Articles in this issue ...

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National Benchmarking of Neonatal Physiotherapy Services

Current Clinical Practice in the use of Muscle Strengthening in Children and Young People with Cerebral Palsy – A Regional Survey of Paediatric Physiotherapists

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The Effect of Sleep Systems in Sleep-Wake Patterns and Pain Levels in Non-ambulant Children and Young People with Cerebral Palsy

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EDITORIAL
Eva Bower – APCP Editor

Spoonface Steinberg (Hall, 2000) is a monologue which describes the feelings of a 7 year old girl with autism who is dying of cancer. It is currently published as a short paperback book although started life as a BBC4 radio play in 1997. We should all read it if communicating with children who have illness, disorder and/or disability. Spoonface Steinberg tells us in her own vernacular about her faith, her love and her thoughts on the meaning of life; yet she subtly points out that she is judged by the world largely by the way she looks and by her problems, rather than the person she actually is. Apart from the family cleaner, people react to the way she looks and to her inabilities and rarely bother with her feelings or views. We all need to consider children’s wishes, thoughts and views when attempting to support and care for them through illness, disorder and/or disability. The monologue also highlights the need to know and consider a child and family’s cultural background when communicating with them. Spoonface Steinberg comes from a middle class, academic, Jewish background with estranged parents. In this issue Humphreys, Mandy and Pountney, in a series of case studies, explore the views of children with cerebral palsy as young as 3 years old on using a sleep system. We all need to listen to the children with whom we interact in our work as well as in our own daily lives.

We also publish 3 articles surveying the services for children undertaking or undergoing physiotherapy regimes. Two of these are national surveys. The first concerns the amount of physiotherapy time given to individual children with cerebral palsy and the second looks at the amount of time allotted to neonatal physiotherapy service provision in different neonatal units. The third is a regional survey of the current clinical practice in muscle strengthening in children with cerebral palsy. Although there is very little generalisable evidence for physiotherapy intervention in many of these fields, it may nevertheless be helpful to know what is actually occurring. It is interesting to note that in studies undertaken in Canada (Trahan and Malouin 2002, Law et al 2011) Greece (Tsorlakis 2004) and Denmark (Christiansen and Lange 2008) children with cerebral palsy received more physiotherapy intervention than in the UK. One wonders if this applies to all the children with cerebral palsy in countries with insurance-funded services as opposed to our own tax-funded services which are free at the point of delivery.

Please feel free to request advice regarding the submission of suitable manuscripts to the Journal. We still need all your submissions. In the last issue of the Journal there was a slight error in the printing of my email address.

For future reference it is: evabower@tinyworld.co.uk

Please submit your papers for the autumn edition by email in the first instance to va@apcp.org.uk by 1st July 2012.

References


Letter to the Editor:

I was pleased to see my article published in the APCP Journal. However, I was dismayed to see that the abstract had been changed. Removal of the word ‘experienced’ meant that the abstract no longer encapsulated the message of the article, and that this was done without my consent is regrettable.

Editor’s reply:
I would like to apologise to Ms Wilkinson for any misunderstanding in the wording of her abstract in the last edition. I am sorry.
A National Survey of the Amount of Physiotherapy Intervention Given to Children with Cerebral Palsy in the UK in the NHS

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ABSTRACT

Background
Physiotherapists are increasingly requested to provide specific and quantified advice regarding amounts of intervention, yet there is a lack of evidence to support the amount of physiotherapy needed by children with cerebral palsy (CP).

Objectives
This survey aimed to establish the amount of intervention physiotherapists in the National Health Service (NHS) are currently providing for children with CP at different severity levels and ages across the UK. This survey did not aim to establish the amount of physiotherapy that is needed by children with CP, or whether the amount of time spent makes a measurable difference to outcomes for children or to the amount of support required by their families.

Method
A questionnaire was piloted, and paediatric physiotherapists working in the NHS across the UK were invited to participate. Questions asked included the age and severity level of each child, plus the amount of therapy provided each week over one year. Therapy time was defined as time spent in contact with a child or his/her carers by a qualified physiotherapist.

Results
A total of 245 physiotherapists completed the survey between January 2009 and December 2010, reporting intervention levels for 1425 children aged 0-18 years over one year. The children receiving the most intervention over one year were those aged 0-6 years, GMFCS Level V (median 17.6 hours, interquartile range 11.5-23.5), and the children receiving the least intervention were aged 12-18 years, GMFCS Level I (2.3 hours median, interquartile range 1-4.6). Across all ages and GMFCS Levels, the most time spent in one year was on 'Body Functions and Structures' at 3.8 hours (median), with 2.9 hours (median) on 'Activity' and 1 hour (median) on 'Participation' (WHO 2002).

Conclusion
This survey provides a national reference for the amount of intervention that is actually being provided by physiotherapists in the NHS in the UK. This information may be useful for physiotherapists to use as a background against which they can set their own individual advice.

Introduction
Cerebral palsy (CP) is described as ‘a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems’. (Rosenbaum et al, 2007). The Survey of Cerebral Palsy in Europe (SCPE) divides the motor disorders associated with CP into 3 subtypes: spasticity, defined as ‘increased tone, pathological reflexes, hyperreflexia and/or pyramidal signs’; dyskinesia, defined as ‘involuntary, uncontrolled recurring movements, occasionally stereotyped’; and ataxia, defined as ‘movements performed with abnormal force, rhythm and accuracy’ (Cans, 2000). The survey reported that of 4792 children born between 1970 and 1980, the majority (85.7%) were placed in the spasticity subtype, (29.2% unilateral, 54.9% bilateral, 1.6% unknown), with 6.5% placed in the dyskinesia subtype, and 4.3% in the ataxia subtype (Johnson, 2002).
The amount of physiotherapy that should be given to children with CP is more a matter of opinion than of fact. There is a scarcity of generalisable evidence to support any particular amounts of physiotherapy intervention for children with CP, yet physiotherapists are increasingly expected to provide specific and quantified advice regarding the amounts of physiotherapy intervention for individual children with CP in clinical situations, and for educational or legal reports.

Generalisable evidence is usually considered to be generated by Level I (Sackett 1986) randomised controlled trials (RCTs) with a calculated sample size for sufficient power. The results of other trials are only applicable to the actual participants under investigation. The inclusion of a base-line period in a study enables consideration to be given to whether changes observed are indeed due to the intervention, or whether they are due to development, maturation and/or spontaneous recovery. The inclusion of a follow-up period in a study enables one to see whether any changes are maintained.

In a number of studies comparing different amounts of physiotherapy, a variety of levels of intervention have been described. Bower et al (2001), in a RCT carried out in the UK referred to routine levels of intervention of 6 hours median over 6 months. When compared with intensive amounts of intervention (44 hours median over 6 months), they found no statistically significant difference in physical outcomes with more intensive intervention when reassessed at 6 months follow up. In the same study, parents’ perceptions of care-giving were measured using the Measure of Processes of Care (MPOC) (King et al 1995), the main finding being that they were least satisfied with the provision of general information. A more recent RCT in the UK compared an unquantified amount of conventional physiotherapy with additional intervention of 1 hour per week from either a physiotherapy assistant or family support worker, and found no evidence of improvements in outcomes related to physical functioning of the child, or psychological needs of family and carers (Weindling et al 2007). The additional interventions were however not provided by qualified physiotherapists.

Trahan and Malouin (2002), in a multiple baseline (AB) designed trial in Canada, referred to conventional amounts of intervention of 45 minutes twice a week. They compared this with intensive amounts of 45 minutes 4 times a week, and found that, at the end of the intervention, the rate of physical improvement increased with intensive treatment. There was however no follow up period. Tsorlakis et al (2004), in a RCT carried out in Greece, compared intervention of 100 minutes per week with 250 minutes per week, and found that the increased treatment resulted in more physical improvement – no mention is made of whether these are usual levels of provision. Again, there was no follow-up period. Christiansen and Lange (2008) in a RCT carried out in Denmark in which 36 hours was provided over 30 weeks, either continuously or intermittently, found no difference in physical improvements between the two groups. Again, no mention is made as to whether this amount is what is usually provided, and there was no follow-up period. Law et al (2011), in a RCT carried out in Canada, compared 18-24 sessions over a 6 month period of child versus context focussed intervention and found no difference in daily living activities between the two groups. Only the Bower and Weindling studies reported on outcomes related to impact on the family and/or caregiver. Table 1 describes some of the features of the trials.

Parkes et al (2002) carried out a parental survey in Northern Ireland to establish physiotherapy provision for 212 children aged 4-14years with moderate to severe CP, and reported that 59% of children received term time intervention levels of at least twice a week for 30 minutes, with 43% of children receiving no intervention during the summer holidays. They also reported that 74% of parents surveyed wanted more physiotherapy for their child.

Physiotherapy interventions and their outcomes can be categorised in terms of their effect on one or more of the components of health, as described in the International Classification of Functioning Disability and Health (ICF) (WHO 2001). These are referred to as Body Structures and Function (BSF), Activity, and Participation (Appendix 1). When considering the relative effectiveness of various types of intervention, there is generalisable evidence that strength can be increased, but although there is some evidence that this results in improvements in other outcomes related to BSF (stamina and endurance), there is little evidence of a general improvement in outcomes related to Activity (gross motor function) or Participation (Dodd et al 2003). In a review of 54 studies carried out by Henderson et al (2008) overwhelmingly positive evidence was identified for the impact of assistive devices on child-focused outcomes across all the components of the ICF.
The ICF Framework recognises the dynamic interaction between the three components of health within the context of personal and environmental factors. For children, the impact for their family and carers is likely to be a significant environmental factor for all health components, but outcomes related to this were rarely examined.

In the absence of any consistent, generalisable evidence of the amount of physiotherapy intervention to be provided, it was decided to undertake a survey to investigate what is actually being provided. The aim was to establish the amount of intervention provided by physiotherapists within the NHS across the UK over one year for children with CP for different severity levels and age groups.

This survey did not aim to establish the amount of physiotherapy that should be provided to children with CP, or if the amount of intervention makes a measurable difference to outcomes for the child or to the support needed by their family and/or carers.

The information in this survey is not intended to be used as a benchmark of what is needed when commissioning services for children with CP and their families and carers.

<table>
<thead>
<tr>
<th>Reference</th>
<th>Study Design</th>
<th>Evidence level</th>
<th>Ages N=</th>
<th>GMFCS levels</th>
<th>Intervention</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bower E, Michell D, Burnett M, Campbell MJ, McLeish DL. (2001) Randomised Controlled trial of physiotherapy in 56 children with cerebral palsy followed for 18 months. Dev Med Child Neurol. 43: 4-15</td>
<td>RCT n=56</td>
<td>IB</td>
<td>3 yrs -12 yrs</td>
<td>III - V</td>
<td>Baseline: 6 months routine intervention (total 6 hours median) Intensive: 6 months, total 44 hours (median) intervention Follow up: 6 months routine intervention.</td>
<td>No statistically significant difference in GMFM or GMFM between routine and intensive amounts of intervention. Any improvements were not maintained in the 6-month follow up period.</td>
</tr>
<tr>
<td>Parkes J, Donnelly M, Dolk H, Hill N. (2002) Use of physiotherapy and alternatives by children with cerebral palsy: a population study</td>
<td>Survey</td>
<td></td>
<td></td>
<td></td>
<td>Questionnaire to parents of children with CP in Northern Ireland to establish service provision and use during term time and school holidays</td>
<td>59% of children received at least 30 minutes twice a week during term time, and 43% of children received no intervention during school holidays.</td>
</tr>
<tr>
<td>Trahan J, Malouin F. (2002) Intermittent intensive physiotherapy in children with cerebral palsy: a pilot study. Dev Med Child Neurol. 44:233-239</td>
<td>Multiple baseline AB design n=5</td>
<td>2B</td>
<td>10m-3yrs</td>
<td>IV - V</td>
<td>Baseline: conventional amount of intervention 45mins twice a week. Intensive: 2 consecutive blocks of 12 weeks comprising 180 mins /week (i.e. 45mins four times a week for 4 weeks followed by 8wks no intervention (rest))</td>
<td>All children improved their GMFM scores over both phases, but rate of improvement increased with intensive phase. No deterioration during 8week rest periods.</td>
</tr>
<tr>
<td>Christiansen AS, Lange C. (2008) Intermittent versus continuous physiotherapy in children with cerebral palsy. Dev Med Child Neurol. 50: 290-293</td>
<td>RCT n=25</td>
<td>IB</td>
<td>1yr -8 yrs</td>
<td>I - V</td>
<td>Continuous Group: 45 minutes twice a week over 30 weeks Intermittent Group: 45 minutes 4 times a week in 6-week blocks with 6-week breaks over 30 weeks.</td>
<td>No difference between continuous and intermittent groups, both improved GMFM scores during study period. No ‘usual therapy’ control group, and no baseline or follow up period.</td>
</tr>
</tbody>
</table>
Physiotherapists were asked:

1. The age group and GMFCS level of each child
2. The type of the movement disorder, as described by SCPE (Cans 2000):
   - Spasticity
   - Dyskinesia
   - Ataxia
3. The distribution of the movement disorder:
   - Hemiplegia (unilateral – limbs on one side of the body involved)
   - Diplegia (bilateral – limbs on both sides of the body involved, lower limbs more than upper limbs)
   - Quadriplegia (whole body)
4. The level of deformity - as there is currently no simple classification of musculoskeletal deformity for children with CP, Bower (2009) suggested the following scale for use in the questionnaire. The scale has not been validated.
   - Level 1 - Passive range of movement not limited, but active range of movement is limited
   - Level 2 - Passive range of movement is always limited
   - Level 3 - Bony surfaces no longer fit together correctly
5. The education setting (mainstream, special school or dual placement)
6. Whether the child had had either Botulinum Toxin A (BtxA) injections or orthopaedic surgery.

Time spent was defined as the actual time that a qualified physiotherapist spent in contact with the child, their family, or carers. It did not include:

1. Physiotherapy assistants’ time
2. Travel time
3. Writing reports and notes
4. Attending meetings not specifically related to a particular child
5. Any other administrative tasks

The type of therapy was recorded to reflect the components of ICF:

1. Body Structures and Functions, which relates to joint range, muscle strength, and changes in the quality of movement
2. Activity, which relates to gross motor function, functional skills, activities of daily living, and the provision of aids
3. Participation, which involves overcoming social and environmental barriers which limit access to

**Method**

The survey covered physiotherapy intervention over one year for each child. Questionnaires were returned at the end of each three-month period, and a new questionnaire started for the subsequent quarter, until four questionnaires had been received. Data collection was complete when data covering a full year’s intervention had been recorded.

Physiotherapists required the permission of their manager before agreeing to participate in the survey. Questionnaires did not identify any participating physiotherapists or children, and as the information collected was completely anonymous, ethics approval was not required. Only the person collecting the questionnaires knew any information regarding the location of participating physiotherapists. It did not form part of any subsequent data analysis.

**Recruitment of Participants**

Paediatric physiotherapists working in the NHS in the UK were invited to participate through:

1. Posters and presentations at Association of Paediatric Chartered Physiotherapists’ (APCP) conferences.
2. Contact through national and regional group networks of APCP
3. Notices in APCP newsletters and journals
4. Notices on the website of the Chartered Society of Physiotherapy (CSP)
5. Letters written to every Child Development Centre in the UK

**Inclusion criteria**

The children who could be included in the survey:

1. With a confirmed diagnosis of CP.
2. Aged between 0-18 years

**Survey design**

A questionnaire was designed and piloted with 10 physiotherapists (Appendix 2). The survey covered physiotherapy intervention over one year, with participating physiotherapists completing a short questionnaire at 3-monthly intervals for each child included. Questionnaires were collected from participants at the end of each 3-month period, until one full year’s data had been received.
every-day life situations, such as leisure, educational, social and community activities.

Recording of the survey data

Each questionnaire was given a unique number for the duration of the survey. The information was entered onto an Excel Spreadsheet at the end of each quarter by an independent observer. These entries were re-checked against the questionnaires for accuracy by another independent observer.

Results

The survey started in January 2009, and recruitment continued over a year, with the last group of participants starting in January 2010. Data collection ended in December 2010.

Participants

A total of 245 physiotherapists completed the survey for one year. Geographical coverage included all 4 countries of the UK, with physiotherapists participating from 45 locations in England, 8 in Scotland, 3 in Wales and 4 in Northern Ireland.

Questionnaires

Total number of questionnaires started: 1968
Total number of questionnaires completed for one year: 1425
Discontinued questionnaires: 543

Of the discontinued questionnaires, 53 were due to the child dying, or being discharged. Reasons, when given, for the others included lack of available time for the survey, or changes in caseloads between therapists, but for many of the discontinued questionnaires, the individual or team of participating physiotherapists withdrew from the survey by not sending any further questionnaires, with no reasons given. Only those questionnaires providing data for one full year have been included in the results.

Of the 1425 completed surveys, 1048 were a sample from caseloads and were selected by the participating therapists to be included in the survey. The remaining 377 surveys were entered as the whole CP caseload of the participating therapists.

The numbers for each GMFCS level and age group are detailed in Table 2a and 2b, and numbers for each type of CP are detailed in Table 3a and 3b.

<table>
<thead>
<tr>
<th>GMFCS Level</th>
<th>N=</th>
<th>Age group (yrs)</th>
<th>N=</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>379</td>
<td>0-2</td>
<td>113</td>
</tr>
<tr>
<td>II</td>
<td>267</td>
<td>2-4</td>
<td>201</td>
</tr>
<tr>
<td>III</td>
<td>189</td>
<td>4-6</td>
<td>232</td>
</tr>
<tr>
<td>IV</td>
<td>261</td>
<td>6-12</td>
<td>552</td>
</tr>
<tr>
<td>V</td>
<td>329</td>
<td>12-18</td>
<td>327</td>
</tr>
</tbody>
</table>

Tables 2a and 2b: Numbers in each GMFCS Level and age group.

<table>
<thead>
<tr>
<th>Type of movement disorder</th>
<th>N=</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spasticity</td>
<td>1152</td>
<td>(80.8)</td>
</tr>
<tr>
<td>Dyskinesia</td>
<td>206</td>
<td>(14.5)</td>
</tr>
<tr>
<td>Ataxia</td>
<td>65</td>
<td>(4.6)</td>
</tr>
<tr>
<td>No information</td>
<td>2</td>
<td>(0.1)</td>
</tr>
</tbody>
</table>

Table 3a: Numbers of children by type of movement disorder.

<table>
<thead>
<tr>
<th>Distribution</th>
<th>N=</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quadriplegia</td>
<td>613</td>
<td>(43)</td>
</tr>
<tr>
<td>Diplegia</td>
<td>457</td>
<td>(32)</td>
</tr>
<tr>
<td>Hemiplegia</td>
<td>354</td>
<td>(24)</td>
</tr>
<tr>
<td>No information</td>
<td>1</td>
<td>(0.007)</td>
</tr>
</tbody>
</table>

Table 3b: Numbers of children by distribution of movement disorder.

The most frequently reported deformity was level 1 (n=656) and level 2 (n=607), with the least number at level 3 (n=162). Most of the children with level 3 deformity were GMFCS level V.

Of the children who attended school, most attended mainstream schools. Numbers for each school setting are detailed in Table 4.

<table>
<thead>
<tr>
<th>School Setting</th>
<th>N=</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mainstream</td>
<td>796</td>
</tr>
<tr>
<td>Special School</td>
<td>409</td>
</tr>
<tr>
<td>Dual</td>
<td>17</td>
</tr>
<tr>
<td>Total</td>
<td>1222</td>
</tr>
</tbody>
</table>

Table 4: Numbers in each school setting.
A total of 339 children received either BtxA and/or orthopaedic surgery during the year in which they were surveyed. The numbers of children receiving one or more episodes of BtxA injections and/or orthopaedic surgery are shown in Table 5.

<table>
<thead>
<tr>
<th>No. of episodes during the survey year</th>
<th>Btx A N=</th>
<th>Orthopaedic surgery n=</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>133</td>
<td>85</td>
</tr>
<tr>
<td>2</td>
<td>66</td>
<td>37</td>
</tr>
<tr>
<td>3</td>
<td>24</td>
<td>7</td>
</tr>
<tr>
<td>4</td>
<td>14</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>237</td>
<td>134</td>
</tr>
</tbody>
</table>

Table 5: Children receiving BtxA or Orthopaedic Surgery.

**Intervention levels**

For different ages and GMFCS levels

Most intervention was reported for children in age group 0-6 years who received a median amount of 12 hours per year (interquartile range 7.1–19.3 hours). The least amount was received by children aged 12-18 years, at a median of 7.1 hours per year, (interquartile ranges 2.6-14.5) (Figure 1a).

Intervention levels were highest in GMFCS levels IV and V at a median of 14.9 hours per year (interquartile range 9.2–21), and 14.8 hours per year (interquartile range 8.8–23.1) respectively. The least amount was reported in GMFCS level I at median 4 hours per year (interquartile range 2.1–7) (Figure 1b).

Overall, the most intervention was provided to the youngest age group 0-6 years with GMFCS level V, at median of 17.6 hours per year (interquartile range 11.5–23.5). The lowest intervention levels overall were reported for children in the oldest age group 12-18 with GMFCS Level I at median of 2.3 hours per year (interquartile range 1-4.6). A full table showing intervention levels for all age groups at all GMFCS levels is shown in Appendix 3.

In general, intervention levels reduced as ages increased and as severity levels decreased (Figure 2).

Intervention reported from sampled caseloads compared to whole caseloads

Median intervention level reported from the sampled caseloads was higher than from whole caseloads (Figure 3), and the number of children reported at very low or no intervention over the year was also lower in sampled caseloads. Of the surveys from sampled caseloads, 35 children received less than 2 hours intervention over the year, and only 1 received no intervention, whereas from whole caseloads, 111 children received less than 2 hours intervention over the year, and 20 received no intervention.
Intervention levels within each of the ICF components of health.

Overall, most treatment was directed at the Body Structures and Functions component of health and the least amount was directed at Participation (Figure 4). This was the case for each age category (Figure 5) and for most GMFCS levels (Figure 6).

Intervention levels by level of deformity.

Intervention levels were highest overall for children with Level 3 deformity (Figure 7). For all levels of deformity, most of the intervention was directed at Body Structures and Functions, especially for those with Level 3 deformity (Figure 8).
Intervention levels in different school settings

More intervention was reported for children attending special schools than those attending mainstream schools (Figure 9), and this applied across all GMFCS levels (Figure 10).

Figure 9: Intervention levels by school setting.

Figure 10: Intervention levels in mainstream and special schools for each GMFCS level.

Intervention levels for children having BtxA and orthopaedic surgery.

Intervention was higher for children who had BtxA and/or orthopaedic surgery than for those who had neither of these interventions, with most intervention (median 14.6 hours per year) reported for children who had orthopaedic surgery (Figure 11).

Figure 11: Intervention levels for BtxA and Orthopaedic Surgery.

