Assessment of pain in children with profound cognitive impairment

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Overview

- Context
- Challenges
- Pain (under) assessment
- Pain assessment tools
- Experiences of parents and health professionals
PAI

TOO BIG A SUBJECT
Overlapping/inter-related terms are used when referring to children whose communicative, social and motor skill functioning is well below that expected of their chronological age and who are unable to adequately verbalise pain:

- Non-communicating
- Non-verbal communicating
- Cognitive impairment
- Neurocognitive impairment
- Complex needs
- Development delay
- Developmental disability

These terms often qualified by adjectives e.g., ‘severe’, ‘profound’.
Context

- Neglected area
- Evidence base growing
- Assessment tools exist; rarely used
- Focus needs to shift to tailoring pain treatment (Valkenburg et al. 2010)
- Children often in contact with many healthcare professionals and carers
- ‘Lack of confidence’
Challenges

**Diagnoses**
- Underlying diagnoses
- Associated co-morbidities
- Number of co-morbidities increase with age

**Pain sources**
- Incidence studies rare
- Pain burden often high
- Multiple sources including iatrogenic and ‘usual’ pains of childhood
- Chronic/acute exacerbations

**Pain cues**
- Can be ambiguous
- Open to subjective interpretation
- Contextual

**Treatment**
- Can be difficult to access
- Involves difficult decisions
- Requires multi-disciplinary input
Children with PCN: complex issues

- **Underlying diagnoses:** e.g., birth asphyxia, cerebral palsy, neurodegenerative and metabolic disorders and autism.

- **Associated co-morbidities:** e.g. seizure disorders, perceptual disorders (such as severe visual and hearing impairments) and physical impairments (such as high levels of spasticity and motor dysfunction), as well as respiratory and feeding problems.

- **Number of co-morbidities:** increase with age (Bottos & Chambers, 2006).

- **Require full time – often highly technological - care:** from parents / care givers / nurses / other HCPs (Bottos & Chambers, 2006).
Children with PCN and pain

Incidence studies are rare. However, evidence shows children with PCN have:

- **Pain from a range of different sources** (Carter, 2002, Hunt et al. 2004)
- **Higher number of pain episodes** compared to their healthy peers (Breau et al., 2003, Carter et al., 2002, Hunt et al., 2004).
- **Pain on an on-going basis** (Parkinson et al. 2010, Stallard et al., 2001).
  - Breau et al.’s (2003) study of caregivers (94 children with complex needs, aged 3-18 years) showed that 35%-52% of children in the sample experienced pain each week for an average of 9-10 hours per week with a mean intensity of 6.1 (0-10 rating scale).
- **A common set of pain behaviours** that are not related to children’s functional level, intellectual level, sex or chronological age (Breau & Camfield, 2010 pp6-7)
Pain management

- Structured pain management requires conscientious and ongoing attention to:
  - Prevention and protection
  - Assessment
  - Intervention
  - Evaluation

- Particularly challenging in relation to children with PCN
Pain assessment
Scenario: Ruby, aged 8 years

- Ruby has complex health care needs.
- She is profoundly cognitively impaired and unable to communicate verbally or using augmented aids.
- She is now 48 hours post-orthopaedic surgery.
- Despite having been given your standard epidural analgesia (+/- additives), she appears distressed and she did not sleep last night.
- Her mother has had to go home
- You are the person who needs to assess Ruby to see if she is in pain.
Thinking about the scenario presented about Ruby, and using the 0-10 scale below (where 0 is extremely poor and 10 is extremely good),

**Overall, how confident would you be assessing pain in child like Ruby?**

Level of confidence
Thinking about the scenario presented about Ruby, and using the 0-10 scale below (where 0 is extremely poor and 10 is extremely good),

**Overall, how good do you think your team/institution is in assessing pain in children like Ruby?**
Under-assessment of pain

“Perceptions about the pain experienced by particular groups of children, such as children with neurological impairment may need to be challenged to address issues of under-assessment of pain”.

