild is contributed by a generous donation from  
an Education Grant from Mead Johnson Nutrition (Hong Kong) Ltd