Discussion

The aim of this survey was to establish the amount of time spent by qualified physiotherapists in contact with children with CP, their families and carers, within the NHS, across the UK. It is important to emphasise that it did not seek to establish:

- whether the amount of time spent makes a measurable difference to any outcomes for the child or their family and carers
- whether the time spent is the right amount of time.

What the survey does show is that the level of intervention increased as GMFCS levels increased, and reduced as age groups increased. Whilst most intervention overall was provided to the youngest, most severely affected children, the majority (75%) of this group still received no more than just over 2 hours a month, or the equivalent of around 30 minutes a week. The older, least severely affected children received the least amount of intervention, with the majority receiving no more than the equivalent of 1 hour every 3 months, and half receiving no more than the equivalent of 1 hour every 6 months.

In a UK study, Bower et al (2001) reported a routine amount of intervention equivalent to 1 hour a month (median). The median monthly equivalent intervention for those children of similar ages and GMFCS levels in this survey was 1.2 hours. Parkes et al (2001) reported intervention in Northern Ireland equivalent to at least 4.3 hours per month, but this amount of intervention was limited to term-time intervention for moderate to severely affected children attending special schools. Studies carried out in other countries report various levels of
intervention; in a study in Canada, Trahan and Malouin (2002) referred to a conventional amount of therapy equivalent to 6.5 hours per month. Tsorlakis et al (2004), in a study in Greece, set a baseline amount of intervention equivalent to 7.2 hours per month, and Christiansen et al (2008) in Denmark set an amount of intervention equivalent to 5.6 hours per month. In a further study in Canada, Law et al (2011) did not report the amounts of intervention, only the frequency of sessions, which were provided weekly.

It is interesting to note that for the equivalent children (i.e. age groups and GMFCS levels) the UK study (Bower et al 2001) reported similar amounts to those in this survey, whereas the stated levels provided in the studies in other countries are all higher than the highest levels reported in this survey. This may reflect the different arrangements for funding and/or models of service delivery that operate in those countries. Law et al (2011) did acknowledge that many children in Canada in the same age category as those in their study would normally receive therapy only once a month.

There is often a perception among parents and physiotherapists that more is better (Weindling et al 2007, Parkes et al 2002), and it would be interesting to know whether the participating physiotherapists and/or parents and carers considered these intervention levels to be adequate.

The decision to limit the categories of ‘time’ included in this survey was made in order to ensure that the results could be comparable regardless of geographical location, organisational structures or skill mix. There are two further elements impacting on time spent that would have influenced intervention levels if included in this survey, as follows:

(a) Travel time was not recorded. It is acknowledged that a rural location with the same resources as an urban location for the same number of children may spend more time on travel. Therefore, some rural locations may have recorded lower intervention levels than some urban locations. Although the distance of their home or school from the physiotherapist’s base does not influence a child’s therapy needs, the reality is that the available provision may be limited by the amount of time spent travelling to see children in their various community settings.

(b) Intervention time from anyone other than qualified physiotherapists was not included. Different locations and departments have different policies and staffing structures/skill mix. As such, some areas may provide more non-qualified intervention than others. In addition, some school children may receive intervention from support assistants, and many children have daily interventions from parents and carers. In order to avoid these possible inconsistencies, only time spent by qualified physiotherapists was recorded. In the context of total intervention time, it is very likely that the time spent by qualified physiotherapists is only a small proportion of the total time spent on the management of children with CP. This may be something that could be explored in the future.

The questionnaire requested information about deformity and additional interventions, specifically BtxA injections and orthopaedic surgery, as these factors could affect the perceived clinical need of the child, and thus affect levels of intervention.

The results confirmed that these factors did affect intervention levels. Most children did not receive any additional interventions, but the overall levels of intervention for those who did were around 50% higher over the year. Intervention also increased with the degree of deformity. For example, the children with level 3 deformity received more intervention, the increased amount mainly directed at BSF, than those with deformity levels 1 and 2.

While perceived increased clinical need might explain higher intervention levels for children who had orthopaedic surgery or BtxA, or for those who had the severest level of deformity, this does not explain why the children in special schools received more intervention than those in mainstream schools across all GMFCS levels. An inequity of provision to children attending special and mainstream school was also highlighted by Parkes et al (2001), where children in mainstream school received at most only half of the amount of intervention of those in special schools during term time. A possible explanation may relate to the historic structure of some physiotherapy services. Prior to the policy of ‘inclusion’, children with CP were mainly educated in special schools, where many physiotherapy services are still located. Increasing numbers of children with CP, particularly at the lower severity levels, now attend mainstream schools. It is likely that more resources are required, not least in terms of travel time, to provide the same level of service to the same number of children, when they are
scattered across a number of mainstream schools.

Notably across almost all age groups and GMFCS levels, time spent on BSF accounted for the majority of intervention time. This was especially so for GMFCS level V. The least amount of time was spent on Participation across all groups.

It could be argued that as children move towards independence in adulthood, relatively more time should be directed at aspects of the ICF related to Activity and Participation, especially for children at the lowest GMFCS levels. However, intervention was consistently concentrated in the BSF category for children aged 12-18 years through all GMFCS levels. Further, it might also be argued that those interventions addressing BSF may be more likely to be effective where children are at risk of, but have not yet developed, fixed deformity. Perhaps surprisingly then, interventions addressing BSF were highest for those children who already had the most severe level of deformity. In fact, almost half of all time spent with all children was directed at BSF, and less than 15% of all time was directed at Participation. This may be due to physiotherapists feeling that they are less able to influence outcomes related to Participation than those related to BSF and Activity (Wright et al, 2008).

The traditional model, assuming that changes made at the impairment level (i.e. BSF) will eventually translate into greater involvement in daily activities, or ‘doin’ stuff’ (Harper) (i.e. Activity and Participation), is increasingly being challenged (Wright et al, 2008; Rosenbaum and Gorter 2011). These authors discuss changing attitudes to childhood disability, and suggest that reversing the traditional approach, by directing interventions at improving outcomes in ‘Participation’, with fun activities that are meaningful to the child and family, may also impact positively on the Activity and BSF dimensions. Physiotherapists are well placed to work with the child and family to identify their individual ‘Participation’ priorities, and should perhaps be taking a more pro-active role in helping the child and family to achieve those outcomes that have greatest impact on what is important to them as life goals.

It is likely that there are a number of additional factors which influence the decision as to how much physiotherapy intervention to provide to individual children with CP, such as the support required by the child, family and carers, and the resources available to provide that intervention. Parents and carers of the most disabled children may be considered to have the highest need for support, and this could be a factor in why those children in the highest GMFCS levels in this survey received the most intervention. However, Weindling et al (2007) did not find a relationship between the services provided and the level of disability of the child, or the level of needs of the family. Physiotherapists are not specifically trained to provide this support, but in reality they are often in a position of being the main professional involved with the family, and as such, play a key role in supporting the family. The impact of this role is rarely measured.

A weakness of this survey is that the information was obtained from a convenience sample, and that physiotherapists could, but were not required to participate with their entire CP caseload. Where physiotherapists included their whole caseload, there were many more children who had very little or no intervention during the survey period. In addition, the intervention levels were lower for whole caseloads than for sampled caseloads. This may be due to physiotherapists selecting children who were actually receiving intervention to include in the survey. An alternative method, which would have avoided this, would have been only to include physiotherapists who were willing to survey their entire CP caseloads. It was considered that this would have discouraged participation, resulting in much lower numbers in the survey overall.

There is currently no reliable information regarding the number of qualified physiotherapists in the NHS working with children with CP, or even the number of children with CP in the UK. The membership of APCP in 2009 was 1799 and in 2010 was 1854. However, not all physiotherapists working with children are members of APCP, and not all members of APCP have children with CP on their caseload.

It is not possible, therefore, to assess either the proportion of possible participants who took part in the survey, or the proportion of the total CP caseloads across the UK that are included in the survey. However, the proportions of children within the different subtypes of type and distribution of the movement disorder are similar to those reported by SCPE, (Johnson 2002) with the majority of children (80.8%) in this survey presenting with spasticity (of those 24% were unilateral and 56.8% bilateral).

In addition, the survey did achieve a wide geographic and demographic representation, and there is no reason to assume that physiotherapists...
who did not participate were providing any more intervention than those who did, especially as many reasons given for non-participation were related to pressure of work and lack of time.

**Conclusion**

Intervention levels reported in this survey are influenced by a number of factors, mainly related to the age and GMFCS level, presence of deformity, and whether the child received other interventions. Most intervention was directed at Body Structures and Function, with the least amount of time spent on Participation for all ages and GMFCS levels. Although it is not possible to conclude whether this sample is representative of the whole CP population in the UK, the proportions within the different subtypes are very similar to those reported in previous surveys.

It would be reasonable to conclude, given that intervention levels reported for whole caseloads were generally lower than for sampled caseloads, that this survey provides, if anything, a slightly overstated representation of the amount of intervention being provided.

This information may be helpful for physiotherapists to use as a national reference for the amount of physiotherapy being provided by physiotherapists in the NHS in the UK for children with CP at different ages and severity levels, as a background against which they can set their own individual advice. It should not be regarded as a benchmark for the amount of physiotherapy that children with CP should be receiving.

**Acknowledgements**

This survey was carried out on behalf APCP, with their financial and practical support. We would like to thank all of the physiotherapists who participated, and their managers for giving them the permission to do so.

**References**


Harper D. AACPDM Meeting, University of Iowa. Personal Communication


Rosenbaum P, Gorter J. (2011) The ‘F-words’ in childhood disability: I swear this is how we should think! *Child: care, health and development*. Doi:10111/j.1365-2214.2011.01338.x
C. Appendix 1:

Definitions of Key Terms for the WHO's International Classification of Functioning, Disability and Health

Functioning and Disability are umbrella terms that are conceived as a dynamic interaction between health conditions (diseases, disorders, injuries, etc.) and contextual factors (environment and personal factors).

In the context of health, the ICF provides the following definitions:

Body Functions are the physiological functions of body systems (including psychological functions).

Body Structures are anatomical parts of the body such as organs, limbs and their components.

Impairments are problems in body function or structure such as a significant deviation or loss.

Activity is the execution of a task or action by an individual.

Activity limitations are difficulties an individual may have in executing activities.

Participation is the involvement in a life situation.

Participation restrictions are problems an individual may experience in involvement in life situations.

Environmental Factors make up the physical, social and attitudinal environment in which people live and conduct their lives.

Personal Factors are the particular background of an individual’s life and living, and comprise features of the individual that are not part of a health condition or health state. (Note: Personal Factors are described but not "classified" in the ICF because of the large social and cultural variance associated with them).

More information about the ICF model in childhood disability can be found on the CanChild website: www.canchild.ca
### Appendix 2: APCP NATIONAL SURVEY  Period: January – March

Child No: [ ]

Please tick against each item/category applicable to this child:

<table>
<thead>
<tr>
<th>Age band (in years)</th>
<th>0 to &lt;2</th>
<th>2 to &lt;4</th>
<th>4 to &lt;6</th>
<th>6 to &lt;12</th>
<th>12 to &lt;18</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>GMFCS Level (see attachment)</th>
<th>Level I</th>
<th>Level II</th>
<th>Level III</th>
<th>Level IV</th>
<th>Level V</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Distribution and type of movement disorder (please tick one for each line)</th>
<th>Hemiplegia (unilateral)</th>
<th>Diplegia (bilateral lower limb)</th>
<th>Quadriplegia (bilateral 4-limb)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spasticity (see note 1)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dyskinesia (see note 1)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ataxia (see note 1)</td>
<td></td>
<td></td>
<td></td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Severity of musculoskeletal deformity (see note 2)</th>
<th>Educational setting (if applicable):</th>
<th>Within the last three months (if applicable):</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Mainstream school</td>
<td>Special school</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Dual placement</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Orthopaedic Surgery</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Botulinum Toxin A</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Type of therapy intervention (see note 3)</th>
<th>Time spent in minutes, for weeks commencing:</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>4/1 11/1 18/1 25/1 1/2 8/2 15/2 1/3 8/3 15/3 22/3 21/12 29/3</td>
<td></td>
</tr>
</tbody>
</table>

| Body Functions and Structures             |                                    |       |
|------------------------------------------|                                    |       |
| Activity                                 |                                    |       |
| Participation                            |                                    |       |
Appendix 3: Intervention levels for each age category at each GMFCS level

<table>
<thead>
<tr>
<th>Age</th>
<th>GMFCS level</th>
<th>N=</th>
<th>Intervention in hours per year</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Min</td>
</tr>
<tr>
<td></td>
<td>I</td>
<td>12</td>
<td>2.3</td>
</tr>
<tr>
<td></td>
<td>II</td>
<td>21</td>
<td>3.0</td>
</tr>
<tr>
<td></td>
<td>III</td>
<td>17</td>
<td>3.1</td>
</tr>
<tr>
<td></td>
<td>IV</td>
<td>25</td>
<td>6.2</td>
</tr>
<tr>
<td></td>
<td>V</td>
<td>38</td>
<td>8.3</td>
</tr>
<tr>
<td>Total 0-2</td>
<td></td>
<td>113</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>I</td>
<td>57</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>II</td>
<td>24</td>
<td>2.5</td>
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<tr>
<td></td>
<td>III</td>
<td>32</td>
<td>1.6</td>
</tr>
<tr>
<td></td>
<td>IV</td>
<td>42</td>
<td>7.3</td>
</tr>
<tr>
<td></td>
<td>V</td>
<td>46</td>
<td>0.5</td>
</tr>
<tr>
<td>Total 2-4</td>
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<td>0</td>
</tr>
<tr>
<td></td>
<td>I</td>
<td>58</td>
<td>0.5</td>
</tr>
<tr>
<td></td>
<td>II</td>
<td>48</td>
<td>2.0</td>
</tr>
<tr>
<td></td>
<td>III</td>
<td>31</td>
<td>5.3</td>
</tr>
<tr>
<td></td>
<td>IV</td>
<td>51</td>
<td>4.8</td>
</tr>
<tr>
<td></td>
<td>V</td>
<td>44</td>
<td>3.3</td>
</tr>
<tr>
<td>Total 4-6</td>
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<td>232</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>All in</td>
<td></td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>II</td>
<td>93</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>III</td>
<td>80</td>
<td>1.6</td>
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<tr>
<td></td>
<td>IV</td>
<td>118</td>
<td>4.8</td>
</tr>
<tr>
<td></td>
<td>V</td>
<td>128</td>
<td>0.5</td>
</tr>
<tr>
<td>Total 0-6</td>
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<td>546</td>
<td>0</td>
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<tr>
<td></td>
<td>I</td>
<td>160</td>
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<tr>
<td></td>
<td>II</td>
<td>125</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>III</td>
<td>81</td>
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<tr>
<td></td>
<td>IV</td>
<td>86</td>
<td>2.4</td>
</tr>
<tr>
<td></td>
<td>V</td>
<td>100</td>
<td>0.9</td>
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<tr>
<td>Total 6-12</td>
<td></td>
<td>552</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>I</td>
<td>92</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>II</td>
<td>49</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>III</td>
<td>28</td>
<td>0.3</td>
</tr>
<tr>
<td></td>
<td>IV</td>
<td>57</td>
<td>1.1</td>
</tr>
<tr>
<td></td>
<td>V</td>
<td>101</td>
<td>0</td>
</tr>
<tr>
<td>Total 12-18</td>
<td></td>
<td>327</td>
<td>0</td>
</tr>
<tr>
<td>TOTAL ALL AGES</td>
<td></td>
<td>1425</td>
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</tr>
</tbody>
</table>
National Benchmarking of Neonatal Physiotherapy Services

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ABSTRACT

Background and purpose:
There is thought to be wide variation in neonatal physiotherapy services offered nationally. Existing guidelines recognise the need for access to physiotherapy services whilst offering only limited information on staffing. This survey aimed to benchmark current neonatal physiotherapy service provision and establish other Allied Health Professional (AHP) presence.

Method
Following piloting, a 12 item postal questionnaire was sent to all neonatal units in the United Kingdom. Data was collated and analysed for levels of unit and type of service offered (regular and ad hoc services).

Results
A response rate of 52% (93/179) was achieved. 83.9% of units received physiotherapy cover, of which 47.3% was a regular service and 36.6% was an ad hoc service. Regular services occurred more frequently in units of a higher level. Whole time equivalents (WTE) were calculated per cot for the respondents to provide a staffing reference. Level 3 units had the highest mean staffing levels, achieving 0.0152 WTEs per cot. Neuro-developmental services had the greatest representation (96%), followed by orthopaedic services (82%), follow up clinics (52%) and respiratory services (48%). Respiratory services were significantly more prevalent in level 3 units (86%). Other allied health professional (AHP) availability was variable. Self assessed competence to undertake clinical treatment did not match service provision in neuro-developmental, orthopaedic or respiratory conditions. Decreased self reported competence levels correlated to ad hoc services.

Conclusion
This benchmarking survey highlights the disparity in service provision nationally and provides a reference point for preliminary service evaluation. Further development is needed in this area to establish optimum staffing for high quality care.

Introduction
Neonatal care is an evolving medical speciality yet no current standards exist for the provision of physiotherapy services on neonatal units. Physiotherapists are experts in age appropriate movement and postural control, allowing early identification of gross motor dysfunction and optimisation of brain development, as well as addressing orthopaedic conditions such as Erb’s palsy and Talipes (BAPM, 2010). It is recognised by national guidelines that neonatal units should have access to physiotherapists for respiratory, neuro-developmental, orthopaedic and follow up roles (NHS & Department of Health, 2009; BAPM, 2010). The amount of input required to provide sufficient quality of care is not ascertained and in practice the provision of such services varies greatly.

The evolution of medicine has seen survival of preterm infants increase to 66% (EPICure, 2001-2011), and with this comes additional medical and developmental sequelae. A study of infants (n=810) born at <25 weeks gestation demonstrated that upon reaching one year of age 18% had developmental problems and 17% had neurological impairments (EPICure, 2001-2011). At 30 months of age a larger proportion of infants (51%) had a disability of which 22% were classified as ‘severe’ (Wood et al, 2005). With early and timely physiotherapy intervention the problems associated with an immature nervous system can be addressed (Symington and Pinelli, 2001) to improve functional outcomes in later childhood (Blackman, 2002; Gardner, 2005).

Respiratory sequelae are common in preterm infants. Lung function in survivors of extremely preterm birth can remain abnormal even up to 11 years of age (Fawke et al, 2010). In an extremely preterm state, infants require long periods of respiratory support until their physiology is able to adequately meet their respiratory demands. During
Within nursing care there are optimal standards for staffing in some areas, such as 1:1 nursing to patient ratio within intensive care. The presence of this standard infers a suitable level of staffing under reasonable conditions inclusive of care quality. Currently there are no standards available for the amount of staffing provision for physiotherapists on the neonatal unit, however recommendations for banding of such posts do exist (BAPM, 2010; APCP, 2011). In reflecting the specialist skills required in the neonatal area, both the Association of Paediatric Chartered Physiotherapists (APCP) (2011) and the British Association of Perinatal Medicine (BAPM) (2010) guidelines recommend that physiotherapists possess a Master’s degree or relevant Master’s level professional experience. This is in recognition of the clinical expertise and skills associated with clinicians possessing this level of knowledge. It is further recommended that clinicians be at agenda for change levels 7 or 8, dependent on specific job requirements (BAPM, 2010; APCP, 2011). Clinicians with paediatric experience, at any agenda for change grade, but who do not meet this recommendation should be provided with individual clinical preceptorship and supervision by an experienced neonatal clinician (APCP, 2011).

As the intensity of care needed by infants within a neonatal unit varies greatly, within neonatal medicine 3 categories of care were designated by BAPM (2001). The purpose of these guidelines was to define these levels and the provision of nursing care required in order to match the requirements of this spectrum of patients. Units were allocated a three point level representing the degree of care provided; level 1 units provide special care only; level 2 units provide short term intensive care; level 3 units provide long-term intensive care (BAPM, 2001). These levels are accepted terminology in current clinical practice.

The process of benchmarking enables a structured review to outline current practice and enable comparison amongst peers and, where able, against best practice guidelines. This process can provide assurance as to the effectiveness of current practice as well as identifying areas for improvement. The scope of this benchmarking project aimed to determine current national services provided to neonatal units. Primary outcomes were to establish a national benchmark for overall provision of physiotherapy services. This included calculating average whole time equivalents (WTE) per cot for each level of unit and determining which specific specialities of physiotherapy were demanded. Banding of staff was also considered to ascertain adherence to national guidelines. Secondary outcomes of this survey included establishing training and self rated competence of physiotherapists, and the presence of other allied health professional (AHP) within the multi disciplinary team.

Method

A survey design postal questionnaire was chosen as the method of data collection to target every neonatal unit within the United Kingdom. The questionnaire consisted of twelve short questions. These explored unit demographics; number and banding of physiotherapists; scope of services provided; training received and self reported competence. The questionnaire was initially piloted on two APCP neonatal group members who were outside the United Kingdom and therefore would not be part of the final data collection. Changes were effected in response to their feedback to incorporate level 8b physiotherapists on the banding questions and improve question clarity.

In June 2011, the BAPM website identified 179 neonatal units in the United Kingdom (Level 1 n=56; Level 2 n=78; Level 3 n=45). The contact details for these units were established for postal contact. As not every unit had a physiotherapy service, the questionnaire and covering letter were sent directly to the neonatal unit matron or lead nurse rather than the physiotherapy department. If no physiotherapy service was provided only basic information regarding the level of the unit and number of cots was required. The questionnaire was to be returned in an enclosed stamped addressed envelope. If a physiotherapy service was provided, recipients were requested to pass the questionnaire to the physiotherapist on the unit for further completion. A response deadline of three weeks from receipt was requested and no follow up reminder was given to non-responding units.

The data from returned questionnaires was collated into a database and analysed using Microsoft Excel. From the database, results were analysed per question in Microsoft Excel in line with primary and secondary outcomes. To meet the primary outcome of service provision, responses were collated to analyse: service provision overall and per unit level;
physiotherapy services offered; physiotherapist grade and staffing; WTE per cot; and service funding. Secondary outcomes analysed the presence of other AHPs, level and source of physiotherapist training and self reported competency.

Results

A response rate of 52% was achieved, reflecting 93 returned questionnaires out of 179 units. Total data sets available for analysis varied per question due to missing data. Just over half of the responses came from level 2 units (50.5%, n = 47), with the remaining responses being split equally at 24.7% (n=23) each for level 1 and level 3. This reflected a response rate from Level 1 units of 41%, Level 2 units of 60% and Level 3 units of 51%.

Primary Outcomes

Service Provision Overall

Of the 93 recipients, 16.1% stated that no physiotherapy service was available on their unit. Of the remaining units 47.3% had a regular physiotherapy service, and 36.6% had an ad hoc service that was primarily in response to direct referrals only. This is shown in Figure 1.

