

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

> April 2001 Volume 2 No. 1





Hong Kong Society of Child Neurology & Developmental Paediatrics

香港兒童腦科及體智發展學會

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Publisher Medcom Limited Unit 1310, Olympia Plaza 255 King's Road, North Point, Hong Kong Tel: 2578 3833, Fax: 2578 3929 E-mail: mcl@medcom.com.hk

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The Hong Kong Society of Child Neurology & Developmental Paediatrics Brainchild - April 2001 Issue



First of all I would like to thank you for your overwhelming support, generous compliments, and constructive comments to the Inaugural Issue of Brainchild which was widely distributed to medical, nursing and allied health professionals both locally and internationally. We appreciate your encouragement and will endeavour to incorporate your invaluable recommendations into our future publications. We keenly look forward to your continual support and guidance for future publications to come.

Encouraged by the favourable responses, the Editorial Board strives to enrich the contents of the current issue by including scientific papers from our Bi-monthly Meeting on *Multidisciplinary Management of Cerebral Palsy*, so that readers may have access to the full details of the excellent presentations. At the same time, we are pleased to present several reviews by colleagues of our Society on cutting edge topics within our subspecialties. We appreciate their effort and would strengthen this section in the future to keep members updated on the most recent developments.

The Consultative Paper on Healthcare Reform by the Health and Welfare Bureau of the Hong Kong SAR Government is an important event for medical and health professionals in Hong Kong. The Hong Kong Society of Child Neurology and Developmental Paediatrics, comprising of professionals dedicated to the care and welfare of children with neurological and developmental problems, finds it obligatory to respond to the Document. The Council of the Society, with the support of its members, has submitted an Official Response to the Secretary for Health and Welfare to which we have stressed our conviction and commitment *that every child should enjoy good health, well-being of the body and mind, and the opportunity to realize its full developmental potential and enjoy full participation in the community. Furthermore we regret to note that the Document contains very few recommendations to the Government and urge the Secretary for Health and Welfare to take into consideration our Response in the formulation of the Healthcare Policy for Hong Kong. As this is an important document for our Society and for all professionals dedicated to be Child Health*

Advocates, we have included the full text of the Response for your kind reference and information. The Council will maintain close surveillance on the developments and will keep members informed of the progress duly. Your comments at any point will be most welcome.

In order to improve the diversification of the Publication, we aim at enlarging our sections on Members's News and would strongly recommend members to fully utilize the Correspondence Column on any issues of current interests related to our subspecialties, and to any events which you might like to bring to the notice of your colleagues or to invite their comments. The events can be clinical, scientific, ethical, child health advocate issues and others which you would like to air out. This is one of our endeavours to promote the interactive nature of Brainchild and we appeal to you for support.

Finally I am pleased to report to you that the Annual Scientific Meeting in November 2001 will be on Paediatric Neuro-ophthalmology. Members can look forward to updating their knowledge on the basic investigations and recent advances in the management of children with visual disorders through this event to be directed by a leading world authority in the field. Please do mark your diary.

We wish you all reading pleasure and look forward to your support and comments.

Charclut Dan

Editor-in-Chief, Brainchild President, HK Society of Child Neurology & Developmental Paediatrics

Response to Health Care Reform

The Hong Kong Society of Child Neurology & Developmental Paediatrics Response to the Health & Welfare Bureau Consultation Document on Health Care Reform

March 2001

The Hong Kong Society of Child Neurology & Developmental Paediatrics (HKCNDP), comprising of medical and allied health professionals dedicated to the care and welfare of children with neurological and developmental problems, strongly believes that every child should enjoy good health, well-being of the body and mind, and the opportunity to realize his full developmental potential and enjoy full participation in the community.

We *regret* to note that the Health Care Reform document contains few specific recommendations on the health care of children, and we would like to make the following comments and recommendations to the Bureau for consideration.

For All Children

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- 1. We believe that health care for all children is the responsibility of the government, and that no child should be deprived of necessary care because of social or financial factors. We agree in general with the document's proposal to review fee structures to influence patient behaviour and distribution of workload between and public and private sectors.
- 2. We agree that there should be a multi-disciplinary and multi-sectoral approach to health care that has strong integration at the community level.
- 3. We agree that primary medical care for children should be strengthened through coordinated service and structured training of paediatricians as well as other physicians and allied health professionals who provide primary care to children. The government should play an active role in facilitating this area.
- 4. We believe that preventive care for children's health should be free and the sole responsibility of the government.

For Children with Chronic Neurological Conditions and Developmental Disabilities

We feel that attention should be given to the following with the view to effect necessary change during the reform.

