Emotional, behavioural & psychological impact of stroke in childhood

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A parent focus group highlighted the following:

- the diagnosis was ‘traumatic’ and families were in shock
- families needed help to adjust
- families would welcome support from others families
- parents reported significant emotional problems in their child
- lack of information for families
- difficulties accessing therapy
Stroke Association: parent support day (March 2014)

An education workshop and social activity highlighted:

- a lack of information from medical professionals for schools
- need for help in coordinating information
- the impact of their child’s stroke on the whole family
- the value of friendship groups for their child
- concerns about bullying and acceptance
- specific psychological issues such as phobias
- Schools not recognising ‘hidden’ learning and behavioural difficulties following stroke
Factors impacting on outcome after stroke

- recovery
- type of stroke
- lesion size or volume

- mental health
- structure
- cohesion
- acceptance

- environment
- family
- child
- brain

- school
- hospital
- therapy
- social inclusion

- age
- adjustment
- resilience
Areas of functional outcome

- Motor
- Cognitive
- Social/emotional
- Behaviour
Behavioural and emotional outcome

- children often have difficulties with emotional and behavioural regulation (O’Keefe et al 2014)
- with ischaemic stroke, children may have significantly lower quality of life across most areas (O’Keefe et al 2012)
- may be associated with cognitive deficits (executive)
- may be a function of having a chronic illness
- 1/3rd parents reported a change in their child’s behaviour following their stroke (Ganesan et al 2000)
- 44% of parents reported behavioural problems at home (Steinlin, M et al 2004)
Anderson et al (2014) looked at the influence of family functioning as well as ‘brain insult’ on social competence after paediatric stroke. Key findings were:

- Social competence did not differ according to age of onset.
- Lesion location/ volume did not have any significant effect.
- Parents of children with stroke reported more social problems than in other chronic conditions.
- Family function was the sole contributor to social adjustment.
- Younger age of onset was linked to better self esteem and social interaction in the child.
- As well as the brain insult, the home environment influences social outcome.
Factors affecting behaviour after stroke

- Ability to cope with stress
- Adjustment to chronic condition
- Family cohesion
- Developmental appraisal
- Disease characteristics
- Treatment characteristics
- Cognitive deficits
- Behaviour management
An emotional journey

initial worry, fear and uncertainty

anger: after diagnosis

grief: what has been lost

anxiety: about the future

depression: being different, limitations, things will not be the same again

acceptance: new roles, new ‘me’
In the balance.....

**Risk factors**
- disability
- functional independence
- cognitive appraisal
- social isolation
- non-acceptance

**Resilience**
- personality
- optimism
- coping skills
- sense of mastery
- social inclusion
- acceptance
Interventions

- ‘on-line’ interventions have been successful for families with acquired brain injury more generally and include:
  - Cognitive behavioural family intervention (Wade, S et al 2006)
  - ‘SIGNPOSTS’ phone or face to face sessions (Anderson, V et al 2013)
- Positive Behaviour Supports (Ylvisaker, M et al 2005)
- Applied Behavioural Analysis
- Individual/ family therapies
Function of behaviour

- to express emotions such as fear or anxiety
- to communicate inner state
- a response to changes in the environment/people
- to obtain social contact/ comfort
- to distract or stimulate
- to obtain a favourable outcome
- to avoid an unfavourable outcome
### Managing challenging behaviour

<table>
<thead>
<tr>
<th>A (Antecedent)</th>
<th>B (behaviour)</th>
<th>C (consequence)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interrupting repetitive behaviour</td>
<td>child bites</td>
<td>carer shouts</td>
</tr>
<tr>
<td>Carer gives medication</td>
<td>child bites</td>
<td>carer withdraws</td>
</tr>
<tr>
<td>Child wants a sweet and carer refuses</td>
<td>child bites</td>
<td>carer gives a sweet</td>
</tr>
</tbody>
</table>
Some tips

- try to keep environment as calm and familiar as possible
- have a discussion about which behaviour is the most difficult to manage and which to address first
- be aware of early signs of arousal and distract/relaxation
- try not to ‘second guess’ what is underlying behaviour and be aware of triggers
More tips

- try to introduce a positive outcome in seemingly negative or painful situations

- appear confident in putting down boundaries even when you are feeling anxious or distressed yourself

- lots of reassurance and comfort when your child is distressed- and for yourself.....