Service Provision per Unit Level

Physiotherapy input varied depending on the level of the unit (Table 1). The units which had the highest proportion of available service were the level 1 units at 90.9%. Of this 40.9% had a regular service and 50% had an ad hoc service. This was followed by the level 3 units at 87% of which 60.9% had a regular service and 26.1% had an ad hoc service. The level 2 units had the lowest proportion of available physiotherapy at 78.7% of which 44.7% had a regular service and 34% had an ad hoc service. Although the level 3 units did not have the highest proportion of overall service it was much more likely to be a regular service than for any other level unit (Table 1).

<table>
<thead>
<tr>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regular</td>
<td>40.9%</td>
<td>44.7%</td>
</tr>
<tr>
<td>Adhoc</td>
<td>50.0%</td>
<td>34.0%</td>
</tr>
<tr>
<td>Regular &amp; Ad hoc</td>
<td>90.9%</td>
<td>78.7%</td>
</tr>
<tr>
<td>None</td>
<td>9.1%</td>
<td>21.3%</td>
</tr>
</tbody>
</table>

Table 1: Percentage of neonatal units per unit level with a physiotherapy service.

Areas of Physiotherapy Provided

The speciality of physiotherapy services were identified via multiple choice questions, with provision for alternative answers in an ‘other’ section. All levels of units provided a high proportion of neuro-developmental input, with orthopaedic input (e.g. Erb’s palsy, Talipes) as the next most common service (Table 2).

<table>
<thead>
<tr>
<th>Overall</th>
<th>Level 1 Mean</th>
<th>Level 2 Mean</th>
<th>Level 3 Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neuro-developmental</td>
<td>96%</td>
<td>100%</td>
<td>95%</td>
</tr>
<tr>
<td>Orthopaedic</td>
<td>82%</td>
<td>89%</td>
<td>76%</td>
</tr>
<tr>
<td>Respiratory</td>
<td>48%</td>
<td>56%</td>
<td>19%</td>
</tr>
<tr>
<td>Follow up clinics</td>
<td>52%</td>
<td>44%</td>
<td>57%</td>
</tr>
<tr>
<td>Ward Rounds</td>
<td>18%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Psychosocial</td>
<td>11%</td>
<td>0%</td>
<td>0%</td>
</tr>
</tbody>
</table>

Table 2: Services provided in neonatal units

Whole Time Equivalent per Cot

Respondents provided information on the level of the unit, number of beds and number of whole time equivalents (WTEs). Based on this, the range of physiotherapy WTEs per cot for units with a regular service was calculated for each level of unit. For level 3 units WTE this was 0.0009 - 0.0455 per cot. For level 2 units WTE this was 0.0009 - 0.0143 per cot. For level 1 units WTE this was 0.0014 - 0.0125 per cot. The maximum, minimum and mean values figures are demonstrated in Table 3 and Figure 2.

<table>
<thead>
<tr>
<th>WTE per Cot</th>
<th>Min</th>
<th>Mean</th>
<th>Max</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 1</td>
<td>0.0014</td>
<td>0.0070</td>
<td>0.0125</td>
</tr>
<tr>
<td>Level 2</td>
<td>0.0009</td>
<td>0.0046</td>
<td>0.0143</td>
</tr>
<tr>
<td>Level 3</td>
<td>0.0009</td>
<td>0.0152</td>
<td>0.0455</td>
</tr>
</tbody>
</table>

Table 3: Minimum, mean and maximum WTE per cot
Physiotherapist Grade
Band of therapists varied with some units having individual physiotherapists working in isolation on the unit and others employing a team approach. These results are visible in (Figure 3). The most common structure and banding found was for a Band 7 to be working in isolation on the unit, with this occurring in 64.3%, 63% and 50% of the cases in level 1, 2 & 3 units respectively (Figure 3). Units that met national guidelines by providing a Band 7 or Band 8 therapist in isolation or in a team were 87.9% of units, breaking down to 100% of level 1 units, 78.6% of level 2 units and 85.2% of level 3 units.

Source of Provision of Services
Acute paediatric physiotherapy teams provided the service to the neonatal units in most cases, representing 41.9% of the physiotherapy provided to regular services and 48.5% of those that received an ad hoc service. Community services in-reached to acute neonatal units in around a fifth of cases (20.9% of regular and 18.2% of ad hoc services). Units which had a regular established physiotherapy service were much more likely to have a specific neonatal physiotherapist (16.3% compared to 0%), and a network employed physiotherapist (3.0% compared to 0%). Although adult based physiotherapists provided input to both types of service, this was more commonly seen in units where the service was ad hoc (4.7%) rather than regular (15.2%) (Figure 4).

Secondary Outcomes
Allied Health Professionals
A secondary outcome of this project was to explore the provision of other AHP support on neonatal units. Respondents were asked to provide information on whether other professions gave a regular service, an ad hoc service, or no service; the results of which are summarised in Figure 5. Provision of AHP support was slightly variable in different levels of unit. From the respondents, Occupational Therapy (OT), Dietetics and Speech and Language Therapy (SALT) input were all most prevalent on the level 1 units, reducing sequentially through level 2 to level 3 units.

Level and Source of Physiotherapist Training
Physiotherapists working on neonatal units gained their knowledge and skills in a variety of different ways (Figure 6). This included formal channels, such as undertaking an MSc or attending neonatal specific courses, and informal channels such as working with seniors or being self taught. Membership of the APCP neonatal group was more prevalent in units with a regular service (22.4%) compared to ad hoc services (9.1%). Only small differences occurred in training sources between regular and ad hoc services.

Self Reported Competency
The questionnaire asked if respondents felt they had the clinical competence to undertake neuro-developmental, orthopaedic and respiratory interventions on infants within a neonatal unit. Numerous respondents stated that they did not
Figure 4: Provider of Physiotherapy to Neonatal Units for Regular and Ad hoc Services.

Figure 5: Allied health profession services to neonatal units.

Figure 6: Support and Training Received by Physiotherapists Working in Neonatal Units for Regular and Ad hoc Services.
have the clinical competence to carry out treatments for services they did not offer. Additionally, a proportion of respondents did not feel competent to provide a service they currently provided. The respondents who worked within an ad hoc service were more likely to feel they did not have the appropriate skills and training. In this category, 33.3% of those that provided a neuro-developmental service, 23.1% of those providing a respiratory service and 36.4% of those providing an orthopaedic service felt they did not have the necessary skills to carry out this role. In established regular service this number was less, at 7.1%, 9.5% and 2.7% for neuro-developmental, respiratory and orthopaedic services respectively (Figure 7).

Figure 7: Percentage of respondents reporting that they do not feel competent to provide a service that they currently offer

Discussion

Existing national guidelines state that there needs to be “access to” physiotherapy services (NHS & Department of Health, 2009; BAPM, 2010). This terminology allows a variable interpretation of what constitutes acceptable access and this survey begins to demonstrate this range in current practice. From the results gained, 16.1% of units do not have access to physiotherapy and of the 83.9% of units that do receive physiotherapy input only 47.3% of respondents report this to be a regular service. Appropriately, level 3 units were more likely than the other levels to have a regular service (60.9%).

The biggest difference between levels of unit was in regards to respiratory input, where 85.7% of level 3 units provided a respiratory service in comparison to just 19% of level 2 units. Whilst the increased demand for respiratory services is understandable in level 3 intensive care environments, level 1 units had a higher incidence of respiratory input than level 2. This could be hypothesised to reflect level 1 units possessing a higher proportion of mature infants and therefore with fewer contraindications for respiratory physiotherapy. Unfortunately, establishing patient demographics were outside the scope of this review.

Neuro-developmental physiotherapy was the most represented speciality (96%) followed by orthopaedics (82%). Half (52%) of departments provided a service in follow up clinics. Community paediatric services in-reaching to neonatal units were also less common in level 3 units. This may reflect the specific respiratory skills required at different levels of units.

These results have found that a significant proportion of physiotherapists who currently provide services within neonatal units do not feel competent to provide these treatments. This is dramatically higher in units that provide an ad hoc service (Figure 7) which may reflect a lower frequency of exposure to this environment. Of interest, a larger proportion of physiotherapists at level 3 units felt competent in the management of neuro-developmental, orthopaedic and respiratory conditions. Correspondingly, the level 3 units were more likely to have a regular service.

In this survey 87.9% of units met national guidelines for banding (BAPM, 2010; APCP, 2011), with band 7 physiotherapists being the most prevalent on the neonatal unit. In units that did not meet these guidelines band 6 and band 5 staff worked in isolation. The presence of appropriate clinical support mechanisms in these instances was not evident.

Whilst recalling the guidelines by APCP and BAPM for neonatal specialist clinicians, 4.5% of regular services and 14.7% of ad hoc services were provided by adult physiotherapists. Additionally, services were predominately provided by acute paediatric physiotherapists with only a small number of specific neonatal posts identified. This may reflect the small number of units that receive enough WTEs to make a substantive post. Further introduction of network physiotherapists may allow the development of specific neonatal physiotherapy posts. Indeed, one network has demonstrated this to be a feasible option as units have grouped together to form a substantial WTE post. Such collaborative network posts may also have additional financial benefit in the current economic climate.
The quantity of staffing across levels of units varied widely with the level 3 units having the highest mean average staffing. This greater staffing is likely to reflect increased demand for respiratory interventions as well as greater patient complexity. Interestingly, level 1 units had a higher mean average staffing level than level 2. This may reflect a higher demand on level 1 units due to infants being more medically stable and therefore more appropriate for neuro-developmental assessment and intervention before discharge home.

This benchmarking established the current range in minimum and maximum WTE staffing levels per cot (Table 3). In practice, this reflects current mean staffing of a 0.5 WTE to cover a 33 cot level 3 unit, a 0.1 WTE to cover a 22 cot level 2 unit, and a 0.2 WTE to cover a 29 cot level 1 unit. These mean averages could be a starting point for pinpointing acceptable staffing levels. This questionnaire did not explore whether the time spent on the unit was adequate and therefore quality of care cannot be inferred. Despite this, in the absence of any other reference points it may give guidance for therapists reviewing their services.

Additional AHP presence was varied, with breast feeding specialists, dieticians and SALT more represented in regular services. SALT services were more prevalent in level 1 units, which may reflect the importance of establishing oral feeding in special care units before discharge home. Occupational therapy and play specialists were least represented in both service capacities across all unit levels.

From a professional perspective, evidence of continuing professional development acts to ensure high quality evidence based efficacious practice. Due to the vulnerability of small infants, appropriate training and support is imperative to avoid harm. While the quality of self-study cannot be ascertained, respondents described themselves as solely self taught in 16.8% of regular services and 18.2% of ad hoc services. Attendance at specific neonatal courses, or membership of a special interest group, occurred in only a fifth of respondents. Whilst a large proportion of respondents relied on peer support or senior teaching, the appropriateness of this is dependent on the skill level of the team.

It is acknowledged that this benchmarking survey has several limitations which impact on the reliability and national representation of the results gained. Firstly, a response rate of only 52% was achieved. Although acceptable for this method this could have been increased by follow up reminder for non-responders, or by targeting named physiotherapists via email or telephone. The decision not to make reminder contact removed possible reviewer bias from inadvertently selecting units to contact. Retrospectively, there was also a high risk of failure to return where services were present but required internal forwarding between departments. This is likely to have been to the greatest detriment to the representation of the ad hoc services, where the details of a forwarding recipient may not have been known. Adversely there may also have been a particular positive bias to the absent services as no further action other than return was required. It is therefore appropriate to state that the results gained provide a snapshot of current services for benchmarking which could be significantly altered with a higher reply rate. Furthermore, whilst the questionnaire was piloted and changes were made in response to this, some respondents did not fill in the questionnaire appropriately leading to incomplete full data sets. This suggests that the questionnaire design could have been improved.

Conclusions

This benchmarking survey is the first project to chart the current provision of neonatal physiotherapy services nationally. From this it is evident that there is a disparity of services and that the limited national guidelines are not always being met. Additionally, self reported competence levels are not always sufficient for this patient group.

As existing guidelines are not extensive in their recommendations of physiotherapy staffing on neonatal units this benchmarking review aimed to ascertain a snapshot of current staffing. By establishing current maximum, mean and minimum staffing levels on neonatal units, therapists may have some initial guidance for reviewing services. The ability to calculate WTEs per cot may also give service managers guidance for staffing requirements. With this said it is important to acknowledge that numerical staffing levels do not confer quality and therefore further work is required to ensure standardised, high quality care.

Whilst acknowledging study limitations and restrictions to the applicability of the results a snapshot of current physiotherapy neonatal care has
been successfully captured. The aim of this benchmarking was not to provide standards or set clinically significant recommendations, but rather to provide a baseline of current service provision. From this, further research can be launched and practice evaluated. In particular the generation of staffing recommendations which incorporate the assurance of quality should be ascertained. As neonatal care evolves and the role for physiotherapy input increases appropriate staffing and staff competence is of particular pertinence.

**References**


EPIcure studies, (2001 – 2011), www.EPIcure.ac.uk


Current Clinical Practice in the Use of Muscle Strengthening in Children and Young People with Cerebral Palsy - A Regional Survey of Paediatric Physiotherapists

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ABSTRACT
Objective:
The aim of this study was to conduct a survey of paediatric physiotherapists in the North West region of England to ascertain their current clinical practice in the use of muscle strengthening in children and young people with cerebral palsy. A questionnaire was devised to capture information on:

i) use of muscle strengthening programmes,
ii) types of muscle strengthening techniques used,
iii) frequency of sessions,
iv) progression of exercises,
v) assessment methods and outcome measures,
vi) training and education in muscle strengthening.

Design
A postal questionnaire including closed and open questions was the most suitable method to acquire qualitative data. The region comprised of 24 paediatric physiotherapy centres (data obtained from the North West Primary Care Trusts).

Results
Physiotherapists primarily use functional activities to strengthen muscle in GMFCS levels I-III. These are also used as assessment and outcome measures. Physiotherapists increase the frequency of programmes immediately post intervention across all groups. They progress strengthening programmes and advise physical activity on cessation of treatment.

Conclusions
Functional activities were the main method for strengthening muscles. Physiotherapists work towards functional outcomes to enable maximal participation and independence in activities of daily life. Functional activities do not necessarily strengthen individual muscle groups; however targeted muscle strengthening does not necessarily improve function. This questionnaire has highlighted the need for guidance and post graduate training when implementing muscle strengthening programmes with children and young people with cerebral palsy.

Introduction
Cerebral Palsy (CP) affects 2 to 3 infants per 1000 live births. It is thought to be the most common cause of serious physical disability in childhood (Odding et al 2006). CP has been defined as ‘a group of permanent disorders of development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of CP can be accompanied by: reflex excitability; disturbances of sensation, perception, cognition, communication and behaviour; epilepsy; and secondary musculoskeletal problems’ (Rosenbaum et al 2007; Bax et al 2005).

Physiotherapy plays a fundamental role in the management of children with cerebral palsy. Treatment aims to encourage normal development, improve function and prevent secondary musculoskeletal complications (Scrutton et al 2004; Murr & Walt 2009).
Neurodevelopment physiotherapy (NDT), widely used from the 1960s, focused primarily on affecting spasticity and associated abnormal patterns of movement through the use of inhibition and facilitation techniques (Bobath 1971). Despite muscle weakness being reported as a common symptom in children with CP it was not considered to be a major contributor to motor dysfunction. Furthermore, progressive muscle strengthening was thought to increase spasticity and abnormal movements and so interfere with motor control. Strengthening of specific muscle groups was considered ineffective due to the lack of isolated control of targeted muscles (Damiano et al 1995). With research advances in the field of neurophysiology, muscle physiology and morphology these concepts have been challenged and there is now a move to address muscle weakness using strengthening therapies (Elder et al 2003; Shortland et al 2002; Damiano et al 2002; Verschuren et al 2008).

Systematic reviews to date demonstrate conflicting evidence as to the effectiveness of muscle strengthening interventions (Verschuren et al 2008; Dodd et al 2002; Darrah et al 1997; Mockford & Caulton 2008; Scanni et al 2009). Although investigators (Damiano et al 1995; Damiano 2002; Dodd et al 2002; Fowler et al 2001) have found improvement in muscle strength without adverse effects, changes in functional abilities remain unclear. Scanni et al (2009) discussed the effects of strengthening which did not produce clinically worthwhile improvements in activity. More recent evidence by Damiano et al (2010) stated that the effect of strength training on gait kinematics with people with CP is unpredictable. Methodological quality has been reported as low in some trials by authors (Verschuren et al 2008; Mockford & Caulton 2008; Antilla et al 2008) and evidence is inconsistent.

It is unlikely that muscle strengthening approaches are used uniformly as there is no clear guidance as to the timing, frequency, intensity or type of strengthening interventions for achieving goals. The North West Muscle Strengthening in Cerebral Palsy Working Group (NW MSCP) plans to provide guidance for use by paediatric physiotherapists taking into account evidence from existing systematic reviews and a Cochrane systematic review that is currently in progress.

The aim of this study was to conduct a survey of paediatric physiotherapists in the north west of England to ascertain their current clinical practice in the use of muscle strengthening in children and young people with CP. The NW MSCP group will use the survey findings to inform and aid implementation of the guidance.

Method

A questionnaire (Appendix I) was designed by the NW MSCP to capture information from physiotherapists treating children and young people with CP within the North West region of England on:

1. use of muscle strengthening programmes,
2. types of muscle strengthening techniques used,
3. frequency of sessions,
4. progression of exercises,
5. assessment methods and outcome measures
6. training and education in muscle strengthening.

For the purposes of this paper, we describe a muscle strengthening programme as the use of resistance methods to increase one’s ability to exert or resist force that are progressed as ability changes (Council on Sports Medicine and Fitness 2008).

It can incorporate the use of the individual’s own body weight or gravity with or without functional activities (i.e. sitting to standing), resistance (i.e. theraband, free weights, manual resistance,) general gym equipment and hydrotherapy to attain goals.

Within these broad categories a number of open and closed questions were included to gain information about specific patient groups treated (i.e. age groups and Gross Motor Function Classification System (GMFCS) levels) and clinical interventions or events that may prompt additional muscle strengthening interventions (i.e. pre- and post-surgery, post serial casting, botulinum toxin injections, muscle weakness identified, for example, following gait analysis and signs of deterioration). A pilot survey of physiotherapists (n=10) from the Liverpool locality was undertaken to assess for question design and clarity and the questionnaire refined in the light of feedback.

Due to the geographic size of the area to be covered by the survey, a postal questionnaire was chosen as the most suitable method for administering the survey. The region comprised of 24 paediatric physiotherapy centres all of which were targeted (data obtained from the North West Primary Care Trusts, Map 1).
Questionnaires, covering letters and stamped addressed envelopes were sent to the managers of each centre for distribution amongst their staff.

Further awareness of the survey was raised at the regional CP course (two weeks after the survey was distributed) and via the Interactive CSP website. This was intended to enhance response rate to the questionnaire. Replies were collated and entered into SPSS version 13 by one investigator and validated by a second. Responses to open questions were analysed and key themes and points of interest identified.

Results

Ninety paediatric physiotherapists within the North West region submitted completed questionnaires. 37 respondents chose to identify their place of work revealing that submissions were obtained from at least 18/24 surveyed centres.

Muscle strengthening Programmes

Several respondents, 23% (21/90), stated they did not use muscle-strengthening programmes as part of their treatment with CP. Reasons given were:

i) Therapists lacked knowledge (10%),

ii) Muscle strengthening was considered inappropriate (7%),

iii) Muscle strengthening was felt to be contra-indicated in their patients (6%),

iv) Therapists lacked equipment (4%).

The majority of respondents, 77% (69/90), reported using muscle strengthening programmes, although not all of these treated patients across the different age groups or GMFCS levels and the results below take account of this.

Methods of muscle strengthening

The most commonly used methods reported were: functional activities, 97% (67/69); gravity, 88% (61/69); and body weight, 87% (60/69). Hydrotherapy was used by 72% (50/69) of respondents. Other methods reported as being used were: gym ball, 71% (49/69); manual resistance, 56% (39/69); and less frequently, static bicycle, 37% (26/69); theraband, 37% (26/69); gym equipment, 33% (23/69); free weights, 29% (20/69) and treadmill, 11% (8/69).

Responses were examined separately for different age groups, GMFCS levels, and clinical interventions (pre surgery and post-surgery, serial casting, following botulinum toxin injections), also muscle weakness identified following gait analysis and signs of deterioration. Use of treatment methods varied across these groups as shown in Figures 1, 2 and 3.
The most commonly used methods across all age groups were: functional activities; gravity and body weight. The use of these peaked in the 5-12 year age groups. Muscle strengthening methods were used least in the 0-2 years and 17-19 year age groups. These methods remained consistent for all clinical interventions with the exception of hydrotherapy which increased following single or multi-site surgery.

Strengthening methods were used predominantly in GMFCS Levels I-III. Similar strengthening methods were used in Level IV but by fewer physiotherapists. Hydrotherapy was the most popular method of muscle strengthening in Level V. Gym equipment and resistance techniques were least used.

**Assessment**

A variety of methods were used to assess strength of specific muscle groups for the purpose of devising and progressing strengthening programmes. Functional activity was used by 89% (62/69); the Oxford Scale by 61% (39/69), and weights, 1% (1/69). 3% (2/69) did not assess muscle strength.

**Outcome Measures**

Functional activities were used by 88% (61/69); SMART goals, 68% (47/69); GMFM 88/66, 48% (33/69). Other outcome measures reported included Bayley; Chailey; patient specific function measures; quality of movement; video analysis and observational gait tools.

**Frequency of muscle strengthening programmes following clinical interventions**

Daily treatments were more frequent immediately post intervention across all groups and then reduced. From 6 months there was no consensus regarding treatment frequency following surgery. These results are shown in Figures 4a-d.

Several therapists commented that frequency of sessions was directly related to patient and family compliance. Some responders reported that frequency of sessions was limited by lack of support from local services and large clinical caseloads.

The majority of physiotherapists instruct key people to supervise strengthening programmes including; parents and carers, physiotherapy assistants and school support staff.
Progression

All physiotherapists reported that they progress their strengthening programmes using a variety of methods, which are shown in Figure 5. Respondents were allowed to identify more than one option.

The most common reasons for discontinuing a muscle-strengthening programme were: poor adherence, 78% (54/69); goals achieved, 68% (47/69); plateau of function, 49% (34/69); and no improvement, 55% (38/69).

The majority of physiotherapists recommended activities following cessation of muscle strengthening programmes. These included swimming, cycling, football, dancing, horse riding or gym attendance.

Education and training

Physiotherapists reported that they gained their knowledge and experience in muscle strengthening: at pre-registration level, 85% (59/69); peer discussion, 87% (60/69); paper reviews, 47% (33/69); postgraduate muscle strengthening courses, 44% (31/69); research, 10% (7/69); and higher degree, 4% (3/69).

Discussion

The majority of respondents reported using muscle strengthening programmes. Others commented they lacked knowledge or found it inappropriate due to the adverse effect on spasticity. Evidence states that muscle strengthening has no detrimental effect on spasticity (Scianni et al 2009; Scholtes 2010), this identifies a training need.