- To develop centralized subspecialties in child neurology, such as epilepsy surgery, through conjoint efforts of all paediatric neurology units in Hong Kong and the leadership and coordination of professional bodies like the Hong Kong Society of Child Neurology and Developmental Paediatrics.
- 2. Public education on positive parenting and healthy lifestyles, together with mental and physical health screening and identification of special developmental needs throughout all years of childhood and adolescence, should be the primary responsibility of the government. These could be provided either directly by the government, or through strategies and financing to encourage private sector provision of these services.
- 3. A strong operational link should be present between paediatric neurology and developmental paediatric services. This allows treatment of acute neurological diseases, early assessment of subsequent structural or functional impairments, subacute, ambulatory and community rehabilitation measures to be conducted as an integrated continuum.
- 4. In order to build up a strong body of local clinical expertise for complex paediatric neurological conditions, as well as gathering data for research, an effective arrangement between paediatric departments for clinical cooperation and keeping of a valid central registry on these cases is essential for service development, academic advancement, and professional training.
- 5. Multidisciplinary teams with medical and allied health input are needed for most children with chronic neurodevelopmental disorders. Multi-sectoral collaboration among health, education and social services, parent representations and community groups is essential for successful delivery of services to these children. However, complex organizational and funding support and professional expertise are required for this to materialize, and the system cannot rely heavily on interagency good will or efforts of front line workers.

The community based integrated health care model recommended in this document gives responsibility to "physicians in primary care, in partnership with nurses, allied health professionals and allies from the welfare sector and the local community", to realize the mission to provide integrated service through multi-sectoral cooperation. Published studies on similar team efforts have shown that patchy and fragmented service is most often the result, where professionals from different disciplines and organizations lack

consensus on aims and objectives. Specifically and importantly for children with neurodevelopmental disabilities, the specialized nature of this field makes it mandatory that there are team leaders at consultant levels who have broad-based training, multi-specialty knowledge as well as commitment to these children to serve as inter-sectoral and neurodevelopmental team coordinators, as champions for quality assurance, and as advocates for these children's life long medical, educational and psychosocial needs.

6. Currently, child assessment centres for children with neurodevelopmental problems are located within the community, and aside from one which is operationally linked with a Hospital Authority paediatrics department, there is no connection between the Department of Health assessment centres and hospital paediatric departments which serve mutual clients.

At the establishment of the Department of Health's Child Assessment Service, as well as at subsequent progress reviews, consulting experts recommended that this service should serve not only as a comprehensive assessment centre, but also as a focal point for study of child development and neurodevelopmental disabilities, for maintaining a central registry of these children, and as a local resource centre and meeting place for disabled children and their families, The consultant paediatrician heading a regional centre should also provide consultative support to community child health services, work in close conjunction with hospital paediatric units including providing specialty input for non-acute cases, and be responsible for monitoring multidisciplinary work in the area. *Today, the scope and mode of service delivery, professional training and career structure of paediatricians in the service have made little progress along these lines, and could in part account for various aspects of under development in the field.* Prompt action is requested to review earlier recommendations and to take necessary measures towards rectifying the situation in line with the upcoming health care reform.

- 7. Today, cooperative networks between assessment centres or hospital paediatric departments with rehabilitation service providers from other sectors are ad hoc and patchy at best. Services under different organizations have essentially different organizational goals, professional cultures and operational patterns. Without external structural and professional support, physicians and other health care providers in the community have little chance of pulling such teams together effectively and professionally.
- 8. Overseas expert consultants in this field invited by the Government and Universities over the past 3 decades, have called repeatedly for administrative coordination of services, funding and professional practice for disabled children between departments and organizations. It was stressed that these children have problems and needs that are distinct from adults in many respects, and should have their own legally constituted body which coordinates policy and plans concerning them. The Rehabilitation Advisory Committee (RAC) (formerly Rehabilitation Development Coordination Committee), and a Commission for Rehabilitation at the Health & Welfare Branch were established by the government over the past years

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to advise, formulate and coordinate execution of rehabilitation policies. Yet no committee or working group with government mandate has been set up to coordinate and meet the specific needs of disabled children. Membership of the RAC currently does not include any paediatrician specializing in neuro-developmental disabilities or rehabilitation, and the Commissioner for Rehabilitation together with other government administrators deal with the full range of rehabilitation issues within Hong Kong.

- 9. For an integrated team to function effectively, a Commissioner for Rehabilitation for Disabled Children should be appointed, who will work in consultation with a committee vested with the authority and represented by relevant departmental and sector specialists, to bring about the required interdisciplinary and interagency collaboration.
- The Department of Health's Child Assessment Service which is headed by paediatricians trained in 10. child development and disabilities should be run through public support as part of a centralized service with financial autonomy under the Hospital Authority, to provide secondary and tertiary referral services to children with developmental problems. One consultant post was recommended at the time when there was one assessment centre under the Department of Health, with the view of creating additional posts when functionally justifiable in light of workload, complexity and the number of centres. Today after 24 years, 6 centres are in place, with the 7th coming into service within the next 1-2 years, with one consultant developmental paediatrician posted to head the recommended work. The gross inadequacy of developmental paediatric specialist manpower leading the service is seen a key reason for the limited professional and service development witnessed over the years. Action should be taken to address this shortfall such that an adequate number of well trained consultants can lead the centres' services, participate in the full range of activities that should be within the jurisdiction of the service, and be responsible for establishing and maintaining effective network systems with their regional medical, educational, social and community services. These teams, with policy and administrative support from the government, would serve to deliver the range of specialist service which is consistent, coordinated and monitored, and which is accessible to the child and family as part of their community's local services, and of their daily lives.
- 11. The proposed Research Office, in cooperation with child neurology and development units, should maintain valid statistics and trends on neurological and developmental conditions in Hong Kong's children for the recognized and essential purposes of professional progress and service development.