Association of Paediatric Anaesthetists: Good Practice in Postoperative and Procedural Pain (2008)

Pain (under)assessment

- Communication impairment creates challenges for HCPs & parents (Hauer, 2010).
- Some HCPs perceptions about pain in children with PCI may need challenging (APA, 2012).
- Parents/carers often develop knowledge and assessment skills experientially (Carter et al., 2002, Hunt et al., 2003, McGrath et al., 1998, Voepel-Lewis et al., 2005).
- Many parents are sensitive pain detectors (Symons et al., 2008) but “.. will probably underestimate the true extent of pain within this vulnerable group” (Stallard et al., 2002 p148) and may have mistaken beliefs about their child’s pain (APA, 2012).
- Training and access to information increases parents’ skills and confidence in pain assessment (Voepel-Lewis et al., 2005).
Pain assessment tools

- Validated pain assessment tools with clinical utility exist for children with PCI.
- Using specifically validated tools increases the recognition of treatable moderate to severe pain scores (Anand et al. 2009; McJunkins 2010).
- Good tools should encourage the engagement of the family/carers who know the child well.
Specific vs generic tools

Anand et al 2009: RCT

- Control group had pain assessed using Modified Objective Pain Scale (MOPS) and experimental group (NCCPC-PV).
- MOPS group: a third had mod-severe pain (mean pain score =4); NCCPC-PV group: 60% had mod-severe pain (mean pain score 20)
- Using tools specifically validated for CIC increases the recognition of moderate to severe pain

McJunkins et al. (2010)

Study looked at MOPS, CHEOPS, NCCPC-PV and parental assessment using VAS.

- Using CHEOPS or NCCPC-PV more than doubled recognition of treatable pain scores in CIC (compared to MOPS)
- NCCPC-PV had clinical utility and more sensitive to moderate to severe pain in population

Despite heterogeneity of children’s disabilities, “global and specific behavioral measures can help clinicians discriminate pain” (Voepel-Lewis 2011, p106)
Good practice: APA (2012)

Good Practice in Postoperative and Procedural Pain (2012) recommends:

- **Procedural/disease related pain**
  - PPP (The Paediatric Pain Profile): intended for 1-18 year olds (Hunt et al. 2004)

- **Post operative pain**
  - PPP (The Paediatric Pain Profile) : valid for 1-18 year olds (Hunt et al. 2004)
  - Revised FLACC valid for 4-19 year olds (Malviya et al. 2006)

- **Parent Report of their child’s post op pain**
E-survey of anaesthetists in UK and other parts of Europe

25 questions; 3 scenarios (one related to a child with profound cognitive impairment)

185 respondents (mostly working at consultant level)
Q17 How would you assess Ruby’s pain?

- Clinical assessment, behavioural & physiological indicators (20%)
- History, examination, pain history (12%)
- Exclude other causes of distress (5%)
- Discuss with nurse (5%)
- Exclude other causes of distress (5%)
- FLACC (6%)
- FLACC modified (5%)
- NCCPC (2%)
- Inspect sites, pump connections (10%)
- Other behavioural tool (5%)
- Assess block (7%)
- Exclude surgical complication (2%)
- Administer epidural bolus (4%)
- Simple analgesics (4%)
- Dizapepam for spasm (4%)
- Analgesia review (5%)

Simons et al., 2017
Q19 What pain assessment tool or tools would you use, if any, to assess Ruby’s pain?

- FLACC: 34%
- FLACC (mod): 12%
- NCCPC: 5%
- KUSS: 3%
- VAS/NRS: 6%
- FACES: 5%
- COMFORT: 3%
- CHEOPS: 5%
- SAN SALVADOR: 3%
- Hartwig: 1%
- PPP: 4%
- Guided by nurses: 4%
- Parents' view: 11%
- Don't know: 3%
- Hartwig: 1%

Simons et al., 2017
Q20: How confident would you be in assessing Ruby's pain?

- **Very confident**: 4 (UK) 6 (Europe)
- **Confident**: 30 (UK) 42 (Europe)
- **Not at all confident**: 14 (UK) 15 (Europe)

Simons et al., 2017
Revised FLACC (revisions in italic)

