Care planning in paediatric acquired brain injury (ABI) complicated by high medical support needs and severe aggressive behaviour: a case study

Brent Hayward RN CMHN
Practice Advisor – Disability
Office of Professional Practice
Department of Human Services
Introduction

• 338,700 Australians (1.9% of population, 1 in 50; Kerr et al., 2011)

• 4,000 children admitted to Australian hospitals every year (Jordan & Linden, 2013)

• 140 people with severe ABI living in SSA in Victoria (Winkler et al., 2010)

• Inaccurate expectations of recovery in childhood ABI (Forsyth, 2010)

• Significant variation in ABI outcome

What children with ABI report themselves (Roscigno et al., 2011)

• Like waking up in a bad dream
• Going home did not get me back to my old life
• Everything is such hard work
• Never being like the person you were before
• Many people do not get it

The needs of mothers and families (Braine, 2011; Jordan & Linden, 2013; Roscigno & Swanson, 2011; Roscigno et al., 2011; Turner et al., 2011)

• Anxiety, guilt, loneliness, grief
• Balancing the service and support equation
• Negotiating the rehabilitation maze
• Working against ‘the system’
• Grateful to still have my child
• Concerns for the future
• Family functioning
• Family coping
Background

• 14 year old boy
• Lives at home with mother, sister and step-father in outer metro area
• Encephalitis aged 10 years with resultant acquired brain injury (ABI)
• Long-term hospitalisation
• Pre- and post-cognitive testing: low average (FSIQ 80-89) to moderate intellectual disability (FSIQ 35-40 to 50-55)
• Bilateral vision impairment
• Frequent tonic clonic seizures with respiratory dysfunction (ventilation intervention)
• Impaired thermoregulation
• Hyperphagia with resultant obesity
• Frequent and severe physically aggressive behaviour towards others and property damage
• Inconsistent and unreliable in-home support services
• High family stress, increasing ED presentations due to behaviour, eventual admission to RCH medical ward
• Recommended that he not return home due to high support needs exceeding family capacity
Figure 1. Neurodevelopmental model of sequelae of pediatric acquired brain injury.

From: Dise-Lewis, Lewis & Reichardt (2009)
Factors associated with outcome in paediatric ABI

- Little known about outcomes in children with infectious causes of ABI (Johnson et al., 2009)
- Hematogenous viral infection most common - HSV, mumps, varicella, arbovirus (Parmer & Ibrahim, 2012)
- Premorbid cognitive ability, family function and access to rehabilitation (Anderson et al., 2012)
- Those with seizures have increased risk of mortality and cognitive impairment. Late unprovoked seizures increased x16 in viral encephalitis (Misra et al., 2008)
- Optic nerve involvement predicts poor outcome, later disability and risk of relapse (Mikaeloff et al., 2007; Tenembaum et al., 2002)
- Adolescence requires specific attention in ABI, especially in relation to behaviour (Ylvisaker et al., 2003)
- Disinhibition, apathy, inattention, behavioural immaturity, irritability, increased anger and aggression, impulsivity, social awkwardness and depression most common (Noggle & Pierson, 2010)
Assessment of support needs

Paediatric Quality of Life Inventory (PedsQL 4.0)

<table>
<thead>
<tr>
<th>Scale</th>
<th>Self Rating</th>
<th>Mother’s Rating</th>
<th>Published Norms (Upton et al., 2005)</th>
<th>Comparison Study (Limond, Dorris &amp; McMillan, 2009)</th>
<th>Comparison Study (Erickson et al., 2010)</th>
<th>Comparison Study (McCathy et al., 2005)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Functioning</td>
<td>200</td>
<td>50</td>
<td>89.1</td>
<td>82.8</td>
<td>66.5</td>
<td>65.3</td>
</tr>
<tr>
<td>Emotional Functioning</td>
<td>200</td>
<td>50</td>
<td>78.3</td>
<td>68.7</td>
<td>59.8</td>
<td>69.9</td>
</tr>
<tr>
<td>Social Functioning</td>
<td>200</td>
<td>100</td>
<td>86.8</td>
<td>81.0</td>
<td>63.5</td>
<td>75.5</td>
</tr>
<tr>
<td>School Functioning</td>
<td>200</td>
<td>75</td>
<td>81.5</td>
<td>66.8</td>
<td>47.0</td>
<td>59.1</td>
</tr>
</tbody>
</table>

Strengths & Difficulties Questionnaire (SDQ; Goodman, 1997)

<table>
<thead>
<tr>
<th>Scale</th>
<th>Self Score</th>
<th>Published Norms (Mellor, 2005)</th>
<th>Comparison Study (Limond, Dorris &amp; McMillan, 2009)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional Problems</td>
<td>7</td>
<td>1.5</td>
<td>3.3</td>
</tr>
<tr>
<td>Conduct Problems</td>
<td>7</td>
<td>1.7</td>
<td>2.3</td>
</tr>
<tr>
<td>Hyperactivity</td>
<td>8</td>
<td>3.5</td>
<td>4.8</td>
</tr>
<tr>
<td>Peer Problems</td>
<td>7</td>
<td>1.8</td>
<td>2.0</td>
</tr>
<tr>
<td>Total Difficulties Score</td>
<td>29</td>
<td>8.5</td>
<td>12.1</td>
</tr>
</tbody>
</table>
### Assessment of support needs