The Hong Kong Society of Child Neurology and Developmental Paediatrics is dedicated to promoting the welfare of children under its specialty's purview, and is keen to offer its service and expertise to the Bureau for planning, developing and implementing polices required to meet the needs of children with neurological disorders and developmental disabilities.



Bimonthly Scientific Meeting, January 2001 "Insights from Annual Meeting of American Academy of Cerebral Palsy and Developmental Medicine (AACPDM) 2000"

Multidisciplinary Management of Spasticity in Cerebral Palsy in the Context of Evidence Based Medicine

Dr. Sophelia CHAN Central Kowloon Child Assessment Centre, Department of Health, Hong Kong

What is Evidence-based Medicine? In 1989, Dr. David Sachett has described the five levels of clinical evidence that is commonly quoted in literatures nowadays.

- Level I : Evidence from large randomized controlled trials (RCT) with low false positive (α) and low false negative (β) errors.
- Level II: Evidence from small-randomized trials with high false positive (α) and/or high false negative (β) errors.
- Level III: Evidence from well designed **non-randomized concurrent cohort comparative studies** (comparing subject who did and did not receive the intervention).
- Level **IV**: Evidence from **non-randomized historical cohort comparisons** (between current subjects who did receive the intervention and former who did not).
- Level V: Cases series without control.

Grade A evidence is supported by \geq one **level I** study. **Grade B evidence** is supported by \geq one **level II** study. **Grade C evidence** is supported by **level III**, **IV**, **or V** studies only.

So What are the Best Recommendations from the Clinical Evidence?

Best recommendations are made from:

- Ia: Evidence from meta-analysis of RCT
- Ib: Evidence from at least one **RCT**
- IIa: Evidence from at least one well designed controlled study without randomization
- IIb: Evidence from at least one other type of well designed experimental study

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- III: Evidence from well designed **non-experimental descriptive studies**, e.g. Case studies, comparative studies
- IV: Evidence from expert committee reports or opinions and /or experiences of respected authorities

What is "Evidence Based Practice"?

- Practice which has a theoretical body of knowledge
- Use the best available scientific evidence in clinical decision
- Standardized outcome measures to evaluate the care provided

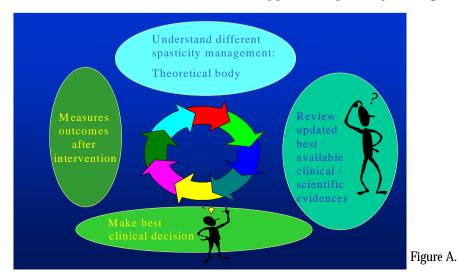
What are the Criteria for Standard Therapy?

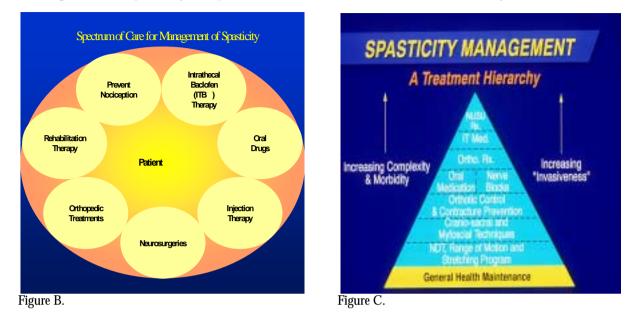
- The theories underlying the treatment are supported by valid anatomical and physiological evidence
- The treatment approach is designed for a specific patient population
- Potential side effects of the treatment are present
- The proponent of treatment approach is open and willing to discussion of its limitation
- Peer-reviewed studies are available

How about the Criteria for Studying Efficacy of a New Intervention?

- To have uniform type of patients
- Standardized well described intervention technique
- Objective and reliable outcome measures
- Inclusion of a control or placebo group
- Blinded outcome evaluation
- Comparison to existing treatment

What is Evidence Based Practice when Applied to Spasticity Management?





Management of Spasticity: A Spectrum of Care or A Treatment of Hierarchy?

One can consider the different treatment intervention as a matter of choice (Figure B), or we can think of it as a choice of hierarchy (Figure C), with the more specific, more complex and more invasive intervention modalities to be considered as the child grows older and presenting with a more stable and definite pattern of movement and gait abnormalities, and irreversible deformities.

Before we consider the different type of spasticity management, one must know the possible advantages as well as the undesirable consequences of spasticity.

What are the Possible Advantages of Spasticity?