**FLACC-R**

- 5 item scale
  - Face
  - Legs
  - Activity
  - Cry
  - Consolability

- Each item rated 0-2
- Total score 0-10

<table>
<thead>
<tr>
<th>Item</th>
<th>Rating</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Face</td>
<td>0</td>
<td>No particular expression or smile</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>Occasional grin, frown; withdrawn or disinterested; appears sad or worried</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Consistent grin or frown; frequent/constant quieting, chin, clenched jaw; distressed looking face</td>
</tr>
<tr>
<td>Legs</td>
<td>0</td>
<td>Normal position or relaxed; usual tone &amp; motion of limbs</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>Unsteady, restless, tense; occasional tremors</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Kicking, or legs drawn up; marked increase in spasticity, constant tremors or jerking</td>
</tr>
<tr>
<td>Activity</td>
<td>0</td>
<td>Lying quietly, normal position, moves easily;</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>Regular, rhythmic movements; squirming, shifting back and forth, tense or guarded movements;</td>
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<tr>
<td></td>
<td></td>
<td>mildly agitated (e.g., hand back and forth, aggression);</td>
</tr>
<tr>
<td></td>
<td></td>
<td>splinting respirations, intermittent sighs</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Arching, rigid or jerking; severe agitation; head banging; shivering (not rigors);</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Holding, gasping or shallow intake of breaths; severe splinting</td>
</tr>
<tr>
<td>Activity</td>
<td></td>
<td>Individualized behavior___________________________</td>
</tr>
<tr>
<td>Cry</td>
<td>0</td>
<td>No cry/verbalization</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>Moans or whimpers; occasional complaint; occasional verbal outburst or grunt</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Crying steadily, screams or sobs, frequent complaints;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>repeated outbursts; constant grunting</td>
</tr>
<tr>
<td>Consolability</td>
<td>0</td>
<td>Content and relaxed</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>Reassured by occasional touching, hugging or being talked to; Distraight</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Difficult to console or comfort; pushing away caregiver, resisting care or comfort measures</td>
</tr>
</tbody>
</table>
NCCPC-R

- 30 item scale (past 2 hrs)
- 7 categories
  - Vocal
  - Social
  - Facial
  - Activity
  - Body and limbs
  - Physiological
  - Eating and sleeping
- Each item rated 0-3
- Total score 0-90
Paediatric Pain Profile

- 20 item scale
- Each item rated 0-3
- Total score 0-60

http://www.pprofile.org.uk
### On a good day

1. For each item please circle the number that best describes your child's behaviour on a good day, when they are at their best.
2. Enter the number you have circled in to the "score" column.
3. Add up the numbers in the "score" column to give the total score.
4. Record the score on the Summary Graph.

#### On a good day my child...

<table>
<thead>
<tr>
<th>Item</th>
<th>Not at all</th>
<th>A little</th>
<th>Quite a lot</th>
<th>A great deal</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is cheerful</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Is sociable or responsive</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Appears withdrawn or depressed</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Cries / moans / groans / screams or whimpers</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Is hard to console or comfort</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Self harm e.g. biting self or banging head</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Is reluctant to eat / difficult to feed</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Has disturbed sleep</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Grimaces / screws up face / screws up eyes</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Frowns / has furrowed brow / looks worried</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Looks frightened (with eyes wide open)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Grinds teeth or makes mouthing movements</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Is restless / agitated or distressed</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Tenses / stiffens or spasms</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Folds inwards or draws legs up towards chest</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Tends to touch or rub particular areas</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Resists being moved</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Pulls away or flinches when touched</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Twists and turns / tosses head / writhes or arches back</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Has involuntary or stereotypical movements / is jumpy / startles or has seizures</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

#### Total

Is your child like this? All the time, Most of the time, Some of the time, Hardly ever.

Do you think your child has pain even on a good day like this? All the time, Most of the time, Some of the time, Hardly ever.

## Current pain problems

### Most troublesome pain (Pain A)

- What is your child's most troublesome pain?
- How long has your child had this pain?
- When does this pain usually occur?
- Approximately how often does this pain occur, e.g. all the time, every day, weekly etc.
- What usually helps?

Please can you now score this pain using the Pain Profile on the opposite page (page 7).

Completed by: ____________________________ Date: ____________________________

Completed by: ____________________________ Date: ____________________________
**Pain Profile**

**Most troublesome pain (Pain A)**

1. For each item please circle the number that best describes your child's behaviour when they have this pain.
2. Enter the number you have circled in to the "score" column.
3. Add up the numbers in the "score" column to give the total score.
4. Record the score on the Summary Graph.