Physiotherapists are most commonly using gravity, functional activities, or body weight to strengthen muscle. We should however consider that in choosing these methods, muscles may not be sufficiently loaded to achieve an increase in strength (Scianni et al 2009). To stimulate strength development the amount of resistance should be increased as strength increases (Council on Sports Medicine and Fitness 2008; Scholtes et al 2011). Some respondents commented that lack of equipment, e.g. free weights and gym equipment, often prevented them from achieving effective progressive strengthening.

Limited use of free weights by responders may partly be explained by the observation that the majority of children treated are in the 5-12 year age range and have skeletal immaturity and reduced ability to undertake this type of strengthening.

When considering GMFCS levels, muscle strengthening programmes were most commonly used in Levels I-III. These groups are more able to participate with a specific progressive exercise programme as they have more selective control and reduced co-activation. The use of muscle strengthening in Level V patients is controversial because of issues around motor control. Physiotherapists reported using hydrotherapy for children with GMFCS Level V. Although this cannot be regarded as muscle strengthening in this group it is acknowledged that in children with CP, water provides a medium enabling activity, which is otherwise limited.

For clinical interventions such as surgery and post-botulinum toxin, functional activities, gravity and body weight continued to be the preferred muscle strengthening methods. The exception to this was hydrotherapy. The use of which increased following surgery and may have been chosen as an aid to mobilisation in addition to activating weak muscles.

When measuring muscle strength, 90% (62/69) of respondents used functional activity for assessments, e.g. sit to stand, use of stairs. Functional activities are however not muscle strength specific; many variables including strength, stamina and range of movement contribute to functional skills. The Oxford Scale was used by 61% (39/69) of physiotherapists, which indicates that measurements of strength of specific muscle groups are being undertaken. Other objective measures such as cybex/dynomanometer were not reported as being used. It is possible that this reflects the inappropriateness of their use in this client group. In the community setting, there may be financial constraints and access to this type of equipment may be limited or unavailable. Darrah et al (1997) suggest that changes in muscle strength should be related to functional outcomes and Dodd et al (2002)
found functional outcomes to be more meaningful to clients as it improves motivation. Our results support this as many physiotherapists chose to use functional outcome measures in their practice. Specific formal assessment of muscle groups is required in order to clearly identify weakness. Programmes can then be devised to address weakness and aim to contribute to improving function.

The results show physiotherapists increase the frequency of muscle strengthening over the first 3 months following all clinical interventions. Although this may be appropriate following botulinum toxin injections, research indicates that following surgery improvements in function can continue up to 2 years (Nene et al 1993). It could be inferred that muscle strengthening in this period may further enhance this function. The questionnaire shows that beyond 6 months muscle strengthening input reduces. This may be because maintaining compliance and motivation for this length of time challenges the skills and resources of the physiotherapists. Interestingly, poor patient compliance was the principle reason for discontinuation of a strength programme in the large majority of cases. It is possible this reflects inappropriate patient selection, which would indicate a need for stricter inclusion criteria. Another suggestion could signify issues around our treatment programmes and that patients may lose interest and therefore motivation to continue. It may indicate that as a group of physiotherapists we need to re-evaluate our treatments and become more inventive with exercises to challenge and stimulate. This patient group have a life long condition requiring on-going management and treatment, muscle strengthening being one contributing aspect. Research has indicated the importance of physical activity in patients with CP in order to offset the decline in function associated with this group (Verschuren et al 2008).

All physiotherapists understood the need to progress a strengthening programme. The most common methods used were increasing repetitions, changing starting position or the way the muscles work. i.e. concentric/eccentric. It is of interest that less than a quarter of respondents used weights for progression. One reason may be that this patient group is unable to participate in this type of approach, necessitating other methods. Reasons for this could be multifactoral, including the child’s level of comprehension and ability, the relevance of the method to the patients functional goals. Qualitative responses taken from the data highlight that some physiotherapists may not be fully applying the principles of progressive muscle strengthening as answers described reducing support and emphasising balance and shifting body weight. Developing guidance to give a standardised approach along with further practical training is recommended.

Since their initial training, 44% (31/69) of physiotherapists report having updated their skills with courses on muscle strength training. This is encouraging but were the courses relevant to the CP population? A study identified by Tyson and Selley (2007) found that UK physiotherapists treating this population appear to follow NDT although they perceived their treatments as eclectic. One key reason for this was that Bobath Courses were the main post graduate training chosen by the physiotherapists working in the neurological field. The evidence based culture is challenging our interventions and our acceptance of other concepts and as a result physiotherapy treatments are changing.

Respondents indicated they value peer discussion and participate in paper reviews considering these to be important in their clinical practice. The complex presentation of CP is acknowledged with both its neurological and musculoskeletal components making its management challenging. With greater emphasis on evidence based practice we look for information to support treatment philosophy.

One physiotherapist remarked that a ‘health for life’ strategy involving the whole family and carers is important and not to focus on a one-off programme as described by Damiano (2006) which concluded the importance of encouraging activity. Physiotherapists work to improve muscle strength enabling patients to access activities for a more inclusive lifestyle (Rimmer 2001). Working together with staff from the sport and leisure industry to promote inclusion may well give children with CP a more active future. Developing our practice requires reliable evidence, in order to establish guidance to inform practice and relevant training.

Conclusions

Physiotherapists are primarily using functional activities for muscle strengthening. Addressing muscle weakness is an important part of treatment and this survey demonstrates that physiotherapists do use muscle strengthening programmes.
Evidence suggests functional outcomes are more meaningful, and the survey indicates that physiotherapists are using function to assess outcome. This is important as physiotherapists work towards functional outcomes to enable maximal participation and independence in activities of daily life. A functional outcome however does not capture muscle strength changes exclusively; further work to clarify this issue in order to demonstrate muscle strength changes would be beneficial. It is important to study in more depth how and if muscle strengthening impacts on functional outcomes.

One factor highlighted was related to patient selection. Additional work is needed to investigate if there is a particular type of patient who has more potential to gain from muscle strengthening programmes. This needs to take into account GMFCS levels, age bands, compliance and cognitive ability.

Although all physiotherapists stated progressing muscle strengthening programmes, further information is necessary to determine if some methods of progression are more effective or suitable than others.

This questionnaire has highlighted the need for guidance when implementing muscle strengthening programmes with children and young people with CP.

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References


Damiano DL, Dodd K, Taylor NF (2002). ‘Should we be testing and training muscle strength in cerebral palsy?’, Dev Med Child Neurol. 44, 68-72


Tyson SF, Selley AB (2007). ‘The effect of perceived adherence to the Bobath concept of physiotherapists’ choice of intervention used to treat postural control after stroke’. Disability and Rehabilitation 29, 395-401

Appendix 1: Muscle Strengthening Questionnaire

Dear Colleague

SURVEY OF PAEDIATRIC MUSCLE STRENGTHENING PRACTICE IN CEREBRAL Palsy IN THE NORTH WEST REGION

We are a group of physiotherapists currently undertaking a survey as part of a review of muscle strengthening in Cerebral Palsy. We are looking at practice within the North West region.

- This survey is to provide us with information about our current clinical practice in the use of muscle strengthening.
- Our ultimate aim is to use this information, together with best research evidence, to develop evidence-based guidelines on the use of muscle strengthening programmes within the paediatric Cerebral Palsy population.

In this questionnaire the assumption is made that the definition of muscle strengthening is ‘progressive resisted exercise’. This includes using gravity, body weight and/or equipment e.g. treadmill, bike or theraband.

Please complete this anonymous questionnaire, answering all questions frankly and honestly. Please distribute this to all physiotherapist colleagues in your organisation who treat children with Cerebral Palsy. A good response rate is vital to ensure success of this project. When we have collated the results of the survey, we will post them on the ICSP website.

Please contact the Gait Analysis Laboratory at Alder Hey Hospital if you have any queries, tel: 0151 252 5949.

An electronic version is available on ICSP Website which can be downloaded and printed.

Please return your questionnaire in the stamped addressed envelope provided, by 8 JUNE 2007. Return to: The Gait Laboratory, Alder Hey Hospital, Eaton Road, Liverpool, L12 2AP

Many thanks for your assistance.

Hilary Finlay
On behalf of North West Muscle Strengthening in Cerebral Palsy Interest Group
MUSCLE STRENGTHENING QUESTIONNAIRE

THANK YOU FOR TAKING TIME TO FILL IN THIS QUESTIONNAIRE. PLEASE GIVE AS MUCH DETAIL AS POSSIBLE AND ANSWER QUESTIONS HONESTLY. IT SHOULD ONLY TAKE YOU 15 MINUTES TO COMPLETE.

In this questionnaire the assumption is made that the definition of muscle strengthening is ‘progressive resisted exercise’. This includes using gravity, body weight and/or equipment e.g. treadmill, bike or theraband.

1. Do you use a specific muscle strengthening programme as part of your treatment of children with Cerebral Palsy?
   □ Yes          □ No

   If ‘no’, why?
   □ Not appropriate     □ Lack of training or knowledge     □ Lack of equipment
   □ Other (please state)

   If ‘no’, you have now completed this questionnaire, thank you for your time.
   Please return to: The Gait Laboratory, Alder Hey Hospital, Eaton Road, Liverpool, L12 2AP

1.1 If ‘yes’: What methods do you use? (Please tick all relevant boxes that apply)
   □ Body weight          □ Functional activities, e.g. sitting to standing, stepping
   Resistance Training
   □ Use of gravity       □ Theraband          □ Hydrotherapy
   □ Free weights         □ Manual resistance

   Equipment
   □ Bike                □ Treadmill        □ General gym equipment
   □ Gym ball            \n   □ Other method (please state)

2. Identifying which children with Cerebral Palsy are included in a muscle strengthening programme.

2.1 For the following age range(s) what type of muscle strengthening method(s) do you use within your treatment setting? (Please tick relevant boxes)

<table>
<thead>
<tr>
<th>Method</th>
<th>0-2 yrs</th>
<th>3-4 yrs</th>
<th>5-6 yrs</th>
<th>7-12 yrs</th>
<th>13-16 yrs</th>
<th>17-19 yrs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body weight</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Functional activities</td>
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<td></td>
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<tr>
<td>Resistance training: Use of gravity</td>
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<tr>
<td>Resistance training: Theraband</td>
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<tr>
<td>Resistance training: Hydrotherapy</td>
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<tr>
<td>Resistance training: Manual resistance</td>
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</tr>
<tr>
<td>Resistance training: Free weights</td>
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<tr>
<td>Equipment: Gym ball</td>
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<tr>
<td>Equipment: Treadmill</td>
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<tr>
<td>Equipment: Bike</td>
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<tr>
<td>Equipment: General gym equipment</td>
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<tr>
<td>Other (please state)</td>
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</tbody>
</table>
2.2 For the following Gross Motor Function Classification System (GMFCS) levels, what type of muscle strengthening method(s) do you use in your treatment settings? *(Please tick all that apply)*

<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Walks without restrictions limitations in advanced motor skills.</td>
</tr>
<tr>
<td>II</td>
<td>Walks without assistive devices limitations in walking outdoors.</td>
</tr>
<tr>
<td>III</td>
<td>Walks with assistive mobility devices limitations walking outdoors.</td>
</tr>
<tr>
<td>IV</td>
<td>Self mobility with limitations children transported or use powered mobility.</td>
</tr>
<tr>
<td>V</td>
<td>Self mobility severely limited.</td>
</tr>
</tbody>
</table>


<table>
<thead>
<tr>
<th>My caseload does not include this level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body weight</td>
</tr>
<tr>
<td>Functional activities</td>
</tr>
<tr>
<td>Resistance training: Use of gravity</td>
</tr>
<tr>
<td>Resistance training: Theraband</td>
</tr>
<tr>
<td>Resistance training: Hydrotherapy</td>
</tr>
<tr>
<td>Resistance training: Manual resistance</td>
</tr>
<tr>
<td>Resistance training: Free weights</td>
</tr>
<tr>
<td>Equipment: Gym ball</td>
</tr>
<tr>
<td>Equipment: Bike</td>
</tr>
<tr>
<td>Equipment: Treadmill</td>
</tr>
<tr>
<td>Equipment: General gym equipment</td>
</tr>
<tr>
<td>Other <em>(please state)</em></td>
</tr>
</tbody>
</table>

2.3 For the following clinical indications/interventions, what type of muscle strengthening method(s) do you use in your treatment settings? *(Please tick all that apply)*

<table>
<thead>
<tr>
<th>My caseload does not include this indication/intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body weight</td>
</tr>
<tr>
<td>Functional activities</td>
</tr>
<tr>
<td>Resistance training: Use of gravity</td>
</tr>
<tr>
<td>Resistance training: Theraband</td>
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<tr>
<td>Resistance training: Hydrotherapy</td>
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<tr>
<td>Resistance training: Manual resistance</td>
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<tr>
<td>Resistance training: Free weights</td>
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<tr>
<td>Equipment: Gym ball</td>
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<tr>
<td>Equipment: Bike</td>
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<tr>
<td>Equipment: Treadmill</td>
</tr>
<tr>
<td>Equipment: General gym equipment</td>
</tr>
<tr>
<td>Other <em>(please state)</em></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Pre-Surgery</th>
<th>Post-surgery</th>
<th>Serial Casting</th>
<th>Botulinum</th>
<th>Weakness Identified</th>
<th>Strength Analysis</th>
<th>Signs of Deterioration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single Site</td>
<td>Multi Site</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
2.4 Are there any other clinical indications for which you would implement a specific muscle strengthening programme? If 'yes' describe.

3. Assessment

3.1 How do you measure muscle strength? *(Please tick all that apply)*

- Functional e.g. stairs, sitting to standing: *(please state)*
- Validated formal scale: *(please state)*
- Equipment e.g. Dynamometer: *(please state)*
- Other: *(please state)*
- Not measured

3.2 What outcomes do you use? *(Please tick all that apply)*

- GMFM 88
- GMFM 66
- SMART (Specific Measured Achievable Realistic Timed)
- Functional
- Change in muscles strength test score
- Other: *(please state)*

4. Treatment

4.1 With the following clinical interventions, how often do you recommend a muscle strengthening programme should be carried out? *(Please state)*

<table>
<thead>
<tr>
<th>Daily</th>
<th>Three times per week</th>
<th>Twice weekly</th>
<th>Weekly</th>
<th>Other (please state)</th>
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<table>
<thead>
<tr>
<th>Daily</th>
<th>Three times per week</th>
<th>Twice weekly</th>
<th>Weekly</th>
<th>Other (please state)</th>
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</tbody>
</table>

Please add any comments below, that you may have regarding frequency of treatment. **(please state)**
4.3 Following assessment who else, if any, would supervise the strengthening programme?

<table>
<thead>
<tr>
<th>Physiotherapy assistant</th>
<th>Never</th>
<th>Occasional</th>
<th>Frequently</th>
<th>Majority of the time</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents/carer</td>
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<tr>
<td>Educational support</td>
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<tr>
<td>Other (please state)</td>
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</table>

Please give comments regarding supervision, if any ________________________________

5. **Reassessment and Progression**

5.1 For the following patient groups, please state how frequently you reassess their muscle strength. Please tick all relevant boxes.

- [ ] No formal reassessment

### Signs of Deterioration

<table>
<thead>
<tr>
<th>Measures</th>
<th>0-2 wks</th>
<th>3-5 wks</th>
<th>6-8 wks</th>
<th>2-3 mths</th>
<th>4-6 mths</th>
<th>7-9 mths</th>
<th>10-12 mths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not relevant to my caseload</td>
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<tr>
<td>Functional Measure</td>
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<tr>
<td>Formal Scale</td>
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<tr>
<td>Use of Equipment e.g. Dynamometer</td>
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<td>Other (please state)</td>
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</table>

### Post Surgery

<table>
<thead>
<tr>
<th>Measures</th>
<th>0-2 wks</th>
<th>3-5 wks</th>
<th>6-8wks</th>
<th>2-3 mths</th>
<th>4-6 mths</th>
<th>7-9 mths</th>
<th>10-12 mths</th>
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<tbody>
<tr>
<td>Not relevant to my caseload</td>
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<td>Functional Measure</td>
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<tr>
<td>Formal Scale</td>
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<tr>
<td>Use of Equipment e.g. Dynamometer</td>
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</table>

### Serial Casting

<table>
<thead>
<tr>
<th>Measures</th>
<th>0-2 wks</th>
<th>3-5 wks</th>
<th>6-8 wks</th>
<th>2-3 mths</th>
<th>4-6 mths</th>
<th>7-9 mths</th>
<th>10-12 mths</th>
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<tbody>
<tr>
<td>Not relevant to my caseload</td>
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<tr>
<td>Formal Scale</td>
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<tr>
<td>Use of Equipment e.g. Dynamometer</td>
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<td>Other (please state)</td>
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</tbody>
</table>
### Post-Botulinum Toxin

<table>
<thead>
<tr>
<th>Measures</th>
<th>0-2 wks</th>
<th>3-5 wks</th>
<th>6-8 wks</th>
<th>2-3 mths</th>
<th>4-6 mths</th>
<th>7-9 mths</th>
<th>10-12 mths</th>
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<tbody>
<tr>
<td>Not relevant to my caseload</td>
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<td>Functional Measure</td>
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<td>Formal Scale</td>
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<tr>
<td>Use of Equipment e.g. Dynamometer</td>
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<tr>
<td>Other <em>(please state)</em></td>
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</table>

### Specific Weakness Identified Post-Gait Analysis

<table>
<thead>
<tr>
<th>Measures</th>
<th>0-2 wks</th>
<th>3-5 wks</th>
<th>6-8 wks</th>
<th>2-3 mths</th>
<th>4-6 mths</th>
<th>7-9 mths</th>
<th>10-12 mths</th>
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</thead>
<tbody>
<tr>
<td>Not relevant to my caseload</td>
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<tr>
<td>Functional Measure</td>
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<tr>
<td>Formal Scale</td>
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<tr>
<td>Use of Equipment e.g. Dynamometer</td>
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<tr>
<td>Other <em>(please state)</em></td>
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</table>

5.2 What methods do you use to progress your strengthening programme? *(Please tick all that apply)*

- [ ] Do not progress
- [ ] Increase repetitions
- [ ] Increase holds/holding time
- [ ] Increase weight
- [ ] Change starting position
- [ ] Change way muscle works e.g. type of muscle activity (concentric/eccentric)
- [ ] Other *(please state)*

6. **Moving Towards Independence**

6.1 For what reason(s) would you discontinue a muscle strengthening programme? *(Please tick all that apply)*

- [ ] Goals reached
- [ ] Poor compliance
- [ ] No improvement
- [ ] Plateau of function
- [ ] Other *(please state)*
6.2 How long do you continue with a specific strengthening programme? (Please tick all that apply)

<table>
<thead>
<tr>
<th></th>
<th>Post-surgery</th>
<th>Serial Casting</th>
<th>Post Botex</th>
<th>Weakness Identified Post-Gait Analysis</th>
<th>Signs of Deterioration</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Single site</td>
<td>Multi site</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;2 weeks</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2-8 weeks</td>
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<tr>
<td>3-6 months</td>
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<td>6-12 months</td>
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<tr>
<td>Other (please state)</td>
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</tbody>
</table>

6.3 What advice is given regarding maintaining muscle strength following discontinuation of a muscle strengthening programme? e.g. encourage gym attendance.

Please attach or indicate any information/programmes/leaflets/tools that you use.

7. Training and Education

7.1 Where have you gained your experience in the use of muscle strengthening? (Tick all that apply)

- Physiotherapy training
- Research
- Paper reviews
- Peer discussion
- Higher degree
- Other (please state)

Although this questionnaire is anonymous, we would welcome the name of your organization and any other comments.

Thank you for taking the time to complete this questionnaire.

Please return, in the pre-paid envelope attached, to: The Gait Analysis Laboratory, Alder Hey Hospital, Eaton Road, Liverpool, L12 2AP.
Profiles of Respiratory Muscle Weakness in Type II Spinal Muscular Atrophy and Duchenne Muscular Dystrophy

Michelle Chatwin PhD [*], Michael I Polkey PhD, Anita K Simonds MD

NIHR Respiratory Biomedical Research Unit, Royal Brompton Hospital & Imperial College

*Corresponding author: E-mail: m.chatwin@rbht.nhs.uk

ABSTRACT

Background
Clinical experience suggests that patients with intermediate spinal muscular atrophy (SMA) are predisposed to recurrent chest infections, which may precede the development of nocturnal hypoventilation. These often occur in the first and second decade of life. We therefore hypothesised that early development of expiratory muscle weakness is a clinical feature of SMA.

Methods
Inspiratory and expiratory muscle strength was measured as maximal static inspiratory and expiratory mouth pressures (PImax and PEmax) in 29 patients with type II SMA age 23±14 years, 26 patients with Duchenne Muscular Dystrophy (DMD) age 19±6 years and 25 healthy controls age 23±9 years.

Results
SMA patients had greater expiratory (PEmax 29±14 cmH2O) than inspiratory (PImax 39±14 cmH2O) (p=0.009) muscle weakness, unlike both the DMD patients and normal controls in whom inspiratory and expiratory strength was numerically equal (Duchennes PImax 20±13 cmH2O and PEmax 19±12 cmH2O and controls PImax 101±30 cmH2O and PEmax 109±35 cmH2O).

Conclusion
Patients with Type II SMA have disproportionate expiratory muscle weakness. Non-invasive respiratory muscle testing is a simple technique that can identify weakness in this patient population.

Introduction
The ability to clear broncho-pulmonary secretions is essential to prevent sputum retention and associated complications, including lower respiratory tract infection. An effective cough is a vital mechanism to protect against respiratory tract infections, which are the commonest cause of hospital admission in patients with respiratory muscle weakness due to neuromuscular disease (NMD) (Bach et al 1997). The muscles involved in inspiration are the diaphragm, external and parasternal intercostal muscles and ‘accessory muscles’ (scalenes and sternocleidomastoid). The diaphragm is the main muscle of inspiration; contraction of the diaphragm has two actions: i) lowering the dome, and ii) expanding the lower ribcage. Expiration is usually passive. In all expulsive acts (e.g. coughing) the diaphragm is activated to give additional power to each expulsive effort and along with the expiratory muscles (external oblique, rectus transversus, abdominis and the internal intercostal) these contract to cause a rise in abdominal pressure. Other factors can impair cough, such as the ability to fully inspire prior to the cough or vocal cord dysfunction. In a pure muscular respect the ability to mount an effective cough is lost when the maximal intra-abdominal pressure is less than 50 cm H2O (Hughes et al 1998).