The presence of spasticity in some children helps to maintain muscle tone and may assist in activities of daily living. Therefore by taking away the spasticity, some children may present with functional deterioration. Spasticity may also prevent formation of deep vein thrombosis and helps to support the circulatory function.

What are the Undesirable Consequences of Spasticity?

Spasticity interferes with range of joint motion, mobility and exercise. It can cause painful spasm, gait deviation and compromised daily care function. In the long run, it leads to contractures formation and joint osseous deformity.

The Basic Concept of "Spastic State"

- \downarrow ing spasticity $\neq \uparrow$ ing function
- \downarrow ing spasticity $\neq \uparrow$ ing strength
- \downarrow ing spasticity = \uparrow ing range of motion

In Order to Plan Rational Treatment for the Child, We Must Consider the Followings

We must set achievable goals. It can be just a physiological objective (e.g. range of motion), functional improvement, better daily care, or increase satisfaction of patients and family. At the same time, we have to balance the risk vs. benefit when choosing different treatment. If different interventions give similar effect, one can measure and compare the cost in order to help the decision.

With the intervention, we can usually guarantee to make a difference. But can we make the child and the family better?

What are the Usual Goals of Spasticity Management?

- Decrease spasticity
- Improve functional ability an independence
- Decrease pain associated with spasticity
- Prevent or decrease incidence of contractures
- Improve ambulation
- Facilitate hygiene
- Ease rehabilitation procedures
- Save care givers' time

How to Measure Spasticity?

One can use Ashworth and Modified Ashworth scales, spasm and reflex scales, passive quantitative tests and active tests of movement.

What are the Commonly Used Assessment Tools for Children?

- WeeFIM: Functional Independence Measure for Children
- GMFM: Gross Motor Function Measure
- PEDI: Pediatric Evaluation of Disability Inventory
- Child Health Questionnaire
- Pediatric Musculoskeletal Functional Health Questionnaire

Updated Evidence Presented during the 54th Annual Scientific Meeting of the AACPDM

Some of the updated studies presented during the 54th annual meeting were chosen for the presentation discussion, using the principles of "Evidence Based Medicine" during our appraisal. For detail results, please referred to the journal of "Developmental Medicine & Child Neurology", the AACPDM Abstracts 2000, supplement No. 83 August 2000 Vol 42.

- Use of tizanidine in a pediatric population (prospective case series)
- Intrathecal baclofen therapy for the treatment of spasticity in children with cerebral palsy (prospective case series)
- Intrathecal baclofen for the treatment of severe, generalized dystonia (retrospective case series)
- Selective dorsal rhizotomy: meta-analysis of three randomized clinical trial (level Ia evidence)
- An evaluation of the effects of orthopaedic surgery on patients with cerebral palsy 10 years postsurgery using gait analysis (prospective well designed study)
- Rotational deformities of the lower limb following selective posterior rhizotomy in children with spastic diplegia (prospective well designed controlled study without randomization)

"Insights from Annual Meeting of AACPDM 2000"

Critical Issues in the Use of Botulinum Toxin A in Children with Cerebral Palsy

Dr. Wilson Kwan Yee YEUNG Department of Pediatrics, Pamela Youde Nethersole Eastern Hospital, Hong Kong

In recent years, there is growing interest in the use of Botulinum toxin A (BoNT/A) in the management of spasticity in cerebral palsied children. Yet many questions concerning the use of BoNT/A remain unanswered. A panel of experts from Germany and Sweden has critically reviewed these controversial issues.

Critical Issue 1: Good Candidates vs Poor Candidates

- The key feature of the good candidate is the dynamic contracture
- Early treatment before 6 years of age is preferable as dynamic component of contracture decreases with age and children reach their ceiling on gross motor learning by 6 years of age. However the age should not be used as exclusion criteria
- BoNT/A injection is a focal treatment option for spasticity. No more than a few target muscles should be injected at each treatment session
- A clear treatment goal adapted to the cognitive capabilities and selective motor control of patients should be established before injection
- Common treatment goals include delaying or preventing fixed contracture/need for surgery; improved function, ease of nursing and pain relief
- The indications for lower limb treatment are usually dynamic equinus/knee flexion interfering with function or significant scissoring and adduction at the hips as well as crouched gait
- The indications for upper limb treatment are usually thumb-in-palm; persistent wrist/elbow flexion or forearm supination interfering with function

Critical Issue 2: Dose

- There is no consensus about optimal doses. The proven dosage range for Botox was <12 U/kg. Maximum dosage recommended per injection site was 50 U and maximum total dose per visit was 400 U. Higher dosages may be appropriate in the hands of an experienced user
- The dilution of the drug was recommended to be 1-2 ml
- In general 2 injection sites were sufficient for muscles in upper and lower limbs

- The effect of BoNT/A on muscle weakness generally wears off by 3 months but functional improvement may last longer
- Induction of antibodies has been shown to be related to higher doses and shorter interval of injections

