Quality of Life in Children with Cerebral Palsy

Terrence Thomas
Paediatric Neurologist

Quality of Life in Children with Cerebral Palsy

• What is cerebral palsy?
• What impacts on QOL in kids with CP
• Rationaising goals for kids with CP

Understanding Cerebral Palsy

Problem with motor function
Tone, Movement and posture
due to injury to the developing brain

Motor Function:
Posture tone strength balance
Movement speed timing coordination

Scope of presentation

Motor Function:
Posture tone strength balance
Movement speed timing coordination

Understanding Cerebral Palsy

Throwing a ball
Understanding Cerebral Palsy

What problems does the child face?

Motor system
- gait, mobility
- sitting, standing
- hand function
- feeding difficulties
- squint
- scoliosis
- constipation

Associated problems
- learning difficulties
- speech, language delay
- epilepsy
- visual impairment
- hearing impairment
- behavioural disorder

Causes of Cerebral Palsy

Prenatal
- stroke
- brain malformations
- intrauterine infections
- chorioamnionitis
- intracranial bleed

Intrapartum
- prematurity
- asphyxia
- stroke
- meningitis
- intracranial bleed
- kernicterus

Postnatal
- anaemia
- meningitis
- non-accidental injury
- stroke

Caesarean section rate

Cerebral Palsy prevalence

Caused by: 90%

Caused by:
- 10%

Pooled data from Australia, Canada, Scotland, Denmark, England, United States, Norway, and Ireland


The CP Management Team

- community nurse
- family doctor
- rehabilitation physician
- paediatrician
- neurologist
- social worker
- educational psychologist
- NGO's
- special Ed teachers
- occupational therapist
- optometrist
- orthopaedic surgeon
- speech language pathologist

Living with Cerebral Palsy

CP child & Family

Parent (Mom or Dad)

School

Neighbourhood Community

Religious Community

FAMILY UNIT

CP child

Spouse (working)

Sister

Brother

Sister
Living with Cerebral Palsy

- Mobility
- Basic self care
- Communication
- School
- Fitting-in

CP child

Quality of Life

Living with Cerebral Palsy

- Parent (Mom or Dad)
- Perceived progress
- Goals setting
- Burden of care
- Concerns about future

CP child

Quality of Life

Living with Cerebral Palsy

- Parent (Mom or Dad)
- Meeting spouse’s needs
- Meeting children’s needs

CP child

Spouse (working)

Family Unit

Living with Cerebral Palsy

- Parent (Mom or Dad)
- CP child

Spouse (working)

Disability and QOL

- Body function & structure
- Impairment

Parent (Mom or Dad)

FAMILY UNIT
Disability and QOL

Body function & structure
Impairment
Activities
Limitation
Participation
Restriction

Environment
Family
Social set-up

Personality

Measuring Quality of Life

CP QOL-Child
CP Quality of Life Questionnaire for children

• Social well-being and acceptance
• Feelings about functioning
• Participation and physical health
• Emotional wellbeing
• Access to services
• Pain and feelings about disability
• Family health

Rationalising QOL Goals

The Kids Who Can
GMFCS I-III

The Kids Who Need a lot of care
GMFCS IV-V
Severe cognitive impairment
Bed bound
Tube feeding
Visual impairment
Rationalising QOL Goals

The Kids Who Can

GMFCS I-III
+/- some learning issues
visuo-motor issues
manual dexterity
epilepsy

mobility
basic self care
communication
school fitting-in

Motor ability and QOL

<table>
<thead>
<tr>
<th>CP QOL-Child</th>
<th>GMFCS I</th>
<th>GMFCS II</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social well-being, acceptance</td>
<td>71</td>
<td>67</td>
<td>0.25</td>
</tr>
<tr>
<td>Feelings about functioning</td>
<td>65</td>
<td>66</td>
<td>0.77</td>
</tr>
<tr>
<td>Participation &amp; physical health</td>
<td>67</td>
<td>61</td>
<td>0.16</td>
</tr>
<tr>
<td>Emotional wellbeing</td>
<td>69</td>
<td>66</td>
<td>0.54</td>
</tr>
<tr>
<td>Access to services</td>
<td>28</td>
<td>43</td>
<td>0.02</td>
</tr>
<tr>
<td>Pain, feelings about disability</td>
<td>62</td>
<td>50</td>
<td>0.01</td>
</tr>
<tr>
<td>Family health</td>
<td>63</td>
<td>51</td>
<td>0.02</td>
</tr>
</tbody>
</table>

Che CM Am J Phys Med Rehabil 2011

rehabilitation

Important

- physiotherapy
- occupational therapy
- techniques:
  Bobath's neurodevelopmental therapy
  Peto's conductive education
  sensory integration therapy

rehabilitation

Important

- Aids and adaptations

rehabilitation

Important

- speech therapy
- behavioural therapy
- medical treatments
  muscle relaxants - baclofen
  seizure medications

rehabilitation

Sometimes used

- medical treatments
  botulinum toxin
- surgical treatments
  orthopedic surgery - contracture release, hip surgery
  neuro surgery - dorsal rhizotomy
- complimentary therapies
  pool time
  hippotherapy
  acupuncture
  music therapy
**Rationalising QOL Goals**

**Child**
- The Kids Who Need a lot of care
- GMFCS IV-IV
- Severe cognitive impairment
- Bed bound
- Tube feeding
- Visual impairment

**Caregiver**
- Facilitate & ease care
- Anticipate complications
- Respite
- Time for spouse, other kids
- Mental health
- Social integration

---

**Goals of rehabilitation**

- Severely impaired children - improve Quality of Life for family
- Feeding - method, time to feed
- Mobility
- Manage seizures
- Prevent complications that impact on long term care:
  - Respiration
  - Dislocation, scoliosis

---

**Life expectancy in Cerebral Palsy**

- Hutton, Arch Dis Child 2006
Severe cerebral palsy

Quadriplegic cerebral palsy

**Alternative Therapies**

- Parent (Mom or Dad)
- Spouse (working)
- CP child

**FAMILY UNIT**

- Brother
- Sister

- *Medical treatments*
  - health supplements: Palsotab, Ceretitin, Nootropil
  - stem cell therapy
- *Rehabilitation techniques*
  - Glenn Doman (Institute for Achievement of Human Potential)
- Complimentary therapies
  - EEG neurofeedback
  - biofeedback
  - magnetic therapy
  - chiropractic manipulation
  - electrical stimulation
  - craniosacral therapy
  - special diets
  - hyperbaric oxygen

**SingHealth**

- Spouse (working)

**Alternative Therapies**

- Parent (Mom or Dad)
- Spouse (working)
- CP child

**FAMILY UNIT**

- Brother
- Sister

- *Medical treatments*
  - health supplements: Palsotab, Ceretitin, Nootropil
  - stem cell therapy
- *Rehabilitation techniques*
  - Glenn Doman (Institute for Achievement of Human Potential)
- Complimentary therapies
  - EEG neurofeedback
  - biofeedback
  - magnetic therapy
  - chiropractic manipulation
  - electrical stimulation
  - craniosacral therapy
  - special diets
  - hyperbaric oxygen
Practical Issues We Face

• CP management teams
• Resources for aids and adaptations
• School
• Respite care

Growing up with CP
• What happens after school is over?
• Transition to Adult care

Thank You