<table>
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<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Cries / sneezes / screams or whisper</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Is hard to console or comfort</td>
<td>0</td>
<td>1</td>
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<td>3</td>
<td></td>
</tr>
<tr>
<td>Tenses / stiffens or spasms</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Flees towards or draws legs up towards chest</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Tends to touch or rub particular areas</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Restless being moved</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Pulls away or flinches when touched</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
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<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

Please tick the box next to the word that best describes the severity of this pain

- [ ] None
- [ ] Mild
- [ ] Moderate
- [ ] Severe
- [ ] Very severe

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Key objectives

- Describe the frequency, duration and intensity of pain episodes in children with complex needs over an eight week period as reported by parents.

- To explore and analyse how parents and healthcare practitioners develop and acquire knowledge and skills to assess and manage pain in children with complex needs.
Methodology and Methods

- Convergent parallel mixed method design (Cresswell et al., 2011).
- Longitudinal study: followed child for 8 weeks.
  - Survey of pain episodes (telephone & F2F); weekly x 8 weeks (Breau et al. 2003).
  - Interviews (week 1 & 8) to explore parents’ experiences & perceptions of assessing and managing their child’s pain.
- Recruitment via tertiary centre; child’s suitability screened by clinicians.
  - 8 parents (of children aged 2-16yrs) participated
  - 19 health professionals
Findings: parents
### Exemplar survey data from 2 families

<table>
<thead>
<tr>
<th>Family 1: Girl, 16 yrs</th>
<th>Family 2: Boy, 13 yrs</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Comprehensive pain plan</td>
<td>1. Struggling with ongoing pain</td>
</tr>
<tr>
<td>2. Pain experienced: 6 out of 8 weeks</td>
<td>2. Pain experienced: 8 out of 8 weeks</td>
</tr>
<tr>
<td>4. Pain medicine given: paracetamol, diazepam, brufen, on top of regular pain meds given</td>
<td>4. Pain medicine given: paracetamol</td>
</tr>
<tr>
<td>5. Other actions – bath, massaging, positioning</td>
<td>5. Other actions – rubbing back and legs, positioning, new bed and wheelchair,</td>
</tr>
</tbody>
</table>
Left to get on with it

Learning to ‘know’ without a rule book

Enduring the unendurable & things being right

Convincing the uncertain

Trading pain for family life
Parents learned to know their child’s pain (not necessarily cause) through their constant presence in child’s life.

Child’s pain and underlying condition(s) dynamic so confidence in ‘knowing’ shifted.

Parents wanted to learn and know more about their child’s pain (cause and what to do).

“..at the start, you’re just swimming in an ocean and you’re thinking well what do we do”?

“When she reached nine or ten it was like being hit by a bus...we didn’t know what on earth was going on......we found out later it was the scoliosis crushing her lung...... and her hips were dislocating”

“....you never actually stop ... learning things from your child, you are constantly, adapting to the next situation, the next problem and and interpreting it ...and acting on it”
Parents often felt they were on their own (managing pain): their children were different to other children, and they learnt to ‘know’ with little professional support.

They knew their child as a whole being; professionals were interested in parts.

“....you're just sort of left to paddle your own canoe”

“She isn’t like the other children they have experience of, she doesn’t work that way... they don’t know what to do”

“The specialists just look at the bit they’re interested in; it’s up to me to put it all together. The neuro are interested in epilepsy, and the gastro in his stomach but no-one is really responsible for tackling his pain”
Some children had frequent, on-going episodes of persistent pain that were overwhelming and very distressing for parents and siblings.

Some children had excellent proactive pain care packages.

“He goes into a cycle where he thinks ‘I've got pain, my goodness I've got pain, oh my goodness I've got pain’ and no matter then what you do he just still thinks ‘I've got pain, I've got pain, I've got pain, I've got pain’ and he doesn't seem to be able to shut off, so in the end I think it was about three weeks, just under three weeks [then] he started on gabapentin”

“It took a while, but now she's kind of like on track and I think we're all a lot more confident, and know, that we can give this and how much we can give and we have it all sorted”
Despite their own uncertainty, parents talked of having to convince some health professionals that their child was in pain.

As their experience grew, their confidence was enhanced.