Critical Issue 3: Injection Technique

- Injection by simple palpation of target muscles is sufficient for most situation
- Injection via EMG-guidance or USS-guidance may be considered for deep-sited muscles such as tibialis posterior, psoas and in very obese subjects

Critical Issue 4: Outcome Evaluation Measurement

- The use of BoNT/A as novel therapy for spasticity should be evaluated by outcome measurement at baseline and after treatment to gauge the magnitude and duration of response
- Instruments are available for measurement of local effect (EMG; goniometry; Ashworth scale; gait analysis) and functional gain (GMFM; GMPM; Physician rating scale, video; goal attaining scale; Pedi/WeeFim)
- It is recommended at least one measure of local effect and one measurement of functional benefit should be performed for evaluation

Critical Issue 5: Local Effect vs Functional Benefit

- Studies with outcome measurement showed that treatment with BoNT/A produced convincing local effect in most patients. Nevertheless, only about 30% of patients will improve on GMFM, which measures functional limitation
- Classification of patients according to GMFCS indicates that following treatment with BoNT/A, the largest functional gain would be achieved in moderately affected children

Critical Issue 6: Long-term Treatment

- Two to one rule for the short term treatment (<18 months): 2/3 of patients will continue treatment because they showed either subjective or objective improvement and 1/3 of patients will drop out as most of them underwent surgery for correction of fixed contracture
- Some patients may benefit for years of treatment

Critical Issue 7: Adverse Effects

- BoNT/A is a safe drug in the hand of the experienced physician
- Pain and local/general weakness are more common side effects
- Worsening of dysphagia in CP with potential aspiration pneumonia has to be kept in mind
- Anaphylactic reaction has not been reported

Critical Issue 8: Primary and Secondary Non-responders

- About 5-10% of all treated patients can be expected to become secondary non-responders due to development of neutralizing antibodies to BoNT/A
- Most of the other non-responsive patients could be accounted for by the development of fixed contracture or due to failed injection

Critical Issue 9: Combination of BoNT/A with Other Treatment Options

• There is lack of evidence of the efficacy of traditional therapy options such as physiotherapy, casting and orthosis as well as their combination with BoNT/A. Further studies are needed

Although randomized controlled trials have shown promising short term effects of BoNT/A in treating cerebral palsy and dystonia associated with cerebral palsy, further research is needed in the following areas: (i) role of multilevel treatment; (ii) optimal dose and site of injection as well as high dosage treatment; (iii) evidence-based combination therapy; (iv) benefit of very early treatment <1 year old; (v) further galenic development of BoNT to reduce secondary non-responders; (vi) use of BoNT as adjunctive perioperative treatment; (vii) Multi-centre studies based development of every treatment step; (viii) evaluation at the level of disability and societal limitations and (ix) the efficacy for treatment over years.

"Insights from Annual Meeting of AACPDM 2000"

Lower Limb Orthosis for Children with Spastic Diplegic Cerebral Palsy

Dr. Kate LEUNG Tuen Mun Child Assessment Centre, Hong Kong

For children with spastic Diplegic cerebral palsy, a pair of lower limb orthosis is almost always prescribed at some points of their development. This custom-made device is designed in such a way to provide a firm base of support, to prevent or correct deformity, to facilitate training and to improve the efficiency of gait.

The most frequently used lower limb orthosis include solid ankle foot orthosis (AFO) and articulated ankle foot orthosis. Solid AFO can be used in both ambulatory and non-ambulatory child. Its main functions are to prevent contracture of spastic plantarflexor muscle by stretching, to provide a base for foot and ankle stability when standing. In ambulatory child, it helps to control muscle imbalance and to facilitate heel contact for tiptoe walking.

In more mobile and older child, usually after three year old, articulated AFO may be a better choice. With a hinge in situ, it allows movement in both dorsiflexion and plantarflexion direction and hence more closely simulate normal ankle motion. It's particularly useful in child who walks with toe drag during swing phase of gait cycle and in whom active dorsiflexion control is possible (at lease 5°). It's not helpful in child with fixed contracture or significant weakness of plantarflexor muscle. With modern designs incorporating objective data from gait analysis, it is possible to fine-tune the hinge angle to improve quality and efficiency of walking. Having said that, articulated AFO also has some disadvantages. The mechanical ankle is bulky that makes shoe fitting more difficult and hence less able to control foot position. Obviously, it is more costly than a solid AFO.

Floor reaction AFO is specially designed with a pretibial portion that acts to drive the proximal tibia posteriorly, making the knee extend to its passive limits during midstance as the limb progresses over the planted foot. It is particularly helpful in child walking with crouch gait but not with fixed knee contracture.

In summary, orthotic management is one of the modalities of treatment for child with spastic diplegic cerebral palsy. An optimal orthosis not only prevents contracture and deformity, but also facilitates training. And this can only be accomplished by a multidisciplinary team with a well-shared treatment goal.

