The Impact of Chronic Illness on Education & the School Environment

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Outline

• The educational impact of chronic illness in childhood – medical aspects
  – How common is chronic disease in childhood
  – The importance of teachers
    • Diagnosis/ management.
  – Chronic illnesses with physical and cognitive impacts.
• The educational impact of chronic illness in childhood
  – Related to the chronic illness
  – Medication and/or treatment side-effects
  – Absenteeism
  – Indirect implications
  – School re-entry
Chronic illness

- Chronic illness is
  “a condition which last for a considerable period of time or has sequelae which persists for a substantial period and/or persists for more than 3 months in a year or necessitates a period of continuous hospitalisations for more than a month”.

Thompson & Gustafson, 1996, p4
The prevalence of disability in school age children

  - 1 in 12 children had a disability.
  - 317,900 children Australia wide.
- 97% of these children attend school
  - 89% in ordinary schools
  - 8% in special schools.
- 63% of these children experience difficulty at school
  - Learning problems, fitting in socially, communication problems.

The importance of teachers – diagnosis

- **6 year old boy**
  - Only child.

- **Referred because his teacher noted**
  - Multiple episodes during the day of unresponsiveness.
  - Episodes are brief, often associated with blinking.
  - Episodes are unable to be interrupted.

- **Poor concentration.**

- **Parents have noted these and think these are “behavioural”**.
The importance of teachers – diagnosis

- Six year old girl
- Referred because there was a concern she had epilepsy.
- Four episodes of collapse.
  - Followed by stiffening.
The importance of teachers – diagnosis

• History from teacher (telephone).
  – Episodes occur from standing.
  – Mostly on hot days.
  – Pale before all episodes and dizzy.
  – Collapses to the ground.
  – Goes stiff for 10 seconds.

• Diagnosis
  – Fainting/ syncope.
  – Poor blood supply to the brain.
Causes of sudden collapse with recovery

- **Causes**
  - Epileptic.
  - Fainting (syncope).
    - Poor blood supply to the brain.
- **Most common is fainting.**
  - Characteristic description.
The role of teachers – diagnosis

• Teachers are in a unique position.
• Knowledge of normal childhood development.
  – First time parents may not know what is normal in childhood.
  – May have much more intense 1 to 1 involvement with children.
• Objective witness to episodic events.
  – Collapses/ seizures.
  – May support parent’s opinions of events.
• Monitoring the progress of a disease.
The role of teachers – communication

• **Communication with parents**
  – Often very challenging pointing out a child has a medical problem.
  – Parents sometimes may run an issue past you eg have you noticed?

• **Communication with clinicians**
  – Timing often a challenge.
  – Sometimes frustrating
    • Limitations in what clinicians can tell you.
Neuromuscular disease and education

- 5 year old boy
- Never great at running.
  - Parents feel that he is lazy.
  - Not terribly worried.
- Teacher has noticed that he falls over often
  - Has difficulty getting up.
  - Concerned that he is weak.
  - Very different from his peers.
Neuromuscular disease

• Examination:
  – Walked on tip toes.
  – Weak in hips and shoulders.
• Marked enlargement of calf muscles.
• Duchenne Muscular Dystrophy
  – Progressive muscle weakness.
  – Absence of a muscle membrane protein - dystrophin.
  – Loss of walking, profound weakness, respiratory failure.
Impacts of neuromuscular disease

• Progressive versus non-progressive disease.
  – Chronic disease weakness doesn’t worsen eg myopathy.
  – Progressive disease eg muscular dystrophy.
• Limitations in participation.
  – May need wheelchair for some activities.
• Communication and writing.
• Access to school and activities.
• Fatigue/ cognitive impairment (eg DMD).
Impact of brain diseases on education

- Static disease
- Episodic disease
- Progressive disease
Static brain disease
Developmental Trajectory

Children continue to develop but the degree of discrepancy increases with age.
Static brain disease – prematurity

Peri-ventricular leukomalacia
- Damage to white matter surrounding the lateral ventricles.
- eg cerebral palsy.
- Not associated with ongoing brain damage.
Progressive brain disease

Developmental Trajectory

Childhood dementia: eg chemical and metabolic disease.
Epilepsy – fluctuating brain disease

Developmental Trajectory

Chronological Age

DQ

0 1 2 3 4 5 6 7 8 9 10

Epilepsy onset

Normal
Episodic

[The diagram shows the developmental trajectory of epilepsy onset in children, comparing normal and episodic cases. The y-axis represents DQ (Developmental Quotient) and the x-axis represents chronological age. The bars indicate the number of cases for each age group, with a clear peak for episodic cases at around chronological age 5.]
Epilepsy

- **Epilepsy**
  - Recurrent epileptic seizures (>2).