Spinal muscular atrophy (SMA) is a rare congenital disorder which is classified into 3 clinical groups according to the age at which the individual fails to achieve motor milestones (Munsat & Davies 1992). Type I SMA is classified functionally by the individual being unable to sit independently. Type II SMA is florid large group atrophy and many patients never walk but are classified by an ability to sit independently. Type III have an onset after two years of life, they are able to walk and are said to have a normal life expectancy. Anecdotally we have found that recurrent chest infections may precede Type II respiratory failure in SMA patients, unlike the clinical situation in the commonest childhood neuromuscular disease (Duchenne muscular dystrophy (DMD) where ventilatory
insufficiency and frequent chest infections tend to develop in tandem. Carter et al (1995) reported skeletal and respiratory muscle strength in patients with SMA Type II and III. $P_{\text{Emax}} : P_{\text{Imax}}$ ratio was 0.79 only in patients with SMA Type II suggesting predominant expiratory muscle weakness (Carter et al 1995). No studies however have evaluated the profile of respiratory muscle weakness in patients with SMA and DMD, or compared them to a normal population. We hypothesised that early development of expiratory muscle weakness is a clinical feature of SMA type II but not DMD. Detection of impaired cough would be fruitful since augmented cough techniques are available for clinical use (Barach & Beck 1954; Chatwin et al 2003; Mustfa et al 2003). To test this hypothesis we measured the $P_{\text{Emax}} : P_{\text{Imax}}$ ratio in patients with SMA, DMD and age matched control subjects.

**Methods**

**Subjects**

Patients with DMD and SMA attend our ventilation clinic. As part of routine assessment respiratory muscle testing is carried out. These data and data that were collected (and have been previously published) as part of a trial (Chatwin et al, 2003) were gathered. Healthy age matched controls were recruited from staff and their families at the Royal Brompton Hospital. Consent to carry out routine respiratory muscle testing was obtained from the patient group and the normal subjects.

Patients were approached in they had stable NMD with no evidence of respiratory tract infection in the previous 4 weeks and had a history of an ineffective cough. Patients were not approached if there was a history of pneumothorax, moderate or severe bulbar weakness, presence of co-existing lung pathology i.e. asthma, if they were unable to tolerate a facemask or comply with instructions.

**Measurements**

The maximal sniff nasal inspiratory pressure (SNIP) (Heritier, 1994; Harraf, 2008; Nicot, 2006; Steier 2007), $P_{\text{Imax}}$ and $P_{\text{Emax}}$ mouth pressures (Wilson et al, 1984) and maximal whistle mouth pressure ($P_{\text{moW}}$) (Chetta et al, 2001) were used as indices of inspiratory and expiratory muscle strength. SNIP was measured through a plug occluding one nostril during a maximal sniff performed through the contralateral nostril (Heritier, 1994). Repeated sniffs from functional residual capacity (FRC) were performed until no further increase in pressure was seen, with the highest value being recorded as the SNIP (Uldry, 1995). $P_{\text{Imax}}$ was measured during a maximal inspiratory manoeuvre from residual volume via a flanged mouthpiece with nose clip in situ, performed against a closed connector with a small hole attached to a pressure line. $P_{\text{Emax}}$ was recorded using the same equipment during a maximal expiratory manoeuvre from total lung capacity (TLC), the average pressure reading over one second is taken as the result (Black & Hyatt, 1971). We measured $P_{\text{moW}}$ as described by Chetta et al (2001) so that participants were asked to blow as hard as possible from total lung capacity (TLC) ‘backwards’ through a paediatric whistle inhaler trainer (Astra, Pharmaceuticals Ltd. Herts, UK) connected to flanged mouthpiece without nose clips, the peak pressure tracing was recorded (Chetta et al, 2001). Manoeuvres were repeated at least 6 times until three readings were within 10% of each other. The highest of these readings was taken as the result for analysis (Wilson et al 1984). All subjects were given a significant time to rest in between each manoeuvre to prevent fatigue. All signals were measured using a differential pressure transducer (Validyne, USA) and amplified. The signals were passed via an analog-digital board to a computer running Labview software (National Instruments, USA) or via a hand held portable monitor ($P_{\text{max}}$, PK Morgan Gillingham, UK). During testing, patients had strong verbal encouragement as previous studies have suggested (Laporta & Grassino, 1985).

Peak cough flow (PCF) was also recorded; patients were asked to cough as hard as possible into a tight fitting face mask connected to a portable spirometer (ML3500, Micro Medical, Rochester, UK) or by a face mask connected via plastic tubing to a brass tube (41cm long and 3.5cm internal diameter). The brass tubing was inserted into the circuit to ensure laminar flow. The tube was connected to a Fleisch #4 pneumotachograph head (Lausanne, Switzerland) and an electrospirometer (GM Instruments, UK) The signal passed via an analog-digital board to a computer running LabView software (National Instruments, USA).

**Statistical analysis**

For all tests the single greatest value obtained was used for analysis. Results were tested for normality using the Kolmogorov-Smirnov test. Where data was normally distributed they were expressed as mean ± SD, and differences between
the three groups were tested with parametric tests. For comparison of two means an unpaired t-test was used. Where 3 conditions were compared (SMA, DMD and normals), and these were parametric data, analysis of variance (ANOVA) with repeated measures was used. Where the interaction term was $<0.05$ post hoc analysis pairwise multiple comparison procedure (Tukey test) was used. Non-parametric data with repeated measures were tested using Friedman repeated measures analysis of variance. The null hypothesis i.e. there is no difference between inspiratory or expiratory muscle strength, was rejected at $p>0.05$.

**Results**

We evaluated the inspiratory and expiratory muscle test results in 29 patients with SMA type II age 23±14 years (15 male), 26 patients with DMD age 19±6 years and 25 healthy controls age 23±9 years (13 male). All patients had been referred to the Royal Brompton Hospital for evaluation of sleep disordered breathing or presented with a history of recurrent chest infections.

Results for inspiratory and expiratory muscle strength along with peak cough flow (PCF) are shown in Table 1.

There was a significant difference in inspiratory and expiratory muscle tests in the SMA population (SNIP vs. PmoW $p=0.01$, PImax vs. PEmax $p=0.009$) with expiratory muscles being weaker relative to inspiratory muscles (Figure 1a). Post hoc power calculations showed that the sample size of $n=29$, at 0.05 significance level, produced a power of 97% for SNIP vs. PmoW, and 96% for PImax vs. PEmax. There was no difference between inspiratory and expiratory muscle strength for the DMD group (SNIP vs. PmoW $p=ns$, PImax vs. PEmax $p=ns$) (Figure 1b). In order to demonstrate a significant difference in respiratory muscle strength, with a power of 90%, and type 1 error probability of 0.05, a sample size of 1329 patients would have been required. By contrast in normal subjects PmoW was greater than SNIP ($p<0.001$), though no statistical difference was observed between PImax and PEmax (Figure 1c.)

<table>
<thead>
<tr>
<th></th>
<th>SMA</th>
<th>DMD</th>
<th>Controls</th>
<th>$p$ value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sniff nasal inspiratory pressure (SNIP) (cmH$_2$O)</td>
<td>42±16$^{*\dagger}$</td>
<td>21±15$^{*\dagger}$</td>
<td>94±22$^{*\dagger}$</td>
<td>$p&lt;0.001$</td>
</tr>
<tr>
<td>‘Whistle Expiratory pressure’ (P$_{mow}$) (cmH$_2$O)</td>
<td>30±16$^{\dagger}$</td>
<td>21±14$^{\dagger}$</td>
<td>133±45$^{\dagger}$</td>
<td>$p&lt;0.001$</td>
</tr>
<tr>
<td>Maximum inspiratory pressure (P$_{imax}$) (cmH$_2$O)</td>
<td>39±14$^{*\dagger}$</td>
<td>20±13$^{*\dagger}$</td>
<td>101±30$^{*\dagger}$</td>
<td>$p&lt;0.001$</td>
</tr>
<tr>
<td>Maximum expiratory pressure (P$_{emax}$) (cmH$_2$O)</td>
<td>29±14$^{\dagger}$</td>
<td>19±12$^{\dagger}$</td>
<td>109±35$^{\dagger}$</td>
<td>$p&lt;0.001$</td>
</tr>
<tr>
<td>Peak cough flow (PCF) (L$_{min}$-1)</td>
<td>169±80$^{\dagger}$</td>
<td>158±67$^{\dagger}$</td>
<td>608±145$^{\dagger}$</td>
<td>$p&lt;0.001$</td>
</tr>
</tbody>
</table>

Results are shown as mean±SD

$^*$p<0.05 for difference between SMA and DMD

$^\dagger$p<0.05 for difference between SMA and controls

$^\ddagger$p<0.05 for difference between DMD and controls

Table 1: Spinal muscular atrophy (SMA), Duchenne Muscular Dystrophy (DMD) and controls
Figure 1a: Spinal Muscular Atrophy Type II
Respiratory muscle strength characteristics in Spinal muscular atrophy patients
The solid line denotes the group mean. There is a significant difference between inspiratory vs. expiratory muscle strength for both tests (p<0.01). Sniff nasal inspiratory pressure (SNIP), ‘whistle’ expiratory pressure (PmoW), maximum inspiratory (PImax) and expiratory pressure (PEmax) at the mouth over one second.

Figure 1b: Duchenne Muscular Dystrophy
Respiratory muscle strength characteristics in Duchenne muscular dystrophy patients
The solid line denotes the group mean. There was no significant difference between inspiratory vs. expiratory muscle strength. Sniff nasal inspiratory pressure (SNIP), ‘whistle’ expiratory pressure (PmoW), maximum inspiratory (PImax) and expiratory pressure (PEmax) at the mouth over one second.

Figure 1c: Normal Subjects
Respiratory muscle strength characteristics in normal controls. Sniff nasal inspiratory pressure (SNIP), ‘whistle’ expiratory pressure (PmoW), maximum inspiratory (PImax) and expiratory pressure (PEmax) at the mouth over one second. The solid line denotes the group mean. There is a significant difference between SNIP vs. PmoW.
Discussion

In the present study we confirm that expiratory muscle strength is significantly lower than inspiratory muscle strength in Type II SMA but not DMD; our observations in normal subjects confirm prior reports that expiratory muscles tend to be stronger than the inspiratory (Steier et al, 2007). We suggest that this may explain the clinical picture of early chest infections in the absence of overt ventilatory failure in SMA. Early involvement of the expiratory muscles may suggest a role for a specific management plan of this problem beyond the provision of non-invasive ventilation which remains the treatment of choice for hypoventilation due to inspiratory muscle weakness.

A previous study assessed the profile of weakness in SMA. As part of their study maximal static pressures were measured in 17 patients with Type II SMA and 13 with Type III (Carter et al, 1995). The PE\textsubscript{max}:PIm\textsubscript{max} ratio was 0.79 suggesting predominant expiratory muscle weakness consistent with the present data; but similar data were not obtained in Type III SMA. Nicot et al (2006), evaluated invasive versus non invasive respiratory muscle testing in a smaller group which contained both DMD and SMA patients. They showed a good correlation between invasive and non invasive tests however, they did not compare the profile of respiratory muscle weakness for the different diagnoses. From their data a comparison can be made for sniff oesophageal pressure (Sn P\textsubscript{oes}) and cough gastric pressure (Co P\textsubscript{gas}) the ratio for Sn P\textsubscript{oes} and Co P\textsubscript{gas} for DMD and SMA respectively is 1.0 and 1.18. We were not able to directly compare our results to those of Nicot et al., as there are specific differences between maximal static manoeuvres and Sn P\textsubscript{oes} and Co P\textsubscript{gas}, importantly that static manoeuvres are usually performed from extremes of lung volume (residual volume and TLC) rather than FRC and, of course, the latter manoeuvres are dynamic. A further methodological issue concerns gender; our DMD patients were, as expected, all males while only 50% of both controls and SMA patients were males. One explanation for our data could be that gender is a determinant of the ratio of expiratory to inspiratory muscle strength. However, previous studies of adolescent healthy subjects have recorded no difference in the ratio of expiratory to inspiratory muscle strength judged by static measures between genders (Cook et al, 1964; Jones et al, 1981; Leech et al, 1983; Smyth et al, 1984).

Both portable and laboratory based equipment was used to measure respiratory muscle strength and peak cough flow. We compared the same patients inspiratory and expiratory muscle strength with the same piece of equipment. Therefore we can exclude that results for our SMA patients showing predominant expiratory muscle weakness were as a result of using both laboratory and portable testing devices.

A logical question in health care settings where resources are finite, is whether it is better to provide mechanical insufflation-exsufflation or non-invasive ventilation in patients who do not have daytime hypercapnia. Non invasive ventilation and manual assisted coughing have both been shown to decrease respiratory tract infections in children with NMD (Dohna-Schwake, 2008) and prevent chest wall deformity in SMA type I (Bach & Bianchi, 2003; Chatwin et al, 2011). Airway clearance with NIV is possible (Chatwin & Simonds, 2011). It is our opinion however that mechanical insufflation-exsufflation may be most useful for a small subgroup of patients who have recurrent chest infections without hypercapnic respiratory failure; though we acknowledge that this view needs to be tested in a prospective randomised controlled trial. Our data suggest that such a trial might most usefully be performed in patients with SMA rather than DMD.

Coughing is multi-step physiological process; an effective cough requires an individual to be able to breathe in up to 85-90% of their predicted total lung capacity. Bulbar function needs to be intact so that the glottis closes for approximately 0.2 seconds to enable thoraco-abdominal pressures of >190 cm H\textsubscript{2}O to be generated (Leith, 1985), at least in healthy subjects. Prospective screening could identify expiratory muscle weakness in SMA patients with a history of recurrent chest infections so that appropriate back up emergency antibiotic treatment can be provided along with suitable education and provision for appropriate mechanical airway clearance techniques.

We conclude that patients with Type II SMA have disproportionate expiratory muscle weakness. Non-invasive respiratory muscle testing is a simple technique that can identify weakness in this patient population and facilitate rational management.
References


Barach A, Beck G (1954). ‘Exsufflation with negative pressure; physiologic and clinical studies in poliomyelitis, bronchial asthma, pulmonary emphysema, and bronchiectasis’, AMA Arch Intern Med. 93, 6, 825-41


Chatwin M, Simonds A (2009). ‘The addition of mechanical insufflation/exsufflation shortens airway-clearance sessions in neuromuscular patients with chest infection’, Respir Care, 24, 11, 1473-9

Chatwin M, Bush A, Simonds AK (2011). ‘Outcome of goal-directed non-invasive ventilation and mechanical insufflation/exsufflation in spinal muscular atrophy type I’, Archives of Disease in Childhood, 96, 5, 426-32


Munsat T, Davies K (1992). ‘International SMA consortium meeting’, Neuromuscul Disord. 2, 5-6, 423-8


Posture and Sleep in Children with Cerebral Palsy: A Case Study

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ABSTRACT

Aims
To explore the views of children on using a sleep system, the role of their parents and therapists in its use, and the quality of sleep achieved as a result.

Background
Night-time postural support is often recommended for children with bilateral cerebral palsy. The views of the children who use them, their parents and therapists have not been explored.

Design
A multiple case study.

Participants
Seven children aged between 18 months and 9 years with bilateral cerebral palsy in GMFCS Levels III–V, due to be prescribed a sleep system, their parents and therapists were included in the study.

Results
Children as young as 3 years old were able to express their views using a Talking Mat. Sleep difficulties were found in 6 out of 7 children. Quality of sleep in 2 improved with the use of a sleep system. Six children were thought to experience regular pain or discomfort, 2 reported greater comfort when sleeping in their sleep system. Some of the therapists who were prescribing sleep systems seemed to lack knowledge and experience of postural management.

Conclusions
Sleep systems may enable some children to sleep more comfortably and even young children are able to express their views about them if given the appropriate tools. Sleep difficulties are prevalent in this population and families need timely access to sleep services to facilitate change in poor sleep behaviours. Postural management may need to be seen as a specialist area and therapists working in postural management should be able to evidence their competency.

Introduction
Prevention of pain and deformity remain priorities in treatment for the most severely affected children with cerebral palsy (CP). Twenty-four hour postural management is a conservative, non-invasive approach commonly adopted by therapists to try to achieve these aims although there is, as yet, limited evidence of its effectiveness.

Night-time postural support is recommended on evidence provided by an expert group (Gericke 2006) however there is little research evidence to date of its role in the prevention of deformity. Experience from clinical practice and some evidence from available literature (Pountney et al 2009) suggests that families abandon sleep systems more frequently than other pieces of postural management equipment. Poor sleep and inability to adapt to a change in sleeping position is thought to be a cause of abandonment (Hankinson and Morton 2002; Pountney et al 2009). It is also suggested that children with severe difficulties may experience pain while using sleep systems, resulting in parents abandoning the equipment (Gough 2009).

The experiences of children using sleep systems and their parents would inform the causes of non-adoption or abandonment of sleep systems, but this has yet to be explored. Children with little or no verbal communication, who may also have cognitive impairments, are rarely consulted on therapy interventions. The techniques required to consult with young children are not well-tested or described.
It is expected that therapists should have the knowledge, skills and experience to be able to competently assess a child for the requirement for postural management at night (DH 2004). Despite guidance from national bodies and specific interest groups, therapists' provision of sleep systems continues to vary across the country. The clinical reasoning, knowledge, skills and experience of therapists who are prescribing sleep systems has not been investigated.

The aims of the study were to explore the views of children and their parents on using a sleep system, the role of the therapist in the child's and family's experience of using a sleep system, and the effects of using a sleep system on quality of sleep.

Methods

The practical approach to answering the research question was to use case study which is described by Robson (2002) as involving: ‘... an empirical investigation of a particular contemporary phenomenon in its real life context ...’ This was a multiple case study design with each case consisting of a child, the child’s parents or main carers and the child’s therapist (physiotherapist or occupational therapist). The method used within each case was semi-structured interviews for the parents and structured interviews, using Talking Mats where necessary, for the children.

Children were included if: they had bilateral CP classified in levels III, IV or V on the Gross Motor Function Classification System (Palisano 1997); had just been prescribed a sleep system by their local therapist; and were between the ages of 18 months and 9 years.

The study was approved by the University of Brighton’s Faculty Research Ethics and Governance Committee, and the Devon and Torbay Research Ethics Committee. The Peninsula Primary Care Research Management and Governance Unit administered requests for research governance approval and this was gained in 9 trusts in the South-West of England.

The study was presented to therapists in their local settings. They were introduced to the Chailey Sleep Questionnaire version 41 (Khan and Underhill 2006) which when completed with parents not only provides a sleep history but also highlights potential risks from sleep apnoea, reflux and epilepsy.

Therapists were asked to select parents and children on their caseloads who met the inclusion criteria and to explain the study to them. They were asked to contact the researcher if they were interested in taking part. Interested parents were sent information sheets for the child, themselves and the treating therapist. Consent forms for the parents and therapist were also included. Therapists were asked to use the Chailey Sleep Questionnaire prior to prescription of the sleep system and were encouraged to discuss the results with the child’s paediatrician if concerns were raised and before final decisions about sleep system prescription were taken.

Consent for the children was a process rather than a single event and was requested on an ongoing basis. The research team checked with the child throughout the interview process that they were willing to continue, by taking notice of their facial expression, vocalisation, eye-pointing and body movement.

Data collection

Interviews

Therapists were interviewed only once prior to interviews with the parents and child. Knowledge obtained from the therapist concerning the child’s particular circumstances and family situation was used to inform the subsequent interviews with the parents and child.

The interviews with parents were semi-structured but with the opportunity for parents to talk about their experiences freely if they wished. The first interview was just after prescription of the sleep system but before the equipment was in place. The second interview with the parents was conducted between 4 and 6 months after the child received the sleep system.

All children aged 3 and over were interviewed by the researcher and an experienced speech and language therapist using the Talking Mat method (Murphy 1998). This consists of a velcro mat and picture symbols. A question was posed and placed in the centre of the board, at the top. Symbols representing what the child may like to say were then offered which the child could place, either

1 The published version of the Chailey Sleep Questionnaire is available from Chailey Heritage Clinical Services.
physically or by indicating with their eyes, under a “yes” or “no” or in other instances a “like”, “don’t like” column. Likely vocabulary was established in a pilot study in which a number of children with CP with good verbal skills talked about their own sleep preparations and night awakenings in a pass-the-parcel type game. Photographic records were made of the mats after each question had been answered. Children under the age of 3 were not interviewed.

Sleep diaries
Parents were asked to keep a diary of their child’s sleep for 10 consecutive nights prior to each interview. The diary recorded how long it took for the child to get to sleep, the number of hours asleep and the number of awakenings during the night. A record of whether the child fell asleep in their own bed and whether they needed the presence of a parent to enable them to fall asleep was also made.

Data analysis
The Framework method, developed by the National Centre for Social Research, was used to analyse the interview responses from the therapists and parents. Thematic content analysis, in which common themes are identified, was considered appropriate for analysing the children’s responses (Green and Thorogood 2004).

Results

Participants
The details of the children in the study are presented below in Table 1.

Results from the sleep diaries
Only 3 of the 7 sets of parents returned the diaries. The sleep diaries were able to provide valuable information on the length of time taken to settle to sleep, the number of awakenings and length of time asleep, both prior to commencement of sleep system use and following it. Where no sleep diaries were available, details were taken from the interviews with parents and children.

Data analysis
The Framework method clearly described by Ritchie and Spencer (1994), involves a process of familiarisation and the formation of thematic frameworks for each case. With further abstraction and synthesis five key dimensions were identified which distilled the range of views and experiences across the cases.

<table>
<thead>
<tr>
<th>Child number</th>
<th>Age on entry to study</th>
<th>Diagnosis</th>
<th>GMFCS Level</th>
<th>Child Interviewed</th>
<th>Type of sleep system</th>
<th>Prior preferred sleeping position</th>
<th>Sleeping position in sleep system</th>
<th>Outcome at conclusion of data collection period</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>6yrs 6mths</td>
<td>CP Spastic diplegia</td>
<td>III</td>
<td>Yes</td>
<td>Chailey Lying Support</td>
<td>Supine</td>
<td>Supine</td>
<td>Child sleeping well in SS</td>
</tr>
<tr>
<td>2</td>
<td>3yrs 4mths</td>
<td>CP Spastic quadriplegia</td>
<td>IV</td>
<td>Yes</td>
<td>Leckey Sleepform</td>
<td>Supine or side lying</td>
<td>Supine</td>
<td>Child sleeping well in SS</td>
</tr>
<tr>
<td>3</td>
<td>2yrs 2mths</td>
<td>CP or possibly West Syndrome</td>
<td>V</td>
<td>No</td>
<td>Leckey Sleepform</td>
<td>Cuddled up to parent</td>
<td>Supine</td>
<td>Child not using SS</td>
</tr>
<tr>
<td>4</td>
<td>2yrs 3mths</td>
<td>CP Spastic quadriplegia</td>
<td>IV</td>
<td>No</td>
<td>Symmetrical Sleep</td>
<td>Right side lying</td>
<td>Right side lying and supine</td>
<td>Child not using SS</td>
</tr>
<tr>
<td>5</td>
<td>3yrs 6mths</td>
<td>CP Spastic quadriplegia</td>
<td>IV</td>
<td>Yes</td>
<td>Jenx Dreama</td>
<td>Supine</td>
<td>Supine</td>
<td>SS not fully set up</td>
</tr>
<tr>
<td>6</td>
<td>4yrs 5mths</td>
<td>CP Spastic diplegia</td>
<td>III</td>
<td>Yes</td>
<td>Chailey Lying Support</td>
<td>Side lying</td>
<td>Supine</td>
<td>Child unhappy but parents persevering</td>
</tr>
<tr>
<td>7</td>
<td>3yrs 11mths</td>
<td>CP, microcephaly</td>
<td>V</td>
<td>No</td>
<td>Chailey Lying Support</td>
<td>Foetal position</td>
<td>Supine</td>
<td>Child sleeping well in SS</td>
</tr>
<tr>
<td>8</td>
<td>3yrs 8mths</td>
<td>CP, microcephaly</td>
<td>V</td>
<td>No</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>Child excluded due to identification of risks</td>
</tr>
</tbody>
</table>

Table 1: Details of the children participating in the study

SS = sleep system
1. Child’s pain

Of the 7 children, 6 were thought to have pain, or at least discomfort, either during the day or which caused them to wake at night. Of the 4 children interviewed, 2 reported pain at night and were able to identify the site of the pain. Both of these children were only 3 years old at the first interview and said specifically that the pain was in their legs.