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"Insights from Annual Meeting of AACPDM 2000"

Diagnosis, Prevention and Treatment of Osteoporosis in Children and Adults with Cerebral Palsy

Dr. Philiomena TSE Department of Paediatrics, Caritas Medical Centre

Children with Cerebral Palsy, who are non-ambulatory, are frequently found to be osteopenic. Pathological fractures are not uncommon in these children (especially involving long bones e.g. supracondylar fracture of femur). This instructional course in the AACPDM Meeting gave an overview of current management strategies for the diagnosis, prevention and treatment of osteoporosis in children and adults with cerebral palsy with the aim to develop long-term treatment strategies to optimize care for patients with CP.

Main Types of Osteoporosis in Persons with CP

- 1. Nutritional Osteopenia Importance of optimization of nutritional intake especially Calcium and Vitamin D
- 2. Disuse Osteoporosis Weight bearing exercises are encouraged and avoidance of prolonged immobilization
- 3. Drug-induced osteoporosis In prolonged use of steroids, anticonvulsants and hormone therapies

Risk-stratified approach in screening for osteoporosis in persons with CP was recommended (see Figures 1 and 2).

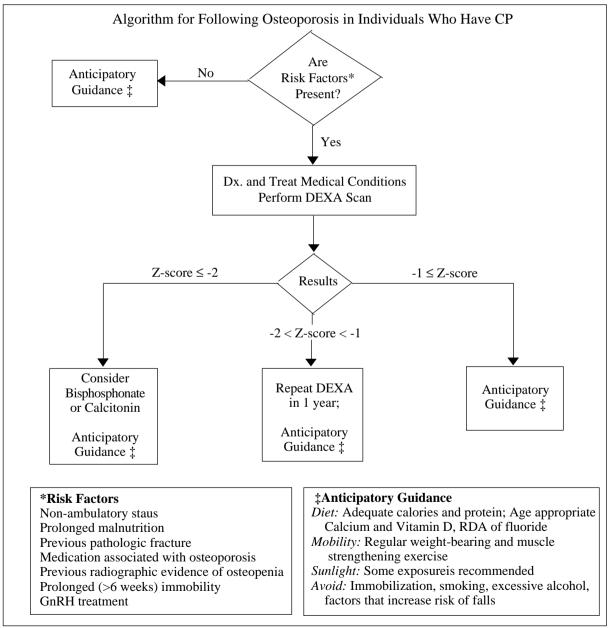
Nutritional assessment, serum and urinary and radiographic studies are useful in evaluation. Dual X-ray absorptiometry (DEXA) for bone mineral density expressed as age-normalized **z-score** is most useful in children.

Treatment

- 1. To optimize Ca and Vit. D intake
- 2. Vit. D 400-800 iu/day for institutionalized children
- 3. Calcitonin
- 4. Bisphosphonates

Meta-analysis of Effectiveness of Regimes

- Vit. D and Ca supplement together is better than no treatment or Ca supplementation alone (+3.2% BMD)
- Bisphosphonates (pyro-P analog which acts by binding to osteoclast resorbing surfaces) is better than Vit. D
- Calcitonin has similar effect as Vit. D
- Fluoride is better than Vit. D



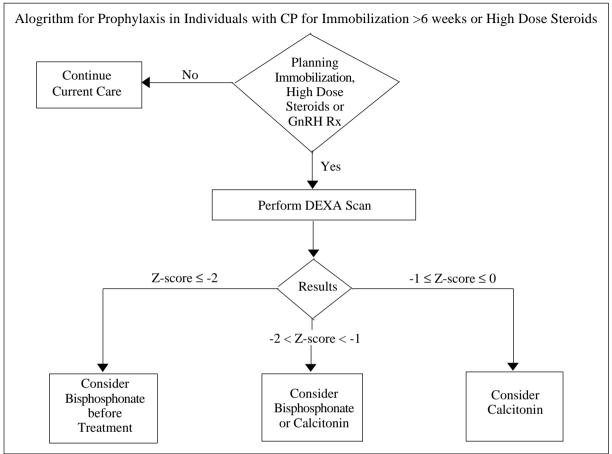


Figure 2.

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Case Management Study Group Archive: 15 Months Old Child with Relapsing Encephalitis

Dr. WL YEUNG Department of Paediatrics, Prince of Wales Hospital, Hong Kong

A 15 months old child with normal health and development presented with 4 days of fever and cough. She had a right-sided focal seizure of the body and limb. Cerebrospinal fluid collected then showed presence of erythrocytes at 9/mm³, no pleocytosis, protein content of 0.9 g/l and glucose 3.2 mmol/l. Magnetic resonance of the brain showed a small lesion over the grey-white junction at the left temporal region. She was diagnosed to have acute disseminated encephalomyelitis. Acyclovir (30 mg/kg/day), cefotaxime and vancomycin were given for ten days. She also received 20 grams of human gammaglobulins intravenous in two separate doses. At the same time phenobarbitone and carbamazepine were started to control the seizures.

She was discharge after staying at the hospital for 12 days. She was back to her normal self on discharge. However nine days later she was found to be less playful and started to be very drowsy and tired. Her gait also turned unsteady. She was therefore admitted again and treated with acyclovir, meropenem, metronidazole and erythromycin. Her condition failed to improve with treatment.