“I kept saying ‘He's in pain’, they'd say ‘It's his head’, I'd say, ‘He's in pain’, they’d say ‘It's his head’... and I said ‘It’s his stomach’ He wasn't eating and he was gurgling he was popping and churning. They said ‘We think he's fine’ but I'd done a little bit of research and I said ‘What about this bug that's in the tummy?’ They said, ‘Mmm yeah maybe...we'll do a blood test’ and it turned out he had helicobacter”

“I’ll go in there with either an idea or I will go in and I will tell them what's wrong with him, I would say - without sort of blowing my own trumpet – I’d say 80% of the time we're right”
Part of the sense of being ‘left to get on with it’ balancing and managing pain against and alongside the child and family engaging in day to day life: e.g., medication vs. ability to engage in family life

“You think that by doing it ...as a mum, you’re doing everything ....to ease their pain, it might not be doing anything, it might not even be touching the tip of the iceberg from her pain ...... it's a difficult call... I don't know whether I'm pumping her full of pain relief to make me feel better or that I'm doing everything I can”

“She’s in less pain when she’s in bed but that’s not a life, just being in bed. She needs to be part of the family, up in her chair and being with us. That’s a trade off”

“He’s in pain whenever he has feeds so we feed him at night. It’s awful, he needs chloral to sedate him and buscopan just so we can get some milk into him. And he screams and arches for hours but we do it at night so he can be part of the family during the day...”
Findings: health professionals
Navigating uncertainty; deficits in knowledge and skills

Framing as different and teasing things out

The settling and unsettling presence of parents
Navigating uncertainty; deficits in knowledge and skills

- All HCPs felt challenged and out of their comfort zone.
- This eroded their confidence.
- Assessment was not fluid or intuitive.
- Unable to develop a reliable skill set due to idiosyncrasies of children.

- "It becomes a dialogue really between the parents, the ward nurses and, well, the carers and ourselves" (AH).
- Learning gained experientially “through experience and by discussing cases with colleagues and seniors” (M).
- "parents of children with complex needs are best placed to look at their needs, they are the ones that know how their child communicates so we would always listen to them in the first instance” (N).
Framing as different and teasing things out

- Children framed as different to non-impaired children
- Knowledge difficult to transfer over to this group of children
- Assessment described as stressful and uncertain
- Children complex and unpredictable

- “every child [with cognitive impairment] really is different” (M), “every little thing they do is different” (N), and they are “really individual and unique” (AH)
- “the trickiest patients” (N)
- “quite stressful . . .because they [child] can’t tell you” (N)
- “the luxury of having enough time. . . [and being able to] build a relationship” (AH)
- “build up a picture. . . to really tease things out and help you focus in” (AH)
- “those minor subtle differences from the way the child would normally behave” (N)
Settling and unsettling presence of parents

- HCPs often turned to parents for help.
- Parental expertise helped reduce clinical uncertainty.
- Parental intuition acknowledged as being hard won and often very systematic.
- Genuine expertise welcomed but some parents seen as challenging.

- “relied on . . .as they are the voice of the child” (M),
- “good historians in that they’ll tell you what they’ve had in the past and what has worked and what hasn’t worked” (M).
- I’ll involve the parents and I’ll say, ‘Do they normally do this? Is this what he normally does? Does he normally cry like that? Does he normally whinge [complain peevishly] like that? Does he ever get spasms? Is he on Baclofen already?’ I find it really, really difficult to do it [assessment] by myself. (N)
- expert parents sometimes “rocked the boat” (N) by challenging decisions, “shaking people’s confidence,” and appearing to “be all knowing and powerful” (N).
What 3 factors do you think would most improve the pain assessment of children like Ruby in your own team/institution?

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<td>More education/training for anaesthetic staff</td>
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<td>More education/training for nursing staff</td>
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<td>3</td>
<td>Better education about pain scales for children/parents</td>
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<td>Making pain assessment using an appropriate scale mandatory</td>
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<td>Better communication between professionals</td>
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<td>Pain is a higher priority within the institution</td>
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<td>Clear policy for effective pain assessment</td>
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And finally

- Mild-moderate pain easier to miss than moderate-severe but even mod-severe pain is under-assessed
- Children may have more than one pain
- Pain has widespread impact on the child and family
- Validated tools specific for this population should be used
- Tools are important but may miss meanings and bigger picture so should never be used in isolation
- HCPs need to work with parents and create pain management plans.
- HCPs needs more education and training
- HCPs need to reassess the ways in which they interact with children with PCI and reflect on their assumptions
- Parents want education, training, pain assessment tools, professionals who listen and question, a pain management plan and regular re-evaluation, someone coordinating pain management.
References