Discomfort at night as a result of being in awkward positions was reported by 3 out of the 7 families. Prior to receiving the sleep system child 7 slept in a tightly curled-up foetal position and was described as being so stiff in the mornings that she screamed whilst being dressed.

“She had awful problems sleeping, her arm got trapped underneath her. She was so stiff in the night it was difficult to stretch out her legs to turn her over. Dressing was uncomfortable and took a long time; she used to scream the house down.” (Mother of child 7)

2. Child’s ability to adapt and parents’ readiness to persevere

Of the 4 children interviewed: 2 said that they liked their sleep systems and were comfortable in them at night; 1 said she definitely did not like hers; and 1 was ambiguous although he continued to sleep well in it (Table 3).

Two children demonstrated significantly improved sleep. One was reported by the child’s nursery also to have increased concentration. Another parent reported improved quality of life for the whole family as a result of the child sleeping well (Table 4).

At the close of the data collection period, parents of 2 of the 7 children were persevering in encouraging their child to adapt to sleeping in their sleep systems. One of these was still awaiting correct set-up of the sleep system 7 months after it was delivered although she was sleeping in it. Her parents were expressing extreme frustration by the wait.

“It feels like it’s been quite a long haul really. …(the physio) did come a few times to try and sort it out but I think she can be unsure of what we need to do and what we need to change so then the rep will have to step in. And I’m just not that very good at waiting. I’m just impatient.” (Mother of child 5)
The remaining 2 children were not using their sleep systems. One was experiencing severe fits, was wakeful at night and could not settle alone. The second child initially slept better in the sleep system but became distressed after 2 weeks. In both cases the parents of these children thought their child’s sleeping position had been improved in the sleep system.

<table>
<thead>
<tr>
<th>Case number</th>
<th>Likes SS?</th>
<th>Comfy in SS?</th>
<th>If not, why not?</th>
<th>Comfy in the morning when wake up in SS</th>
<th>Continues to sleep in SS?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Undecided. Prefers weekends when he is out of his SS</td>
<td>Undecided</td>
<td>“I don’t know”</td>
<td>“Urrr no” Prefers “just in my bed”</td>
<td>Yes</td>
</tr>
<tr>
<td>2</td>
<td>Yes</td>
<td>Yes</td>
<td>N/A</td>
<td>No pain</td>
<td>Yes</td>
</tr>
<tr>
<td>3</td>
<td>Child too young to be interviewed</td>
<td></td>
<td></td>
<td></td>
<td>No</td>
</tr>
<tr>
<td>4</td>
<td>Child too young to be interviewed</td>
<td></td>
<td></td>
<td></td>
<td>No</td>
</tr>
<tr>
<td>5</td>
<td>Yes</td>
<td>Yes</td>
<td>N/A</td>
<td>Fine</td>
<td>Still awaiting correct set-up</td>
</tr>
<tr>
<td>6</td>
<td>No</td>
<td>No</td>
<td>But later said yes</td>
<td>Can’t turn over and wants to turn over Likes to lie on side not on her back</td>
<td>Wakes up out of SS</td>
</tr>
<tr>
<td>7</td>
<td>Child thought by local team to be unable to give her views</td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
</tr>
</tbody>
</table>

**Table 3: Child’s view of sleeping in sleep system**

<table>
<thead>
<tr>
<th>Case number</th>
<th>Parents’ anticipated difficulties</th>
<th>Parents view of child’s experience</th>
<th>Use of sleep system (SS)</th>
<th>Parents attended formal PM training?</th>
<th>Parents’ comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Parents thought child would miss being able to get out of bed at night.</td>
<td>Quite happy to go in SS</td>
<td>5 nights a week, weekends out Supine not prone as anticipated</td>
<td>Yes</td>
<td>Having a SS from an early age would prevent bad habits forming</td>
</tr>
<tr>
<td>2</td>
<td>Told by PT SS may not work for their child</td>
<td>Relaxed in it when demonstrated and screamed “blue murder” when taken away</td>
<td>Used in daytime for nap but also from first night Used every night</td>
<td>No</td>
<td>Had to persevere for 3 weeks of “screaming cabdabs”. Child sleeps much better. Better concentration reported by nursery</td>
</tr>
<tr>
<td>3</td>
<td>Discomfort from having a major fit in the SS Won’t go to sleep without being cuddled</td>
<td>Woken by fits. Needed to be cuddled back to sleep</td>
<td>Tried for 4 weeks</td>
<td>No</td>
<td>Thought position was good until be moved with a fit. Sleep problems just too severe</td>
</tr>
<tr>
<td>4</td>
<td>Uncertain if child would tolerate it</td>
<td>Used for 2 weeks and child slept through 2/3 times which was unusual. Then child not happy and was restricted because she’d learnt to roll</td>
<td>Used for 2 weeks successfully then child resistant</td>
<td>No</td>
<td>Liked the position it held child in especially top leg in side lying. Would have been better when child was younger before she could move</td>
</tr>
<tr>
<td>5</td>
<td>Hopeful child will be more comfortable and with a better posture</td>
<td>Takes time to get used to change but has moved from cot to bed</td>
<td>Still not set up correctly</td>
<td>No</td>
<td>Frustrated with time taken to get right. PT doesn’t have the knowledge to set it up &amp; has to wait for rep</td>
</tr>
<tr>
<td>6</td>
<td>Parents thought child would miss being able to get out of bed at night</td>
<td>Child very unhappy and distressed Doesn’t like not being able to turn over</td>
<td>Is always put into SS but comes out either before going to sleep, early evening or at best at 12.00/1.00</td>
<td>Yes</td>
<td>Parents are determined to continue.</td>
</tr>
<tr>
<td>7</td>
<td>Desperate for anything that might improve child’s sleep</td>
<td>Settled very quickly Not so stiff at night or in morning</td>
<td>Slept through the night from first night</td>
<td>Yes</td>
<td>“SS has improved everybody’s QOL, everyone is sleeping better”</td>
</tr>
</tbody>
</table>

**Table 4: Parents’ views of the sleep system**

<table>
<thead>
<tr>
<th>Case number</th>
<th>Parents’ anticipated difficulties</th>
<th>Parents view of child’s experience</th>
<th>Use of sleep system (SS)</th>
<th>Parents attended formal PM training?</th>
<th>Parents’ comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Parents thought child would miss being able to get out of bed at night.</td>
<td>Quite happy to go in SS</td>
<td>5 nights a week, weekends out Supine not prone as anticipated</td>
<td>Yes</td>
<td>Having a SS from an early age would prevent bad habits forming</td>
</tr>
<tr>
<td>2</td>
<td>Told by PT SS may not work for their child</td>
<td>Relaxed in it when demonstrated and screamed “blue murder” when taken away</td>
<td>Used in daytime for nap but also from first night Used every night</td>
<td>No</td>
<td>Had to persevere for 3 weeks of “screaming cabdabs”. Child sleeps much better. Better concentration reported by nursery</td>
</tr>
<tr>
<td>3</td>
<td>Discomfort from having a major fit in the SS Won’t go to sleep without being cuddled</td>
<td>Woken by fits. Needed to be cuddled back to sleep</td>
<td>Tried for 4 weeks</td>
<td>No</td>
<td>Thought position was good until be moved with a fit. Sleep problems just too severe</td>
</tr>
<tr>
<td>4</td>
<td>Uncertain if child would tolerate it</td>
<td>Used for 2 weeks and child slept through 2/3 times which was unusual. Then child not happy and was restricted because she’d learnt to roll</td>
<td>Used for 2 weeks successfully then child resistant</td>
<td>No</td>
<td>Liked the position it held child in especially top leg in side lying. Would have been better when child was younger before she could move</td>
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<tr>
<td>5</td>
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<td>No</td>
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<tr>
<td>6</td>
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<td>Child very unhappy and distressed Doesn’t like not being able to turn over</td>
<td>Is always put into SS but comes out either before going to sleep, early evening or at best at 12.00/1.00</td>
<td>Yes</td>
<td>Parents are determined to continue.</td>
</tr>
<tr>
<td>7</td>
<td>Desperate for anything that might improve child’s sleep</td>
<td>Settled very quickly Not so stiff at night or in morning</td>
<td>Slept through the night from first night</td>
<td>Yes</td>
<td>“SS has improved everybody’s QOL, everyone is sleeping better”</td>
</tr>
</tbody>
</table>

**SS = sleep system**
3. Knowledge and experience of therapist

Six therapists (5 physiotherapists and 1 occupational therapist) were interviewed with one therapist having 2 children in the study.

<table>
<thead>
<tr>
<th>Case number</th>
<th>Knowledge and experience of therapist</th>
<th>Experience of different SSs</th>
</tr>
</thead>
</table>
| 1           | Worked in community paediatrics for 15 years  
Experience with complex cases  
Involved in the local postural management group  
Conducts parent and carer training  
Applied criteria for care pathway in reasoning why a SS  
Able to quote and use evidence base for PM  
Uses an X-ray protocol | Has prescribed many SSs and uses different types |
| 2           | Worked as a paediatric physio for 20 years but “very, very part-time”  
Does not have many complex cases | Has prescribed one SS previously |
| 3           | Ditto (same therapist as above) | ditto |
| 4           | OT – works with physio  
Has access to specialist in PM  
Takes detailed sleep history  
Considers sensory issues in relation to poor sleep | As a team has provided several but usually use Symmetrisleep |
| 5           | Worked for 3 years then career break then 8 years part-time | Has prescribed one other SS |
| 6           | Newly qualified physio. Has worked in paediatrics for 7 months  
Has had in-house training in PM and a one-day course  
Has access to colleagues experienced in PM | Has inherited children with a range of SSs |
| 7           | Worked in community paediatrics for 18 years  
Experience with complex cases  
Manages the service  
Involved in the local postural management group  
Applied criteria for care pathway in reasoning why a SS  
Able to quote and use evidence base for PM  
Uses an X-ray protocol | Has prescribed many SSs and uses different types |

Table 5: Knowledge and experience of therapist  
SS = sleep system; PM = postural management

From the therapists’ perspective, the desired outcomes for the provision of a sleep system were:
1. to improve posture, reduce asymmetry and/or hip migration - mentioned by the 5 physiotherapists;
2. to improve sleeping - mentioned by 5 out of 7 therapists.

Of the 3 children who continued using their sleep systems, 2 had Chailey Lying Supports and one used a Leckey Sleepform. The sleep systems prescribed are given below.

<table>
<thead>
<tr>
<th>Type of Sleep system</th>
<th>Number of therapists</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chailey Lying Support</td>
<td>3</td>
</tr>
<tr>
<td>Leckey Sleepform</td>
<td>2</td>
</tr>
<tr>
<td>Symmetrisleep</td>
<td>1</td>
</tr>
<tr>
<td>Jenx Dreama</td>
<td>1</td>
</tr>
</tbody>
</table>

4. Process of introduction to a sleep system

Of the 7 families in the study, 3 had previously attended formal postural management training. This was a set programme, led by therapists, in a group setting. The remaining 4 participant families had been given varying amounts of information on an ad-hoc basis as the new equipment was being introduced.

5. Sleep difficulties

Six out of the 7 children in this study had sleep difficulties. One parent reported:

“You just walk around like constant zombies. Me and my husband are both on anti-depressants. You sit down and you think ‘Oh God’, I could just sit here and close my eyes now and we’ve got headaches all the time.”  
(Mother of child 3)

Another parent reported that prior to using the sleep system her child might wake 10 or 11 times a night.
Table 7: Sleep patterns of participants with and without a sleep system

<table>
<thead>
<tr>
<th>Case number</th>
<th>No. of awakenings before SS</th>
<th>No. of awakenings with SS</th>
<th>Average no. of hours asleep before SS</th>
<th>Average no. of hours asleep with SS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Only 1 in 10 nights</td>
<td>0</td>
<td>11 hrs 5 mins</td>
<td>12 hrs 25 mins</td>
</tr>
<tr>
<td>2</td>
<td>2-4 times a night</td>
<td>1 a night</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td>3</td>
<td>Child waking 6-8 times a night but unable to use SS</td>
<td></td>
<td>? but reported as much more</td>
<td>?</td>
</tr>
<tr>
<td>4</td>
<td>2/3 times a night</td>
<td>0 for 3 nights then would not tolerate SS</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td>5</td>
<td>0-2 times a night</td>
<td>1 a night</td>
<td>11 hrs 2 mins</td>
<td>11 hrs</td>
</tr>
<tr>
<td>6</td>
<td>2-3 times a night with night terrors</td>
<td>Wakes several times in evening and then taken out of SS</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td>7</td>
<td>10-11 times a night</td>
<td>0-1 times a night</td>
<td>?</td>
<td>?</td>
</tr>
</tbody>
</table>

Table 8: Causes of night waking.

<table>
<thead>
<tr>
<th>Cause of waking</th>
<th>Number of children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cramp, pain, discomfort</td>
<td>4</td>
</tr>
<tr>
<td>Needing to be turned</td>
<td>1</td>
</tr>
<tr>
<td>Fits</td>
<td>1</td>
</tr>
<tr>
<td>Behavioural / habitual</td>
<td>2</td>
</tr>
<tr>
<td>Night terrors</td>
<td>1</td>
</tr>
<tr>
<td>Having had a nap during the day</td>
<td>2</td>
</tr>
</tbody>
</table>

The parents’ suggestions for the causes of night waking are presented in Table 8.

Four out of the 7 children had not learned to fall asleep alone at commencement of the study. Two of these 4 children learned to fall asleep alone when they had their sleep systems.

None of the parents had received helpful advice or support for their child’s sleep difficulties. A community nurse with a special interest in sleep had said one family’s circumstances were too complex and a paediatrician suggested another parent had a glass of wine and some of her child’s Melatonin when it was her husband’s turn to stay up with the child at night.

Discussion

Seeking the voice of the child

An aim of the study was to gain the views of children about their new sleep system and to use methods to enable children with little or no verbal communication to be included. Interviewing children as young as 3 is novel and not reflected in the literature, yet in this study 3-year-olds were able to make their views known. Three out of 4 of these children, albeit in a limited way, were clear whether they did or didn’t like their sleep system and if not, why not. Therapists will be more confident in encouraging parents to persevere with using a sleep system if the child reports that he or she is comfortable and, if not, with finding alternative solutions.

The child in pain

Pain arose as a central issue in this study in relation to posture and deformity and difficulties with sleep and was specifically mentioned by 2 of the youngest children interviewed.

The causes of pain in children with CP include spasticity and immobility (McKearnon et al 2004). Pain in muscles and joints associated with spasticity was evident in some of the children in this study. A 3-year-old in category GMFCS Level V who frequently complained of pain and was a likely candidate for early hip displacement, had significantly increased muscle tone particularly around her hips and knees. Two other children in this study exhibited pain caused by immobility and the adoption of stereotypical postures as reported by Hodgkinson et al (2001). These children appear to have been more comfortable when supported in a sleep system.

Sleep difficulties

None of the parents interviewed in this study had access to structured services to help them improve their child’s poor sleep. This confirms the consensus in the literature that families of children with disabilities struggle with poor sleep and that help is frequently not available. This situation is acknowledged in the National Service Framework for Children, Young people and Maternity Services (DH 2004) and re-iterated in the Aiming High for Disabled Children programme (DFES 2007). In the
latter document it is suggested that programmes to help families manage their child’s sleep pattern should be available from an early age to prevent parents experiencing the consequences of chronic sleep deprivation.

Competency of therapists
The findings of this study raise the question of whether generalist paediatric therapists are likely to have the required level of knowledge and experience to identify appropriate children and to recommend appropriate sleep systems for them. Postural management may need to be seen as a specialist area and competency levels used to guide and measure the gaining of experience and expertise.

Integrated care pathways may help therapists negotiate the complexities of providing postural management equipment. Therapists, in an earlier study, reported that using a postural management care pathway was useful as a signpost and made their practice proactive rather than reactive (Humphreys and Pountney 2006).

Specialists may be required to lead postural management services, identify the training needs of the families and staff and to provide support for individual patients and their therapist.

Limitations of the study
The number of participants recruited into the study was fewer than anticipated. This was because the majority of children being prescribed sleep systems in the region at the time, did not have a diagnosis of CP and therefore did not meet the inclusion criteria. A further limitation was the poor return of the sleep diaries. It may suggest that keeping a sleep diary is an onerous task for parents who already have an increased burden of care.

Generalisability and transferability
The number of participants in this study is small and their circumstances are unique but concepts arising from the findings of the study may be helpful to therapists considering the use of sleep systems.

Conclusions and clinical implications
In conclusion, when children are given the appropriate tools they can give their views about sleeping in a sleep system and these need to be taken into account when decisions are made.

Parents in this study were generally motivated to encourage their child to become accustomed to using the sleep system but parents need to have information as to why this recommendation is being made if they are to opt for, and continue to persevere with, using a sleep system. Some parents received ad hoc instructions about each piece of postural management equipment as it was acquired but without the wider context of how children with CP change as they grow. Formal training that includes the likely progression of musculoskeletal difficulties and the role that postural management may play in maintaining comfort is important.

Therapists in this study had a wide range of experience with some less competent in making postural management decisions for complex children. Therapy service managers may like to consider the possibility of appointing a specialist clinician to lead postural management services and to put in place training and competency measures to ensure that all therapists involved in postural management services have the necessary knowledge and experience.

The findings from this study suggest that for some children sleep systems enable better sleep. These children were waking frequently during the night because they had discomfort or pain which was relieved when held in a supported more symmetrical position in a sleep system. This would tend to refute the claim that children with the most severe difficulties are more, not less, uncomfortable in a sleep system (Gough 2009).

An exploratory study, a precursor to a randomised controlled trial, to assess the benefits of night-time postural management on quality of sleep, pain and posture is currently underway and the results will be crucial to therapists’ future recommendations for this complex group of children and their parents.

Acknowledgements
Many thanks go to my supervisors at the University of Brighton, Anne Mandy and Terry Pountney, for their knowledge and skills in guiding this study and for their support throughout. Thanks also go to the Posture and Mobility Group for the grant to purchase sleep systems for the participants. Many thanks go to the children and parents who took part in the study and to the therapists who generously discussed their practice and services openly and frankly.
References


Murphy, J. (1998) Talking Mats: speech and language research in practice. Speech and language therapy in practice, 11-14


The Effect of Sleep Systems on Sleep-Wake Patterns and Pain Levels in Non-ambulant Children and Young People with Cerebral Palsy

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Chailey Heritage Clinical Services, Sussex Community NHS Trust

*Corresponding author: E-mail: jessica.underhill@nhs.net

Introduction
The use of sleep systems form part of a child’s postural management programme and are designed to maintain a child’s position whilst sleeping to improve sleep and comfort in the short term and, in the long term, prevent development of deformity. A postural management programme is “…a planned approach encompassing all activities and interventions which impact on an individual’s posture and function. Programmes are tailored specifically for each child and may include special seating, night-time support (sleep system), standing supports, active exercise, orthotics, surgical interventions, and individual therapy sessions” (Gericke 2006).

With an increase in the prescription of sleep systems for children there is the need to undertake further research as, to date, studies have focussed on the management of deformity, particularly hip dislocation (Pountney et al, 2002; Hankinson and Morton 2001; Scrutton et al. 2001). There is limited research on the effects of sleep systems on children’s quality of sleep (Hill et al. 2009; Newman et al. 2006) and no research to date on pain levels. This is despite evidence that children with cerebral palsy (CP) have higher levels of sleep disturbance (Newman et al. 2006; Khan and Underhill 2006; Hemmingsson et al. 2009; Sandella et al. 2011) and a higher prevalence of pain (Hodgkinson et al. 2001; Schwartz et al. 1999) compared to children without CP. Furthermore, Hemmingsson et al. (2009) found an increased risk of sleep problems for children with CP and who experienced pain regularly.

Newman et al. (2006) investigated the frequency and predictors of sleep disorders in 173 children with CP by analysing responses to a sleep disturbance questionnaire. The authors reported that night-time postural equipment (sleep systems) did not influence sleep quality. However, these findings must be interpreted cautiously as only a

ABSTRACT
Purpose
In recent years there has been a significant increase in the prescription and use of sleep systems for children with cerebral palsy. The aim of this study was to investigate the effect that sleeping in a sleep system has on the sleep-wake patterns and pain levels for children with cerebral palsy.

Method
A cross-over design was undertaken. All participants slept for four nights in their sleep system and four nights out of their sleep system, the order of which was randomised. Eleven non-ambulant children and young people with cerebral palsy, who normally use a sleep system participated in this study (aged 5-15 years). Primary outcomes including sleep-wake patterns (using actigraphy) and pain levels (using the Paediatric Pain Profile) were obtained for all participants for both conditions. The Chailey Sleep Questionnaire, sleep diaries and interviews were used to support and supplement the objective data.

Results
Paired t-tests demonstrated no significant difference in actigraphic variables or pain levels between the two conditions (p>0.05).

Conclusions
The use of sleep systems did not appear to have a significant effect on either pain levels or on sleep-wake patterns in children with cerebral palsy. Although no significant differences were found, we did observe varying responses amongst the participants. Therefore we would recommend that both pain and sleep are discussed and assessed with the prescription of sleep systems for children with cerebral palsy.
small proportion of their sample (16%) reported using night-time postural equipment for more than 5 days of the week. Additionally, the data were subjective responses reported by the parents, who may not be able to accurately record sleep disturbance throughout the night.

Hill et al. (2009) carried out a polysomnographic pilot study to investigate the effect of night-time postural equipment (sleep systems) on sleep quality and respiratory function in 10 children with severe CP. Polysomnography was undertaken on two nights, one night with the child sleeping in their sleep system and one night sleeping without their sleep system. The authors found no significant differences in sleep quality or respiratory function between the sleep conditions. A limitation of this pilot study was that the data was not collected for multiple nights and, therefore, did not account for the possibility of night-to-night variability.