She was transferred to Prince of Wales Hospital three days later. MR brain at that juncture showed extensive left temporal lobe lesion. Brain biopsy and polymerase chain reaction on brain tissue showed evidence of herpes simplex infection. Despite treatment at a higher dose of acyclovir (45 mg/kg/day) she remained drowsy and exhibited a lot of involuntary movements. These movements were suppressed partially with nitrazepam, tetrabenazine and sodium valproate. MR brain showed extensive disease later and a resistant strain of herpes simplex virus was suspected.

Foscarnet was given in place of acyclovir later for 21 days. Dexamethasone was given for one week after completion of foscarnet treatment. Her progress of improvement however was very slow. There were still intermittent involuntary movements. She became more alert over one month and started to reclaim motor skills like rolling over, reaching out and grasping. She was kept on oral acyclovir 600 mg per day three months after the onset of relapse.

Discussion

The case demonstrated the possibility of antibiotics-resistant strain of herpes simplex virus infection human being and causing relapsing encephalitis. The American Academy of Paediatrics recommended treatment of herpes simplex encephalitis with 14-21 days of intravenous acyclovir at 30-45 mg/kg/day. The initial treatment was shorter than the recommendation. Resistant strains have been reported to be an increasing problem (Hirsch and Schooley 1989). Increase dosages for longer duration might be advisable.

Despite adequate treatment relapses of herpes simplex infection occur. The prognosis is unfavorable. The persistence of the virus is not necessarily the cause; immunological aberrations might be responsible for such relapses sometimes, and the brain will show extensive demyelination. Recurrent fever and ballistic or choreoathetoid movements are rather characteristic. The treatment for such condition is controversial. In some rare situation maintenance treatment with oral acyclovir might have to continue for over 6 months.

The Study Group agreed that the AAP recommendation should be strictly followed.

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Distribution of Seizure Precipitants among Epilepsy Syndromes

Frucht MM, Quigg M, Schwaner C, Fountain NB Epilepsia 2000;41(12); 1534-9

Is seizure avoidable? If we can learn more about precipitants of seizure, we might be able to reduce or avoid seizures. By definition, seizure precipitants are endogenous (e.g. stress, fatigue, infections, menstrual cycles and sleep) or exogenous factors (e.g. alcohol, caffeine, fasting, flashing light etc.) that promotes the occurrence of epileptic seizures.

This study from University of Virginia recruited 400 paediatric and adult subjects from a tertiary care epilepsy clinic. The mean age was 24.6 years. They were classified into 8 categories according to the classification of the ILAE: idiopathic partial epilepsy (IPE), idiopathic generalized epilepsy (IGE), symptomatic temporal lobe epilepsy (TLE), symptomatic extratemporal (XTLE), symptomatic generalized (SGE), cryptogenic partial (CPE), cryptogenic generalized (CGE) and the unclassifiable epilepsy.

Among all the subjects 62% noted at least one precipitant. Stress (30%); sleep deprivation (18%), sleep (14%), infection (14%) and fatigue (13%) were identified as the 5 major precipitants. Temporal lobe epilepsy is more frequently provoked by sleep. Menstrual cycle effects were ranked highly among women over 12 years old and mostly noted by women with TLE.

32% of subjects identified more than one precipitant. Significantly more female than male

identified at least one precipitant. There was no effect of age as one might think of menstrual cycle effect. Subjects with cryptogenic generalized epilepsy identified least precipitant while those with TLE and CPE had highest proportion of citing at least one precipitants.

Stress was the most commonly cited precipitant by TLE subjects (46%). These patients were significantly older with female preponderance compared to those not citing stress as a precipitant. Sleep deprivation, sleep and infection play an important role in precipitating IPE. Patients with partial epilepsy more frequently reported fatigue than those with generalized or unclassifiable epilepsy.

Considering that more than one third of subjects identified no precipitants, these precipitants are likely to be modulators of seizure occurrence instead of direct triggers. Stress management could be an important tool in patients with poor seizure control.

This study identified that the three major precipitants, namely stress, fatigue and sleep deprivation, clustered together in patients with symptomatic epilepsies. It might suggest that these precipitants work through a common mechanism of action. In order to achieve better seizure control, we may have to tackle more than one precipitant at the same time.

It was found that sleep tends to be an important precipitant in the younger patients with IPE. Sleep deprivation, on the other hand, was significantly affecting older patient with CGE. Only 4% of patients reported flashing light as a precipitant. But increasing exposure to video games and other photic stimuli suggests that photic trigger may become less avoidable and more significant.

The study provided insight into the pathophysiology of specific epileptic syndrome. These findings may facilitate epilepsy diagnosis by use of syndrometailored provoking procedures. Finally, this information may allow clinicians to give more specific counseling to patients in the avoidance of specific precipitants.