- **Epileptic seizures**
  - Sudden.
  - Temporary alteration in brain function.
  - Changed mental state, tonic or clonic movements and various other symptoms.
  - Due to temporary abnormal electrical activity of a group of brain cells.

- **EEG**
  - A recording of brain activity.
  - May show “epileptic discharges” ≠ epilepsy.
How to recognise epilepsy

- **Sudden event.**
- **Stereotyped**
  - All events are similar.
  - Characteristic posture.
- **Not provoked/ can’t be stopped.**
- **Consciousness usually impaired.**
  - Simple stimulation can’t interrupt the event.
  - No recall of events during the episode.
- **Characteristic quality of movement**
  - Jerking, stiffening, automatic movement.
The cognitive impacts of epilepsy

1. Seizures can directly effect cognition.
   Unable to learn during absence seizures.
2. The effects of electrical discharges not associated with seizures.
   Electrical status epilepticus of sleep.
3. The effects of underlying brain disease.
4. Treatment of seizures.
   Medication
Epilepsy due to brain damage
Epilepsy and IQ

Discharges but no seizures

AWAKE

AWAKE
Educational Implications

1. Related to the chronic illness
2. Medication and/or treatment side-effects
3. Absenteeism
4. Indirect implications
Associated with the condition

Physical
- Severity of symptoms
- Body parts affected and functional impact eg. mobility
- Degree of visibility and impairment upon appearance
- Presence of pain
- Fine and gross motor skills
Associated with the condition

Cognitive
• Impaired intellectual functioning
• Learning disabilities
• Poor concentration
• Difficulties sustaining attention
• Organisational and planning problems
• Poor working memory
# Diabetes

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Impact</th>
<th>Strategies</th>
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</thead>
<tbody>
<tr>
<td>Hypoglycaemia (low blood sugar)</td>
<td>• Attention</td>
<td>• Work in short blocks</td>
</tr>
<tr>
<td>• Weak</td>
<td>• Executive functioning</td>
<td>• Have student sit at the front of the classroom</td>
</tr>
<tr>
<td>• Nervous</td>
<td>• Processing speed</td>
<td>• Provide clear and concise instructions</td>
</tr>
<tr>
<td>• Sweaty</td>
<td>• Memory</td>
<td>• Keep tasks short and interesting</td>
</tr>
<tr>
<td>• Mood changes</td>
<td>• Visuospatial processing</td>
<td>• Break downs large tasks into smaller tasks</td>
</tr>
<tr>
<td>• Sleepiness</td>
<td>• Especially if onset before 5yrs</td>
<td>• Teach the student to organise information into smaller units</td>
</tr>
<tr>
<td>• Poor attention</td>
<td>• Poorer academic achievement, boys at higher risk</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Can pass out</td>
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## Diabetes

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<tr>
<td>Hypoglycaemia seizures</td>
<td>• Poorer/decline verbal abilities</td>
<td>• Have the student repeat information</td>
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<tr>
<td></td>
<td></td>
<td>• Provide written handouts of material</td>
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<td></td>
<td></td>
<td>• Observe changes in mood/behaviour</td>
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<td></td>
<td></td>
<td>• Management of food eg. meals, snacks and activities</td>
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<tr>
<td></td>
<td></td>
<td>• Regular monitoring of blood glucose levels</td>
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<td></td>
<td></td>
<td>• Provide visual information and concrete material</td>
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<tr>
<td>Hyperglycaemia (high blood sugar) • Confused • Drowsy • Sleepy • Thirsty</td>
<td>• Blurred vision • No significant impact on cognitive abilities • Can lead to diabetic coma</td>
<td>• Accommodate student’s requests for water or more trips to the bathroom; may signal hyperglycaemia</td>
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# Asthma