The gold standard for assessing sleep is polysomnography; however this is not always affordable or practical (as this assessment is laboratory based). Over recent years actigraphy has been established as a reliable cost-effective and non-intrusive objective method measuring sleep-wake patterns in adult and child populations (Sadeh et al. 2000; Morgenthaler et al. 2007). Actigraphy refers to small wristwatch like devices (Actiwatches) which measure and record movement. They have been used to measure sleep-wake patterns within the home or residential care setting in children with a number of different disorders, for instance autistic spectrum disorders (Wiggs and Stores 2004), attention-deficit hyperactivity disorder (Wiggs et al. 2005; Owens et al. 2009) and Rett’s syndrome (McArthur and Budden 1998). Actigraphy has also been used to record sleep-wake patterns in children and young adults with CP (Orgill et al. 2010; Strang-Karlsson et al. 2008).

Previous research has shown that pain is widely prevalent in adults and children with CP (Tuzun et al. 2010; Houlihan et al. 2004; Hodgkinson et al. 2001; Schwartz et al. 1999). In a study examining the frequency of pain in 93 adults with cerebral palsy Schwartz et al. (1999) found that pain occurred on a daily basis for 56% (n=52) of adults. Houlihan et al. (2004) investigated pain in children (n=198) with moderate to severe CP. The authors reported that the frequency of pain ranged from ‘none’ to ‘every day’, and that pain was related to the severity of motor impairment and the presence of a gastrostomy.

Additionally, Hunt et al. (2004) in the development of the Paediatric Pain Profile reported that the two most troublesome pains for children with CP were of gastrointestinal and musculoskeletal origin. The Paediatric Pain Profile (PPP) is a 20 item behaviour rating scale which has shown to be a valid and reliable tool (Hunt et al. 2004; Hunt et al. 2007) used to monitor changes in pain levels in children with CP (Lundy et al. 2009).

Due to limited research on the effect of sleep systems the aim of this study was to investigate the effect that sleeping in a sleep system has on sleep-wake patterns and pain levels in children with CP.

Method

This was a cross-over study investigating whether there was a difference between sleep-wake patterns and pain levels when sleeping in or out of a night-time sleep system for children and young people with CP. Sleep-wake patterns and levels of pain were assessed during four nights in a sleep system, and four nights out of a sleep system. The data collection periods were undertaken during the week (Monday evening through to Friday morning). The children and young people used their own sleep systems and were randomised to either sleeping in their sleep system or without their sleep system first. The study was approved by the Brighton East Research Ethics Committee.

Sample Size

A sample size of n=20 was calculated to detect a clinically relevant change in sleep efficiency based on previous research (Sadeh et al. 2000). A total of 20 cases based on alpha=0.05, power=0.8, and estimating an effect size of 10% reduction or improvement in sleep efficiency is sufficient to detect a difference between the two conditions.

Participants

Children and young people with CP were recruited through paediatric physiotherapists based at child development centres and special needs schools in the South East and South West of England. The research aims and methods were fully explained in the information sheets sent out to participants prior to consent being obtained from both children and parents/carers. The information sheets were provided in a number of alternative formats:
written and pictorial/symbols dependent on individual need. Children were able to give their consent using their preferred method of communication, and parents gave their written consent.

Participants were included in this study if they were diagnosed with CP, were aged between 5 and 16 years, had a Gross Motor Function Classification System (GMFCS) level of III-V (Palisano et al. 1997), and were currently using a sleep system either at home or in a residential care setting.

Assessments

Sleep-wake patterns
During each data collection period (4 nights in the sleep system, and 4 nights out of the sleep system) each participant wore an Actiwatch type AW7 (CamNTech Ltd, UK). This is a small watch-like device which measures and records movement and is worn on the participant’s wrist during the data collection period. The Actiwatch was set to collect data at 1 minute epochs, and the analysis was performed using the Actiwatch Activity and Sleep Analysis software (v7.27). The sleep parameters derived from the actigraph data and examined in the present study were: sleep latency (the estimated time before falling asleep following bed time), sleep efficiency (percentage of time in bed actually spent asleep) and actual sleep time (estimated amount of sleep minus wake time). The actigraphy data for each participant was averaged over the four nights for each condition (i.e. in and out of their sleep system) and the average scores were analysed.

Subjective measures of sleep-wake patterns were also noted. The parents or carers were asked to complete a sleep diary for each night of the data collection period, recording the child’s sleep and wake times and night waking behaviour. Sleep diaries have “... been shown to be an important adjunct to actigraphy” (Wiggs and Stores, 2004). At the end of each data collection period the child and parents or carers were interviewed briefly to find out how they perceived the experience of sleeping in or out of their sleep system. Additionally, parents or carers completed the Chailey Sleep Questionnaire. The questionnaire is divided into two sections: the Clinical Profile and the Sleep Profile. The Clinical Profile section records information about associated problems of CP which could affect sleep and night-time care and the Sleep Profile section records information regarding sleep.

Pain level
Pain levels were assessed using the Paediatric Pain Profile (PPP), a 20 item behaviour rating scale for assessing pain in children with severe physical and learning impairments (Hunt et al. 2004). The PPP rates pain on a four point scale, from “not at all” to “a great deal” with a maximum score of 60. The PPP scores can be grouped into various levels of severity: mild 10-19; moderate 20-29; severe 30-39; very severe 40+ (Hunt et al. 2004). The parents or carers completed the PPP following the four nights in the sleep system and four nights out of the sleep system. Differences between the Paediatric Pain Profile scores for each condition (i.e. in and out of their sleep system) were analysed.

Procedure
Baseline data, including completion of the Paediatric Pain Profile and the Chailey Sleep Questionnaire by the parents or carers, was collected prior to participation in the study. The participants were randomly allocated to either sleep in their sleep system or to sleep without their sleep system during the initial four night data collection period. During this time the participants wore an Actiwatch AW7 and the parents or carers completed a sleep diary. At the end of the initial four nights the parents or carers were asked to complete the Paediatric Pain Profile and the Chailey Sleep Questionnaire, and the participants, parents or carers were asked how they perceived the experience of sleeping in or out of their sleep system. During the following week the conditions were reversed, the data collection process and assessments were repeated (i.e. the participants who initially slept in the sleep system in the first week slept without their sleep system during the second week).

Data analysis
All data were found to be normally distributed therefore in order to investigate any difference in sleep patterns or pain levels between the two conditions the paired sample t-test was used. Statistical significance was set at a p <0.05. Data were analyzed using SPSS version 17.0 (SPSS Inc, Chicago, Illinois).

Subjective data from the Chailey Sleep Questionnaire, the sleep diaries and the interviews are reported descriptively. This data were compared with the actigraphy data and Paediatric Pain Profile scores.
Results

Eleven children with CP who normally use a sleep system, for 6 - 7 nights a week, either in a residential or home setting participated in this study. The characteristics of the participants are displayed in Table 1. The average age was 10 years (SD 3.2), ranging from 5 to 15 years. Four of the participants were female, 7 were male. All children were unable to walk independently with Gross Motor Function Classification System (GMFCS) levels ranging from III to V (2 children at Level III; 1 child at Level IV; 8 children at Level V). Various sleep systems were used by the children (5 children used a Symmetrissleep system; 5 children used a Chailey Lying Support and 1 child used a Jenx Dreama sleep system). Data was collected within the home setting for 9 children and within a residential setting for 2 children.

Paediatric Pain Profile (PPP)

The PPP scores for each participant are displayed in Figure 1. This data was not available for 1 participant (participant K). The mean pain score for participants in their sleep system was 11.3 (SD 12.1, range 0 – 34), and out of their sleep system was 13.0 (SD 14.6, range 0 – 43). An increase in pain score was observed for 3 children (participants G, H & J) during the 4 nights without their sleep systems. For 7 children no change was found in scores between the conditions. The paired sample t-test demonstrated there was no significant difference in scores between the two conditions (t (9) = -1.68, p = 0.12).

Table 1 – Characteristics of participants

<table>
<thead>
<tr>
<th>ID</th>
<th>Gender</th>
<th>Age</th>
<th>GMFCS</th>
<th>Sleep system</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Female</td>
<td>5</td>
<td>V</td>
<td>Dreama</td>
</tr>
<tr>
<td>B</td>
<td>Male</td>
<td>6</td>
<td>V</td>
<td>Symmetrissleep</td>
</tr>
<tr>
<td>C</td>
<td>Female</td>
<td>15</td>
<td>V</td>
<td>Chailey</td>
</tr>
<tr>
<td>D</td>
<td>Male</td>
<td>13</td>
<td>III</td>
<td>Chailey</td>
</tr>
<tr>
<td>E</td>
<td>Male</td>
<td>8</td>
<td>III</td>
<td>Chailey</td>
</tr>
<tr>
<td>F</td>
<td>Male</td>
<td>8</td>
<td>IV</td>
<td>Chailey</td>
</tr>
<tr>
<td>G</td>
<td>Male</td>
<td>11</td>
<td>V</td>
<td>Symmetrissleep</td>
</tr>
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<td>H</td>
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<td>V</td>
<td>Symmetrissleep</td>
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<tr>
<td>I</td>
<td>Female</td>
<td>9</td>
<td>V</td>
<td>Symmetrissleep</td>
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<tr>
<td>J</td>
<td>Male</td>
<td>10</td>
<td>V</td>
<td>Chailey</td>
</tr>
<tr>
<td>K</td>
<td>Female</td>
<td>14</td>
<td>V</td>
<td>Symmetrissleep</td>
</tr>
</tbody>
</table>

Figure 1: Paediatric Pain Profile (PPP) scores for each participant with and without their sleep systems

Actigraphy data

Sleep Latency (hours), sleep efficiency (%) and actual sleep time (hours) were calculated for each participant for each condition, and are displayed in Figure 2. Actigraphy data was not available for 1 participant (participant H) due to the Actiwatch failing to record.

The mean sleep latency time (time before falling asleep following bedtime) for participants in their sleep system was 1:09 hours (SD 0:49 , range 0:25 – 2:37), and for participants out of their sleep system was 1:20 hours (SD 0:47, range 0:17 – 2:33). For some children (participants B, J and K) substantial increases in sleep latency times were observed when sleeping without their sleep systems, although the paired sample t test demonstrated there was no significant difference in sleep latency between the two conditions (t (8) = -1.33, p = 0.22). Sleep latency times were not analysed for 1 participant (participant A) as her sleep diary revealed that she often fell asleep on her parents lap before being transferred to bed.

The mean sleep efficiency (percentage of time in bed actually spent asleep) data was similar for both conditions: 76.2% (SD 8.2%, range 64% - 90%), with the sleep system and 73.8% (SD 11.1%, range 58% - 89%), without the sleep system. The paired sample t-test demonstrated there was no significant difference in sleep efficiency between the two conditions (t (9) = 1.00, p = 0.34).
The mean actual sleep time (estimated amount of sleep minus wake time) for participants in their sleep system was 8.37 hours (SD 0.54, range 7.20 – 10.30), and for participants out of their sleep system was 8.29 hours (SD 1.12, range 6.20 – 9.57). The paired sample t test demonstrated there was no significant difference in actual sleep time between the two conditions (t (9) = 0.67, p = 0.51).

Supplementary subjective data

Chailey Sleep Questionnaire

The Chailey sleep questionnaire has two sections: a clinical profile and a sleep profile. For 9 children there were no changes reported in the clinical profile during the 4 nights with or without their sleep systems. For 1 child (participant G) an increase in gagging/choking was reported during the 4 nights without the sleep system. For 2 children (participants G & H) an increase in vomiting/regurgitation was reported during the 4 nights without sleep systems.

The sleep profile provided information on the sleep of the children including details about bedtime routine and night time behaviour. For several participants (n=7) some changes in their sleep profiles were observed during the 4 nights without sleep systems, as shown in Table 2.

Table 2: Changes observed in the sleep profile section of the Chailey sleep questionnaire following four nights without the sleep systems

<table>
<thead>
<tr>
<th>Changes observed without the sleep system</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increased need to reposition the child during the night</td>
<td>4, A, G, I, J</td>
</tr>
<tr>
<td>Increased time to fall asleep</td>
<td>3, B, D, J</td>
</tr>
<tr>
<td>Increased waking sweating/screaming and distressed</td>
<td>3, B, H, I</td>
</tr>
<tr>
<td>Increased crying on waking during the night</td>
<td>2, B, H</td>
</tr>
<tr>
<td>Increase in talking / vocalising whilst asleep</td>
<td>2, G, H</td>
</tr>
<tr>
<td>Increased waking during the night in pain</td>
<td>2, G, H</td>
</tr>
<tr>
<td>More tired than usual in the morning</td>
<td>2, A, G</td>
</tr>
</tbody>
</table>

Sleep diaries

Parents/carers were asked to complete a sleep diary, recording times of going to bed, times of night awakenings, times of morning waking and any daytime naps.

Sleep diaries were completed for all children, some more detailed than others.
For 5 children there appeared to be no difference in the sleep diaries with or without the sleep system. For those denoting differences (i.e. taking longer to settle; increased waking; vomiting/regurgitation) these generally supported the questionnaire and actigraphy data.

One participant (participant B) abandoned the ‘4 nights without the sleep system’ after 2 nights due to a severe reaction without his sleep system including repeated vomiting; moaning/crying; and taking a long time to get to sleep.

**Interviews**

All parents/carers were interviewed briefly after both conditions (4 nights in and out of the sleep system). The data generated from the interviews generally concurred with the questionnaire data, the sleep diaries and Paediatric Pain Profile scores.

After completion of both conditions, the parents or carers were asked their preference for their children sleeping in or out of the sleep system. Seven out of 11 parents/carers preferred their child to sleep in their sleep system. This question was asked to 4 children (participants B, D, E & F); 3 of which stated their preference to sleep without their sleep system (participants D, E & F).

**Discussion**

This is the first study to investigate the effect of sleep systems on sleep wake patterns and pain levels in children and young people with CP. The study indicates that the use of sleep systems did not have a statistically significant effect on either pain (as shown by the Paediatric Pain Profile scores) or on sleep wake patterns (as shown by the actigraphy data) in a small sample of children and young people with CP.

The Paediatric Pain Profile scores remained constant for the majority of participants, whether they were in their sleep systems or out of their sleep systems. The average paediatric pain score increased marginally for participants whilst out of their sleep system, but the difference was not statistically significant. There were no reductions in pain score reported without the use of sleep systems, although increases in pain scores were observed for 3 participants without their sleep systems. There was a lot of variability in reported scores within the group; no pain was reported for one participant (participant D) either with or without their sleep system. In contrast, severe pain was reported for another participant (participant H) with the sleep system, and very severe pain without the sleep system. Other studies have reported wide range variability in pain scores for children with CP (Houlihan et al. 2004; Lundy et al. 2009).

The use of actigraphy is well established as a measure of sleep wake patterns (Sadah et al. 2000). Actigraphy has been shown to be most useful for intervention studies to measure change in sleep parameters (Orgill et al. 2010; Sadah and Acebo, 2002). The parameters derived from the actigraphy data in the current study, including sleep latency, sleep efficiency, and actual sleep time, did not differ significantly between the two conditions (with the sleep system and without of the sleep system). This would suggest that the sleep systems had no effect on sleep wake patterns, although substantial variations were found for some participants. The actigraph data showed that several children (n=3) took substantially longer to go to sleep (with increased sleep latency times) when sleeping without their sleep systems. A couple of the parents/carers reported that for the first few nights sleeping without their sleep systems their children were initially anxious and subsequently took longer to fall asleep. Another parent reported that their child enjoyed the freedom of not being in the sleep system and therefore took longer to fall asleep when sleeping without the sleep system. Whilst it is recommended that actigraph data are collected for a minimum period of 5 nights (Acebo et al. 1999) actigraph data was only collected for 4 nights during this study. This was to ensure all data was collected in one location as some of the participants in this study spent four nights a week in a residential school setting.

We are unable to compare the actigraph data observed in this study as there have been no previous studies looking at the effect of sleep systems on sleep wake patterns using the same methodology. A recent polysomnographic study by Hill et al. (2009) also found no significant difference in sleep quality measures (including sleep latency, sleep efficiency and total sleep time) for children with CP whilst sleeping in their night time postural equipment or sleeping unsupported. The participants in Hill’s pilot study (n=10) were of similar age (mean 10 years) and motor ability as the current study (Hill et al. 2009). The limitation of their study is that the data was not collected for multiple nights to ascertain night to night variability. Whilst we recognise the inherent problems of comparing polysomnographic data
with actigraph data, it is interesting to note that neither studies found sleep systems to significantly affect sleep-wake patterns in children with CP.

The subjective data collated from the sleep diaries, the Chailey Sleep questionnaires and the interviews helped with checking and interpreting the actigraphy data. The sleep diaries were particularly useful with regards to confirming bed times, wake times and any night waking episodes. Useful information was gained from the Chailey Sleep questionnaires regarding changes reported by parents/carers when their children slept out of their sleep system. This further supports the view that sleep diaries and supplementary information are a necessary addition when collecting actigraph data (Wiggs and Stores, 2004; Sadeh and Abeo, 2002).

These findings should be interpreted cautiously as a limitation of this study was the small sample size, making it difficult to generalise the findings. The initial aim was to recruit 20 participants but this proved very difficult within the study time period. One possible reason for the low uptake of participants was the concern raised by some parents/carers during initial discussions about their child sleeping “without” their sleep system for any time period. A further limitation was that the actigraphy data was only collected for 4 nights during this study, as opposed to the recommended 5 nights. This decision was made to ensure all data was collected in one location as often children who stay in residential settings go home at the weekends.

Conclusions

Sleep systems (night time support) form an integral part of 24 hour postural management programmes for children and young people with CP. As part of good clinical practice sleep and pain should be discussed and assessed with the prescription and use of sleep systems for children with CP.

The use of sleep systems appeared to have no significant effect on pain levels or sleep wake patterns for the majority of children and young people with CP in this study. In light of the varying individual results obtained and the subjective data from the parents/carers further research is warranted. We would recommend that any future research incorporates a larger sample size, with data collected over a longer time period.

Acknowledgements

This study was funded by the Nancie Finnie Charitable Trust. The authors would like to thank the children and young people for their participation. Additionally the authors thank Ginny Humphreys and Sarah Stone for their assistance with the data collection.

References


BOOK REVIEW

The Hemiplegia Handbook for Parents and Professionals
Liz Barnes and Charlie Fairhurst

Reviewed by Cate Naylor

This book is aimed at children and young people with hemiplegia, their parents and the professionals who work with them. It covers a wide variety of topics which as well as presenting information about hemiplegia offers guidance and practical help. Liz Barnes is a trustee of the charity HemiHelp, a lay member of the NICE Guideline Development Group on Spasticity in Children and Young People, and the parent of a son who was born with hemiplegia. Charlie Fairhurst is a consultant in paediatric neurodisability at the Evelina Children’s Hospital in London with experience in acute and long-term neurological difficulties, and is also a medical advisor for HemiHelp.

This is a paperback book, which has 10 chapters and 160 pages. It begins with an introduction and 3 chapters giving information about brain development and movement, the causes of hemiplegia, and the clinical problems which may arise due to hemiplegia. The following 5 chapters cover topics such as assessment and clinical management, family life, education, adult life and financial support; and offer practical help and advice. The final chapter discusses the emotional impact of having a child with a disability. Each chapter covers a subject which is broken down into sections and at the end of each chapter, a summary is given. In chapters 5 to 9, practical tips are given in dialogue boxes as well as quotes from parents of their own experiences. There are also contact details for organisations that can provide more support, and references to information which is able to be downloaded from the HemiHelp website. Much of the book is written in the first person which may not be to everyone’s taste, but makes it less technical and a more accessible and friendly resource for families.

Charlie Fairhurst gives a good description of how the brain develops from gestation to birth and how the brain and nervous system work together to enable us to function. He also discusses how movement works and what happens when it goes wrong. He presents the causes of hemiplegia thoroughly and clearly discusses the causes of both congenital and acquired hemiplegia. He continues to explain the clinical signs and symptoms that may be associated with hemiplegia from movement and functional difficulties to sensory deficits, cognitive skills and epilepsy. His chapter covering the assessment and clinical management of hemiplegia is extensive. He presents the different assessments that may be used to evaluate how children function and covers all aspects of management such as medical treatments and therapies as well as touching on alternative treatments. I think that both families and professionals will find these chapters very informative.

Liz Barnes provides 3 very helpful chapters on family life, education and adulthood. As well as offering plenty of practical advice about nurseries, school and work, she gives an insight into the many elements of living with hemiplegia and how it affects all members of the family and how everyone can become involved in the child’s management. The information given in these chapters is extremely detailed and extensive and will be an invaluable resource not only for families with a child with hemiplegia, but also those with other disabilities. Professionals will also find a wealth of useful information in these chapters.

The final chapter is written by Claire Edwards who is the parent of a boy with Downs Syndrome. She presents an honest and powerful view of the emotional impact of living with a child with a disability. I was initially unsure about this chapter being written by someone whose child did not have hemiplegia, but I was wrong to worry as the chapter is written with a clear and very personal understanding of what it’s like to cope with the emotional aspects of having a disabled child whatever their disability.

The book is written in a friendly and accessible way and is a useful handbook for young people with hemiplegia, their families and the professionals working with them. I think that the chapters on education and benefits would in particular also be relevant and helpful to other children with special needs. My only criticism is that the chapter ‘After diagnosis – what next?’ which predominantly focuses on financial help, disability awareness and legal acts, national organisations and charities, whilst giving useful information would in my opinion have been better placed at the end of the book.

I would recommend this book as a reference for families who want more detail about hemiplegia and its management and I think it would also be a useful resource for the multi-disciplinary team working with children and young people with hemiplegia.
BOOK REVIEW
The Neurological Examination of the Child with Minor Neurological Dysfunction
(3rd Edition)
Mijna Hadders-Algra

Reviewed by Helen Chamberlain

This book will prove to be a practical guide in the examination and assessment helping to identify the child with a minor neurological dysfunction. For many it will become a valuable assessment tool for the child with learning, behavioural or co-ordination problems. On completion of the examination of the child, one is provided with information forming a neurological profile of the child, which in turn highlights the neurological strengths and weaknesses of the child. The assessment is a criterion-referenced assessment, which has been based on the experience of Bert Touwen and Mijna Hadders-Algra gathered over several decades in the assessment of the child and adolescent with minor neurological dysfunction.

The minimum age for this assessment is 4 years although some items, such as muscle tone and tendon reflexes, could be assessed at an earlier age. Other items are more appropriate for children aged 5 and above. The assessment is suggested for a child, however there appears to be no upper age limit.

Although the assessment may appear to be time consuming, the author anticipates that it will take approximately 30 minutes to complete. It is acknowledged that hearing, speech and vision will need to be assessed separately from the current evaluation and that these may have a bearing on the results.

The assessment requires minimal equipment and therefore lends itself to a wide range of clinical settings as the items used are common place such as a reflex hammer, penlight, skull circumference tape, and a height and weight chart. The majority of the assessment is carried out in sitting (on a plinth), standing or walking.