(Reviewed by Dr. YIM Tak Man, Department of Paediatrics, Queen Elizabeth Hospital)

Parents' Perceptions of Disclosure of the Diagnosis of Cerebral Palsy

Baird G, McConachie H, Scrutton D Arch Dis Child 2000;83:475-80

Breaking bad news is always a difficult task for medical personnel and telling parents that their child has cerebral palsy is an example. We, perhaps, think that if the mother does not come back complaining then we must be doing a good job. It is really article of this kind which let us know about the true feelings of parents and how inadequate our communication techniques are and let alone our counseling skills.

In this total population cohort study, all children with bilateral cerebral palsy born between January 1989 and December 1992 in the South East Thames region, London, UK were included. Eventually 107 children, average age 24 months, were identified and their parents interviewed with specific questions about the *disclosure*. In addition case notes were examined, and mothers completed questionnaires to measure current levels of depression and coping strategies. The result showed that 1/5 were dissatisfied or very dissatisfied with the structure or the manner of the *disclosure* and more than 40% were dissatisfied or very dissatisfied with the information given during the *disclosure*. The dissatisfaction was greater where children had been premature and/or low birth weight. More severe degrees of physical disability, and delayed diagnosis were thought to be the reasons. Dissatisfaction was related to greater degrees of later self reported depression of mother.

The best part of this article is their proposed guidelines for good practice in disclosing the diagnosis of cerebral palsy to parents. The guidelines take account of the findings, in particular the need for early close liaison between neonatology and community paediatric services.

Guidelines on disclosure of diagnosis

onsultant paediatrician
lember of the continuing care team
oth parents
ıfant present
rivate place, uninterrupted
rivacy for parents afterwards
irect, clear information
lanner - honest, warm, sympathetic
pportunity for further interview soon
etter summarising the discussion
formation re premature babies
nformation re cerebral palsy
nformation re local services
offer introduction to another parent
offer to talk to other family members

The guidelines may look familiar and simple but the most important is whether we are practicing it every time.

(Reviewed by Dr. Becky CHIU, Department of Paeeiatrics, Tseung Kwan O Hospital)



Welcome New Members

During the membership drive last year the Society is extremely pleased that the following colleagues have joined the family of HKCNDP:

Associate Members: Dr Chan Kwok Chiu Dr Tang May Ling

Affiliate Members: Chan S Chan Tsz Wai. Rae Cheung Pui Sze Fong Siu Lai, Sanne Fung Ka Yee Ho Kin Kwun, Lucie Huang Hai Yen Kwan Yee Man Lau Kai Tai, Joseph Lau Pui Heung, Beverlv Lee Soo Mei Liu Suk Wai, Linda Liu Kwok Ying, Sally Ng Lai Wa Ngan Chiu Foon Shong Yuk Ling, Susanna Tong Eva Wong Wing Yee Wong Tsan Wing, Selina Yip Lai Ming Yu On Nei, Annie

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Society Homepage on the World Wide Web

The Society Homepage can be accessed directly at **www.fmshk.com.hk/hkcndp**. Members are entitled to visit our restricted areas reserved for paid-up members. They would have received passwords in their latest edition of the Society Newsletter.

So join our Society for full access to our Society website.



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29th March, 2001 (Thursday)

Child Psychiatric Centre, 9/F Yau Ma Tei Polyclinic, Yau Ma Tei, 2 p.m. to 5 p.m. Behavioural Neurology Seminar I - Case presentations: Behavioural manifestations in Neurosurgical and neurological conditions in children.

11th May, 2001 (Friday)

M Block, Ground Floor, Lecture Room, Queen Elizabeth Hospital, 8 p.m. to 10 p.m. Bimonthly Scientific Meeting on Optic Neuritis

20-25th September, 2002, Beijing, China

The 9th International Child Neurology Congress. This will be the first international paediatric neurology congress held in Mainland China. A major theme of the Congress will be epilepsy. For further information please refer to the Congress website <u>www.ciccst.org.cn/icne2002</u>, or contact the Congress Secretary, Dr. Jiang Yu-Wu, Department of Paediatrics, First Hospital, Beijing Medical University, Beijing, 100034. E-mail: <u>icnc@public3.bta.net.cn</u>

Invitation of Journal Reviews

One of the visions of the Society is to broaden the horizons of continuing medical education. While you are reading interesting and important articles in various journals and periodicals, you might have some insights and thoughts that you would like to share with your fellow colleagues.

The Society invites members to submit their reviews on journal articles to the new official publication of the Society. Your contributions to the knowledge of other members would be most highly appreciated.

Please send your reviews to Dr. Wu Shun Ping by fax at 2384 5204 or by e-mail at hkcndp@hongkong.com

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The Brainchild has set a special space for fellow members to exchange ideas and express their views. Opinions and feedback regarding Society matters are most welcome. Please write to the editors at <u>hkcndp@hongkong.com</u> or by mail to the Society at The Federation of Medical Societies, 4/F Duke of Windsor Social Service Building, 15 Hennessy Road, Wanchai, Hong Kong.

We are looking forward to hearing from you!





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