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<tbody>
<tr>
<td>• Wheezing</td>
<td>• Inhalers: Sore throat, headache, sinus inflammation</td>
<td>• Continual monitoring</td>
</tr>
<tr>
<td>• Coughing</td>
<td>• Coughing, nausea</td>
<td>• Observe changes in mood and behaviour</td>
</tr>
<tr>
<td>• Fatigue</td>
<td>Moderate – severe asthma: Inhaled/oral corticosteroids</td>
<td>• Recommend referral to doctor if side-effects observed</td>
</tr>
<tr>
<td>• Chest tightness</td>
<td>Side-effects (most oral):</td>
<td>• Use visual and concrete aids</td>
</tr>
<tr>
<td>• Triggers:</td>
<td>• aggressive behaviour</td>
<td>• Supplement verbal material with written material</td>
</tr>
<tr>
<td>vigorous running;</td>
<td>• psychiatric - mania, depression, mood changes, anxiety</td>
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<tr>
<td>environmental -</td>
<td>• poor verbal memory</td>
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<tr>
<td>inhaling mold, dust,</td>
<td>• weight gain</td>
<td></td>
</tr>
<tr>
<td>chemicals</td>
<td>• limited sporting activities</td>
<td></td>
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<tr>
<td></td>
<td>• loss of sleep</td>
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Indirect implications

• Increased risk for behavioural and emotional problems (1.5 to 3 times higher)
• Decline in cognitive abilities
• Poorer academic performance
• Peer relations
• Bullying
• Teasing
• Fatigue
Absenteeism

• Increased absenteeism – hospitalisations, medical app’tments, overprotective parents, poverty, low levels of parental education
• Severity of illness and number of days absent is not associated with poor academic performance but pattern of absenteeism
• Pattern - absent from school for unusually long period of time (i.e. missing 6 or more consecutive days or 5 days or more in a school term)
• Catching up – 45% of children with chronic illness report falling behind
• Higher incidence of school refusal
Keeping the student connected

• Providing access to the curriculum eg. mail, internet, email, faxes
• With peers - communication book, sending cards, photos, telephone call, hospital and home visits
• Utilise internet eg. webcam from the classroom, from friends
School re-entry

- Returning to school is more difficult – after diagnosis or significant time away
- Importance of school – ‘sense of normalcy’
- Returning to school – student is better, hope for the future, sense of control
- Student reluctant to return due to changes in physical appearance, how to answer questions from their peers, fear of being teased and may feel hopeless about their situation.
Barriers to school re-entry

- Lack of communication
- Lack of information and training
- Unsupportive school system policies
- Lack of resources – funding and time
Recommendations

- Informed about the diagnosis
- Information about the specific illness
- In-service training
- Informed about current treatments
- Medical management plan
- Student's access to school facilities
- Individualised Education Plan (IEP)
- Modifications
Re-entry

- School counsellors
- Gradual re-entry – attendance part-time
- Sensitive to cultural and religious differences
- Communication
- Stage of illness – stress of student and families
- Buddy program
- Special provisions, accident/misadventure and funding for disability
- Disclosure of illness
Disclosure

• Disclosure of the illness to close friends can have a positive influence
• Findings re: disclosure to classmates inconclusive can have negative impacts eg. different
• Providing classmates with medical information resulted in less acceptance and negative attitudes – irrespective of whether condition is visible
• Treatment not followed – seen as different eg. cystic fibrosis, diabetes not following diet and blood testing.
Disclosure

• Peers affect children’s future health by influencing health risk behaviours such as smoking and alcohol eg. cystic fibrosis, asthma and smoking
• Important to discuss with the child and the parents exactly what they would like others to know
• Preparing the student
School reintegration program

- Identification of a school-based or medical team to coordinate services
- Providing direct services to the student
- Consultation with the family
- Education of school personnel
- Providing information to classmates and
- Involvement of the medical team
Current study

Effects of chronic illness on the education on primary aged students

Faculty of Education and Social Work, University of Sydney is currently conducting a study investigating the impact of chronic illness upon literacy, numeracy, general academic progress and coping in primary school-aged children, as well as their families.

If you are involved in a support group for children with chronic illness or their families or would like further information about the study, please contact Mary Cassar Ph: 041 246 7073 or email mcassar@ozemail.com.au