Are boys with severe haemophilia as physically active as the normal population?

BRENDAN EGAN, DR BEV ELDRIIDGE,
DR CHRIS BARNES
ROYAL CHILDREN’S HOSPITAL, MELBOURNE, AUSTRALIA

RORY WOLFE
MONASH MEDICAL CENTRE, MELBOURNE, AUSTRALIA
Physical Activity and Haemophilia

◆ Sport and physical activity are now considered to be essential.
◆ Actively encouraged.
◆ Increase participation in sport and leisure activities.
Importance of Physical Activity

  - Showed regular exercise can reduce bleeding episodes
  - Increased strength and proprioception without an increase in bleeding
Importance of Physical Activity

- Reduced BMD compared with controls
- Recurrent joint bleeds enforce extended periods of non-weight bearing and reduced physical activity.
- Also type of activity encouraged was not high intensity weight-bearing activity.
Measurement of Physical Activity

- No quantitative measurements.
- Various authors have attempted to investigate physical activity.
  - However Falk et al (2000) found a significant difference in activity.
- Results were derived from questionnaires.
- Sallis (1991) raises doubts over validity of data obtained about physical activity from questionnaires.
Measurement of Physical Activity

◆ PAL-1 - a remote activity monitor that records uptime (time spent in the upright position).

◆ Uptime
  ◆ Indication of WB activity
  ◆ Can be used as measure of physical activity. (Sanders, 1983)

◆ Newer version of Uptimer
Measurement of Physical Activity

- Investigated 529 normally developing children.
- Established a normative database for children in Victoria.
- Further studies demonstrated that the Uptimer and PAL-1 were valid measurement tools for children in these diverse clinical settings.
Uptime and Haemophilia

- Study aims
  - Measure uptime in boys with severe haemophilia
  - Compare it with uptime in unaffected children
Uptime and Haemophilia

Subject
- Severe haemophilia
- Patients of Henry Ekert Haemophilia Treatment Centre (HEHTC).
- Age range 6-16 years
- All but two on prophylaxis
- Exclusion criteria - associated neurological problem.
Uptime and Haemophilia

- **Method**
  - PAL-1 placed on lateral right thigh, secured with clear adhesive sheets.
  - PAL-1 has three tilt switches that sense when device is upright.
  - Upright position = uptime
  - Sitting or lying = downtime
Uptime and Haemophilia

- PAL-1 worn for four days.
- Removed at home and returned to hospital via family or courier.
- Data downloaded for analysis.
- Data is in hours and minutes and analysed as four separate 24-hour periods.
- Uptime was summarised as a mean and standard deviation of hours of uptime in 24 hours.
Uptime and Haemophilia - Results

- Seventeen subjects wore PAL-1
- No inhibitors
- Three subjects data unable to be used
- Three subjects had only one day recorded.
- The other eleven boys wore the monitor for four full days.
Uptime and Haemophilia

47 complete 24-hour periods
# Uptime and Haemophilia - Results

<table>
<thead>
<tr>
<th></th>
<th>Haemophilia Boys</th>
<th>Healthy Males (Eldridge, 2003a)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mean Uptime/24 hours</strong></td>
<td>4.9h</td>
<td>5.3h</td>
</tr>
<tr>
<td><strong>SD/24 hours</strong></td>
<td>1.3h</td>
<td>1.5h</td>
</tr>
<tr>
<td><strong>Range</strong></td>
<td>2.0 - 8.2h</td>
<td>1.5 - 10.3h</td>
</tr>
</tbody>
</table>
# Uptime and Haemophilia - Results

<table>
<thead>
<tr>
<th></th>
<th>Haemophilia Boys</th>
<th>Healthy Subjects (Eldridge 2003c)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Within child variability (SD)</td>
<td>1.2h</td>
<td>1.1h</td>
</tr>
<tr>
<td>Between child variability (SD)</td>
<td>0.6h</td>
<td>0.8h</td>
</tr>
</tbody>
</table>
Uptime and Haemophilia - Discussion

- Presumed activity levels were comparable
- Demonstrates haemophilia boys have similar levels of activity as their peers
- Results indicate, on average 24 minutes difference
Uptime and Haemophilia - Discussion

- Limitation - small sample size
- Novel approach to assessing physical activity levels
- Uptime provides accurate data
- Information may lead to change in child’s lifestyle and improvement in health status
- Increase risk of reduction in BMD (Barnes 2004)
  - Imperative boys participate in appropriate activities at appropriate level
Uptime and Haemophilia

◆ Acknowledgments
  ◆ Small clinical grant from the Murdoch Children’s Research Institute
  ◆ My co-authors