To guide the clinician during the assessment the book has clear annotated photographs which are well set out. The scoring system for the assessment is also clear, leaving no uncertainty as to how to award scores for an individual. As certain items are age dependent there is supplementary information to help guide the clinician concerning what can typically be expected from different age groups. In addition the current edition comes with a DVD.

The chapters are clearly set out and easy for the reader to follow, as the assessment is broken down into appropriate sections. The final chapter of the book focuses on the interpretation of the clinical findings and helps to provide further information and guidance for the reader. Overall I think that this the guide will be a useful resource for many therapists and paediatricians.
Descriptions of Rare Diseases Relevant to Paediatric Physiotherapy

A disease or disorder is defined as rare in Europe if it affects less than 1 in 2000. One rare disease may affect only a handful of patients in the EU, and another touch as many as 245,000. There are between 6000 and 8000 rare diseases. On the whole, rare diseases may affect 30 million European Union citizens. 80% of rare diseases are of genetic origin, and are often chronic and life-threatening.

It is estimated that up to 4 million children and adults are affected by rare disorders in the UK according to Contact a Family.

European Alliance for Rare Diseases
www.eurordis.org

Primary Ciliary Dyskinesia

What is Primary Ciliary Dyskinesia?

Primary Ciliary Dyskinesia (PCD), formerly known as Kartaganer’s Syndrome or Immotile Ciliary Syndrome, is an autosomal recessive genetic condition, causing disordered ciliary structure and function. This can lead to recurrent chronic upper and lower respiratory tract infections (Bush et al 2007).

Cilia are complex microscopic hair like structures that line the large conducting airways, paranasal sinuses, middle ear, posterior nose and the ependymal lining of the brain. They waft in a coordinated manner, and in the lungs act as a mucociliary escalator, to remove mucus and debris from the respiratory tract, and are therefore an important primary defence mechanism (Stillwell et al 2011). As the sperm’s flagella can have the same ultrastructure as cilia, males with PCD may be infertile. Females with PCD can have greater risk of ectopic pregnancy due to impaired cilia in the fallopian tube (Barbato et al 2009). 40-50% of patients with PCD also have situs inversus (O’Callaghan et al 2007).

Prevalence

As PCD is relatively rare and under diagnosed, particularly in mild disease, it is difficult to accurately measure prevalence. It tends to be more common in North African than European populations, and in children with consanguineous parents (Barbato et al 2009). Reported incidence is approximately 1 in 15,000 of the general population (Meeks & Bush 2000).

Making the Diagnosis

PCD presents with a clinical history of chronic upper respiratory tract symptoms and rhinitis, recurrent lower respiratory tract infections, wet cough, shortness of breath and recurrent otitis media and hearing deficit (Barbato et al 2009).

PCD should also be considered in a number of the following conditions: congenital heart disease, especially disorders of laterality, asplenia, polysplenia, polycystic kidney or liver disease, retinal degeneration, bronchiectasis of unknown cause and severe upper airway disease (Barbato et al 2009).

Patients with PCD should have access to diagnosis and management at a specialist centre. Clinical phenotype should lead to referral for a variety of diagnostic tests (Bush et al 2007):

Nasal Nitric Oxide is normally low in PCD compared to the normal population and is a highly sensitive and specific screening test (Noone 2001).

Nasal Brushing of the ciliated epithelium allows ciliary beat pattern and frequency to be determined by slow motion video replay. Individual cilia are also analysed using electron microscopy to interpret the ultrastructural defect (Barbato et al 2009).

Ciliary Cell Culture can be used to improve certainty for difficult diagnostic dilemmas. This technique helps to rule out false positives in a patient with secondary dyskinesia or denuded epithelium due to infection (Barbato et al 2009).

Genotyping - Certain genetic mutations in PCD have been found to code for particular ciliary ultrastructural defects. At present, due to the enormous heterogeneity, genetic testing is not recommended until a firm diagnosis of PCD has already been made (Barbato et al 2009).
**Treatment**

Treatment is based on early detection and aggressive treatment of lower respiratory tract infections to restore and maintain lung function and prevent bronchiectasis. Frequent cough swab and sputum specimens should be sent. The mainstay of treatment involves antibiotics and regular chest physiotherapy (Philips et al 1998). Unfortunately, there are no randomised controlled trials and most of the treatment for PCD is based on clinical opinion and extrapolations from Cystic Fibrosis (CF).

Chest physiotherapy usually consists of gravity assisted positioning (GAP) when appropriate, and percussion in the young child, adding in infant Positive Expiratory Pressure (PEP) and Assisted Autogenic Drainage (AAD) where indicated. The Active Cycle of Breathing Technique (ACBT) and a variety of airway clearance devices, such as The Flutter®, and Acapella® (oscillating PEP) and PEP may be introduced as the child becomes older. Autogenic Drainage may also be useful in the older child.

Eaton et al (2007) compared 3 different airway clearance techniques in adults with bronchiectasis. ACBT in GAP proved the most effective in terms of wet weight sputum cleared. Most patients however seemed to prefer the Flutter carried out in sitting.

Cecins et al (1999) contradict this finding as their study of 19 patients with bronchiectasis (1 PCD) found no significant difference in wet weight sputum cleared with ACBT in GAP compared to the horizontal position. When looking at the individual patients results, 1 patient produced 24% more sputum in GAP and 1 patient preferred it. It is unclear which patient this is, and it could be hypothesised that it may be the patient with PCD. The usefulness of GAP for sputum clearance in PCD is unknown and further randomised controlled trials are required. Until such time, it is important to decide about GAP on an individual patient basis, taking into account ease of clearance, uncontrolled gastro oesophageal reflux and patient preference, as it is more likely a patient will carry out treatments they prefer.

A study by Indinnimeo et al (2007) investigated the effects of a 1 month supervised hospital physiotherapy programme on children with PCD. At one month thoracic gas volume was significantly lower and at one year follow up Forced Expiratory Volume in 1 Second (FEV1) was significantly higher in the supervised group compared to the non supervised group.

Adult British Thoracic Society guidelines for airway clearance techniques for patients with bronchiectasis should also be viewed when considering the treatment options for the patient with PCD (Bott et al 2009).

It is widely recognised that exercise is a vital component of treatment and patients should be encouraged to adopt an active lifestyle (Valerio et al 2011). There is no evidence however that exercise improves survival in PCD because no studies have been published.

The activity levels of 10 children with PCD were investigated in 2011. 40% of all patients had impaired FEV1 (less than 85% predicted). Only patients with impaired lung function had reduced VO2 max, as measured by cardiopulmonary exercise test. Time spent in vigorous exercise was also lower in patients compared to controls. There was no relationship between lung function and the difference in the exercise level achieved. Male gender and time spent in vigorous exercise were independent predictors of aerobic fitness (Valerio et al 2011).

Exercise has also been shown to produce a greater improvement in peak expiratory flow rate than a β2 agonist in children with PCD, and therefore may be a useful tool before airway clearance. As some children may bronchoconstrict with exercise it is important that each child’s response to exercise is assessed individually (Philips et al 1998).

It is unclear if therapies that increase the respiratory surface hydration or therapies aimed at reducing inflammation or mucus production, or those aimed at softening the mucus will be effective in PCD and further randomised controlled trials are required (Amirav et al 2009).

Hypertonic saline can be a useful adjunct to chest physiotherapy in certain patients with PCD. A randomised controlled trial in 24 patients with bronchiectasis showed significant improvement in wet weight sputum, sputum viscosity, ease of clearance and small improvements in lung function following ABCT post nebulised tebutiline and hypertonic saline; compared to other treatments. It is unclear whether any of these subjects had PCD (Kellett et al 2005).
A Cochrane review in 2002 looking at the use of hyperosmolar agents in non-CF bronchiectasis only identified 1 study. This was a cross over trial of 11 patients with bronchiectasis compared to controls and measured tracheobronchial clearance of a particulate radioaerosol, after inhalation of dry mannitol on a single occasion. Airway clearance doubled in the central and intermediate regions of the lung but not in the peripheral region. The authors called for further randomised trials to be carried out (Wills & Greenstone 2002).

A single case report of a PCD patient inhaling rhDNase once daily, showed dramatic improvements in cough and sputum volume within 72 hours, and 20% improvement in FEV1 at 4 weeks. It is unclear however whether the patient had optimised their airway clearance technique prior to the commencement of rhDNase (Desai & Spencer 1995).

It is all very well prescribing these nebulisations, promoting exercise and optimal airway clearance, but in reality will patients actually do them? Pifferi et al (2010) surveyed 78 PCD subjects. Progressive worsening of the disease was observed with age, and adherence to physiotherapy was found to be poor, particularly in adolescents and adults. Better strategies for improving compliance to care are urgently needed.

Outcome
The main aim in treating patients with PCD is to prevent recurrent chest infections and the development of bronchiectasis, and thus maintain lung function. If this is achieved the person with PCD should have normal life expectancy. Ellerman and Bisgaard (1997) conducted a prospective review of 24 subjects with PCD. They conclude that PCD is accompanied by progressive deterioration of lung function if left untreated, but lung function can be maintained with appropriate antibiotic treatment and regular chest physiotherapy. They emphasise the need for early diagnosis of PCD.

A study from Italy, retrospectively reviewed high resolution computed tomography (HRCT) severity scores. Despite stable spirometry, subject’s HRCT scores worsened with age. This finding would obviously have important clinical implications if FEV1 was the only marker used to identify disease progression in PCD (Maglione et al 2011).

Lung Clearance Index (LCI) is becoming more widely used as an additional measure of lung function. Green et al (2012) found that 85% of PCD patients had abnormal LCI, and LCI was abnormal in 81% of patients that had a normal FEV1. The authors conclude that none of the lung function measurements correlated with age or age at diagnosis, but that PCD is characterised by marked peripheral airway dysfunction, not always identified with spirometry.

Conclusion
PCD is a relatively rare condition of disordered cilia structure and function. It can lead to a number of symptoms but is characterised by recurrent upper and lower respiratory tract infections. Left untreated these can lead to decline in lung function and poor health outcomes. The mainstay of treatment is regular chest physiotherapy, exercise, and aggressive use of antibiotics. Providing diagnosis is made early and appropriate follow up surveillance and treatment carried out, patients with PCD can lead normal lives. There is a paucity of evidence in this patient group and management is based on extrapolations from CF and clinical opinion. It is vitally important that more trials are carried out, so that clinicians can ensure they are providing the best evidence based quality care for the patient with PCD.

References


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Developmental dysplasia of the hip (DDH) is described as a range of hip abnormalities affecting the newborn in which the femoral head and acetabulum are in improper alignment or grow abnormally, or both (Shipman 2006).

The prevalence of DDH varies from 1.6 to 28.5 cases per 1000 live births. Whilst most cases of dysplasia resolve without treatment in the first few months of life, uncorrected DDH is associated with long term morbidity such as gait abnormalities, chronic pain and degenerative arthritis.

Screening programmes for DDH involve clinical examination, ultrasound examination (universal or targeted to high risk groups) or a combination of the two. There is however no consensus about what level of ultrasound abnormality should be treated. Longitudinal studies of universal hip screening show most hips that are ultrasound positive for DDH in the newborn period become normal without treatment (Woolacott et al 2005). Universal ultrasound hip screening is associated with higher treatment rates, but hip abduction splinting, which is the most common intervention for early DDH, can lead to serious complications.

The aim of the review was to examine the relative benefits and harms of different screening programmes for DDH. The authors compared no screening with clinical examination, and/or ultrasound screening (either universal or targeted).

Only five studies met the eligibility criteria for inclusion in this review. None of the studies compared the effect of no screening and later treatment with any form of screening and early treatment.

The authors conclude that:
- there is inconsistent evidence that treatment is increased with universal ultrasound when compared to targeted ultrasound, or to clinical examination alone;
- delayed ultrasound and targeted splinting for infants with unstable or mildly dysplastic hips reduces treatment without significantly increasing the rate of late diagnosis of DDH, or surgery;
- a large study is needed to determine the benefits and costs of the different screening methods on early detection and treatment of DDH.

The authors were unable to draw any conclusions from the evidence currently available concerning the balance of benefits and harms from newborn screening for DDH compared to not screening for DDH, or to give any clear recommendations for practice.

References (included in the review):


Rosendahl K, Markestad T, Lie RT (1994). ‘Ultrasound screening for developmental dysplasia of the hip in the neonate: the effect on treatment ate and prevalence of late cases’, Pediatrics, 94, 1, 47–52


Other references:

NON-SURGICAL INTERVENTIONS FOR PAEDIATRIC PES PLANUS
Rome K, Ashford RI, Evans A

Pes planus (flat foot) is one of the most common conditions presenting in childhood. It generally applies to a foot with a low or absent longitudinal arch, although there is no universally accepted definition.

There is no agreement as to whether to treat or monitor asymptomatic or symptomatic pes planus. There are many types of non-surgical treatments for pes planus and the pain and disability associated with it, including foot orthoses, stretching, footwear, activity modification, manipulation, casting, and medication for pain and inflammation. There is no consensus however on optimal non-surgical management. The aim of this review was to evaluate benefits and harms of non-surgical interventions.

Only three studies met the inclusion criteria. The main outcomes considered in this review were pain, function and/or disability, plus the experience of adverse events. The review describes the included studies, and summarises the findings in a ‘Summary of Findings Table’. One of the included studies (Powell 2005) investigated 40 children with juvenile arthritis and foot pain, comparing outcomes for pain and physical function with the use of custom made orthoses and supportive shoes, and reported reduced pain and disability with the use of orthoses. Another study (Whitford 2007) investigated 170 children aged between 7 and 11 years, and compared outcomes for pain and/or motor function between custom made orthoses and prefabricated orthoses compared to no treatment, and found no difference. The other included trial (Wenger 1989) investigated 129 children aged between 1 and 5 years with bilateral pes planus, and reported the subjective impression of pain reduction after wearing corrective shoes.

Authors’ main conclusions and implications for practice:
• there is a lack of good quality studies into non-surgical interventions for paediatric pes planus;
• evidence from a single trial indicates that custom-made foot orthoses may improve pain and disability in children with juvenile chronic arthritis and pes planus (Powell 2005) - the authors did question the clinical importance of these improvements;
• there is no evidence from randomised controlled trials on the efficacy of foot orthoses for asymptomatic paediatric pes planus;
• there is no evidence from randomised trials for any other non-surgical intervention.

The authors recommend further trials examining the short-term and long-term benefits of non-surgical interventions, with a follow-up period of at least five years.

Main reference:

References for studies included in the review:


STRETCH FOR THE TREATMENT AND PREVENTION OF CONTRACTURES

Authors: Katalinic OM, Harvey LA, Herbert RD, Mosley AM, Lannin NA, Schurr K

In the last Journal (Volume 2, Number 3 – November 2011) it was stated that no paediatric studies were considered in the Cochrane Review. This is incorrect and was due to a publishing omission. The paediatric articles reviewed are listed below. Nevertheless this should not detract from the message of the review: the routine use of stretch in management of contractures is of little or no benefit over and above the usual care.

Jeanne Hartley

Editor’s reply:
I would like to apologise to Jeanne Hartley and to readers for this omission of paediatric studies in the last edition of the Journal and to suggest that readers interested in the subject might also like to read Pin, Dyke & Chan (2006), Autti-Ramo et al (2006) and Blackmore et al (2007)

References for paediatric studies included in this review:


References


Submissions to the APCP Journal

The APCP Journal aims to disseminate original research, facilitate continuing medical education and to provide an opportunity to debate controversial issues in paediatric physiotherapy. Listed below are the different types of submissions that will be considered for publication in the APCP Journal with guidance on how to write and format your work to maximise the chances of your submission being successful. The Editorial Board also welcome pre-submission questions and will be happy to advise further. Please contact evabower@tinyworld.co.uk in the first instance for guidance or pre-submission advice.

Original Research Reports
Original research in many formats, including quantitative and qualitative research, case series and case reports. These articles should be 4500 words or less, excluding the references and abstract. All submissions in this category will be subject to anonymous peer review by 2 reviewers.

Research Papers
Research papers should generally follow the ‘IMRD’ pattern (Introduction, Methods, Results and Discussion). When writing your paper, it is usually best to start with the most important parts, the methods and results, before writing the discussion, introduction and conclusion.

The methods section should include sufficient information to enable other clinicians to reproduce your work. Any work involving human or animal subjects must have appropriate ethical approval from the relevant Research Ethics Committee. In addition, written permission from children, parents or guardians to publish photographs of individuals must be submitted. The methods section should also include details of statistical methods if they are used and state which software, if any, was used to obtain the results. Any apparatus used in the study should be reported in terms of manufacturer and location (city, county, country).

The results section should be clear and easily understood. Rather than presenting the reader with masses of data, it often helps to construct your results to tell a story, taking the reader step by step through your findings. Do not present data twice in both text and tables/figures, and do not include material that belongs in the discussion, i.e. present results only, not interpretation. Consider how statistical data is presented, ensure that descriptive and inferential statistics are used appropriately to provide meaning to the data collected.

Tables and figures should be numbered consecutively as they are referred to in the text, and placed after the references on a new sheet. Abbreviations should be explained in a footnote and only horizontal lines should be used. Table and figure captions/legends should be included on a separate sheet.

The discussion will allow you to succinctly summarise the major findings of your work and explain its relevance in terms of the available literature and current practice. It is helpful if the first paragraph briefly summarises the major findings. The discussion will also allow you to address any potential weaknesses in the methodology and justify why the research was performed in a particular way. It is important to keep the discussion relevant to the results obtained.

Ideally the introduction should be short and engage the reader, explaining why the paper is relevant to clinical practice. Often a brief summary of the existing literature highlighting the need for this particular research is useful, as it leads directly to the research question being asked.

Finally the title and abstract can be written. The abstract should be structured (limited to 300 words) consisting of ‘Background and Purpose’ (why the research done), ‘Method’ (what was done), ‘Results’ (what was found) and ‘Conclusion’ (what was concluded). The title itself should describe the contents of the paper succinctly and accurately.

Scholarly Papers
Discursive papers sharing ideas or experiences in specific areas of practice can be structured more freely but should still include an ‘Introduction’, ‘Discussion’, and ‘Conclusions’. Scholarly papers should be no longer than 4500 words.

Case Studies and Case Series
The format for case studies and case series differs from that given above and should start with an ‘Introduction’, followed by ‘Case Report’ (history, investigations, treatments, outcome), ‘Discussion’ and ‘Conclusion’. Case reports may be notable because they either focus on a rare condition or on a new method of treatment. The use of false names in case reports is encouraged but if a child is recognisable in the report (due to the condition or the specific nature of the treatment given), then written consent for publication should be obtained. Case reports should be no longer than 2500 words.
Audit Reports
Reports of clinical audit should include an ‘Introduction’, ‘Standard Setting’ (with appropriate reference to the available literature), ‘Method’, ‘Results’, ‘Discussion’, and ‘Conclusion’. These should be no longer than 3000 words.

Review Papers
Systematic reviews undertake specific methodology and focus on a specific question, perform a thorough literature search and critical appraisal of individual studies using strict criteria. Less formal review articles will summarise the current literature on a particular topic. The Cochrane Collaboration has published a handbook on conducting systematic reviews (http://www.cochrane-handbook.org/) and you should structure your review in terms of ‘Introduction’, ‘Objectives’, ‘Methods’, ‘Results’, ‘Discussion’, and ‘Conclusion’. There are published criteria that should be applied to the analysis of randomised controlled trials: the Delphi criteria (http://www.ncbi.nlm.nih.gov/pubmed/10086815) and the PEDro scale (http://www.pedro.org.au/scale_item.html). The MOOSE guidelines should be applied to the analysis of observational studies (http://www.consortstatement.org/mod_product/uploads/MOOSE%20Statement%202000.pdf). Review papers should be no more than 4500 words.

Technical Evaluation
Technical evaluations describe mechanical or technical devices used in clinical practice or education and should include an introduction, methods including the specifications of the equipment used and the means of the evaluation, the evaluation outcome, discussion and conclusions. Technical evaluations should be no longer than 2500 words.

Service Development Report
A service development report should describe changes in service delivery/management. The structure of the report can be less formal but should include an introduction, description of the service change(s), outcome and discussion on the implications for future practice. Service development reports should be no longer than 2500 words.

Abstracts of Theses and Dissertations
Abstracts of research projects, audits and presentations from undergraduate and postgraduate degrees should be no more than 300 words in length and structured as a standard abstract (introduction, methods, results, conclusion). However, the Editorial Board would strongly encourage those considering such a submission to formulate their work instead as one of the above peer reviewed articles. In such cases, a pre-submission enquiry to the editor may be helpful.

Other types of editorial material
The Journal will also consider the following submissions:

Letters to the editor
Letters to the editor can be on any issue pertinent to paediatric physiotherapy or to APCP. Letters should be no more than 500 words long.

Book reviews
Book reviews should be no more than 750 words long.

Referencing
All work submitted for peer review should be referenced in the Harvard style:

In text, cite only the author(s) surname(s) followed by the date of publication, e.g. (Robinson, 1994) or Robinson (1994). ‘a’, ‘b’, etc., is used to indicate more than one publication by the same author(s) in the same year, e.g. 1992a,b). For three or more authors of a cited paper, name the first followed by et al, e.g. (Smith et al, 1990).

In the reference list, include articles in journals and books alphabetically by author. For citations from journals, give the names and initials of all authors (year of publication), title of the article, full name of the journal, volume number, issue number and first and last page numbers, e.g. Brown, A, Green, B and Gold, C (2001). ‘The value of exercise’, Physiotherapy, 87, 1, 77-79. Referring to books, give the names and initials of all authors/editors (year of publication), title, publisher, place of publication, and the chapter number or the page number of the citation or both, e.g. Gardner, M (2001). The Annotated Alice, Penguin Books, Harmondsworth, Chap 10, page 210.

The submission process
Email your submission in the first place in Word format to va@apcp.org.uk, clearly indicating the nature of the submission e.g. case series, research project.
Ensure that your copy includes information about the author (full name, qualifications, email address).

Once your submission has been received you will receive feedback from the reviewers indicating whether the copy has been accepted for publication.

There are a number of levels of acceptance:
- acceptance: no amendments required;
- acceptance: minor amendments required;
- acceptance major amendments required;
- rejection: not suitable for publication in the APCP Journal.
Aims and scope: the APCP Journal aims to publish original research and other scholarly work related to paediatric physiotherapist – its scientific basis and clinical application, education of practitioners, management of services and policy.

For enquiries relating to the submission of articles contact:

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Articles in this issue ...

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National Benchmarking of Neonatal Physiotherapy Services

Current Clinical Practice in the use of Muscle Strengthening in Children and Young People with Cerebral Palsy – A Regional Survey of Paediatric Physiotherapists

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Profiles of Respiratory Muscle Weakness in Type II Spinal Muscular Atrophy and Duchenne Muscular Dystrophy

Posture and Sleep in Children with Cerebral Palsy – A Case Study

The Effect of Sleep Systems in Sleep-Wake Patterns and Pain Levels in Non-ambulant Children and Young People with Cerebral Palsy