#### Family Needs Questionnaire (FNQ; Kreutzer & Marwitz, 1989)

<table>
<thead>
<tr>
<th>Scale</th>
<th>Met (%)</th>
<th>Partially Met (%)</th>
<th>Not Met (%)</th>
<th>Mean % Not Met in Comparative Study (Kolakowsky-Hayner et al., 2001)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Support Network</td>
<td>0</td>
<td>20</td>
<td>80</td>
<td>27</td>
</tr>
<tr>
<td>Emotional Support</td>
<td>0</td>
<td>13</td>
<td>87</td>
<td>28</td>
</tr>
<tr>
<td>Health Information</td>
<td>20</td>
<td>50</td>
<td>30</td>
<td>18</td>
</tr>
<tr>
<td>Instrumental Support</td>
<td>0</td>
<td>0</td>
<td>100</td>
<td>32</td>
</tr>
<tr>
<td>Involvement with Care</td>
<td>0</td>
<td>67</td>
<td>33</td>
<td>24</td>
</tr>
<tr>
<td>Professional Support</td>
<td>20</td>
<td>40</td>
<td>40</td>
<td>28</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td><strong>8</strong></td>
<td><strong>30</strong></td>
<td><strong>62</strong></td>
<td><strong>-</strong></td>
</tr>
</tbody>
</table>

#### Mayo-Portland Adaptability Inventory – 4 (MPAI-4; Malek & Lezak, 2008)

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Raw Score</th>
<th>T-score</th>
<th>Limitation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ability</td>
<td>28</td>
<td>59</td>
<td>Moderate</td>
</tr>
<tr>
<td>Adjustment</td>
<td>41</td>
<td>75</td>
<td>Severe</td>
</tr>
<tr>
<td>Participation</td>
<td>30</td>
<td>74</td>
<td>Severe</td>
</tr>
<tr>
<td><strong>Total Score</strong></td>
<td><strong>87</strong></td>
<td><strong>69</strong></td>
<td><strong>Severe</strong></td>
</tr>
</tbody>
</table>
Assessment of support needs

**Functional Independence Measure (FIM; Granger et al., 1996)**

R = 18-126  
Score = 66

**Patient Competency Rating Scale – Relative’s Form (PCRS; Prigatoano et al., 1986)**

R = 30-150  
Score = 58

**Care & Needs Scale (Tate, 2004)**  
*PCANS (Soo et al., 2010)*

- Constant supervision
- Assistance with basic ADLs

**Cross-sectional Mental State Assessment**

- Appearing older than chronological age
- Not reacting to spectacles falling from his nose
- Exotropia deviation of the right eye
- Bradykinesia and hypokinesia
- Required prompting to greet me, poor strength of handshake
- Warm and friendly
- Able to hold a pen and follow verbal instructions
- Easily distracted by environmental events
- Ego-centric themes, perseveration
- Variable attention
- Easily and visibly fatigued
- Could read text slowly while using phonetics
- Poor generalisability
- Some cognitive strengths evident
Identified support needs

- Accommodation
- Clinical guidelines for ABI rehabilitation
- Family support using developmental and family systems perspective (Byard et al., 2011)
- *Functional model* (Galvin & Mandalis, 2009)
- Applied Behaviour Analysis (ABA; Rispoli et al., 2010; Semrud-Clikeman, 2010)
- Positive Behaviour Support (PBS; Feeney, 2010; Semrud-Clikeman, 2010)
- Feeney’s (2010a) *Ten Principles* governing delivery of services and supports for individuals with brain injury and challenging behaviours
- Established family intervention guidelines for child ABI (Cole et al., 2009)
Reflection on assessment

- Development of new tools
- Use of informants
- Objectivity of assessment using rating scales
- 4 of 7 tools used subsequently recommended (McCauley et al., 2012)

Psychiatric clinicians should use rating scales and questionnaires often, for they not only facilitate targeted diagnoses and treatment; they also facilitate links to empirical literature and systematize the entire process of management (Baer & Blais, 2010)

- Use of standardised assessments in this case
- Nursing observation tends to be ad hoc and unstructured (Theodoridou et al., 2009)
- Standardised assessment by nurses: focus on behaviour rather than psychopathology (Downing & Brockington, 1978; Hall, 1977; McGorry et al., 1988). Development of new instruments perpetuates a focus on behaviour (Bowers et al., 2011)
References


References


References


Turner et al. (2010). Perceived service and support needs during transition from hospital to home following acquired brain injury, Disability and Rehabilitation, 33(10): 818-829.

Upton et al. (2005). Measurement properties of the UK-English version of the Pediatric Quality of Life Inventory generic core scales, Health and Quality of Life Outcomes, 3: 22.
