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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

PA

TOO BIG A SUBJECT

Language and semantics

- 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’

The image shows two medical guidelines side-by-side. On the left is the 'Paediatric Pain Profile' logo, featuring a stylized jigsaw puzzle piece graphic above the text 'Paediatric Pain Profile'. Below it is the 'Acute Pain Management: Scientific Evidence' guide, which is a blue book cover with the title in large yellow and white letters, 'Australian and New Zealand College of Anaesthetists and Faculty of Pain Medicine' at the top, and 'Third Edition 2010' at the bottom. To the right of these is a clinical practice guideline document titled 'The recognition and assessment of acute pain in children'. The document has a blue header with the title and 'CLINICAL PRACTICE GUIDELINES' at the top right. It includes logos for the Royal Australian and New Zealand College of Anaesthetists (RANZCA) and the British Paediatric Society. The main text discusses pain assessment in children, mentioning self-report, proxy measures, and observational scales. It also includes a 'Good practice point' section and a 'Conclusion' section.

**improving practice:
improving care**

CLINICAL PRACTICE GUIDELINES

The recognition and assessment of acute pain in children

Update of full guideline

SEPTEMBER 2009

RANZCA APA

The British Paediatric Society

Pediatric Anesthesia 2008; 18 (Suppl. 1), 14–18

doi:10.1111/j.1460-9592.2008.02429.x

**Section 3
Pain Assessment**

Contents

3.1 General Principles of Pain Assessment
3.2 Guide to Pain Assessment Tools
3.2.1 Self-report
3.2.2 Behavioral
3.2.3 Physiological

Children's pain should be assessed. It is an essential contribution to ensuring that pain is both prevented and relieved (1,2) and this is enshrined in many guidelines (3–6).
based guideline
Pain in Children
Royal College of
undergoing revised
in 2001 by
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Practice (8) which
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Face

0 = No particular expression or smile
1 = Occasional grimace/frown; withdrawn or disinterested; *appears sad or worried*
2 = Consistent grimace or frown; frequent/constant quivering chin, clenched jaw; *distressed-looking face; expression of fright or panic*
Individualized behavior: _____

Legs

0 = Normal position or relaxed; *usual tone & motion to limbs*
1 = Uneasy, restless, tense; *occasional tremors*
2 = Kicking, or legs drawn up; *marked increase in spasticity, constant tremors or jerking*
Individualized behavior: _____

Assessment

to the prevent
as well as the
There are three
assessment in

Activity

0 = Lying quietly, normal position, moves easily; *Regular, rhythmic respirations*
1 = Squirming, shifting back and forth, *tense or guarded movements; mildly agitated (e.g. head back and forth, aggression); shallow, splinting respirations, intermittent sighs*
2 = Arched, rigid or jerking; *severe agitation; head banging; shivering (not rigors); breath holding, gasping or sharp intake of breaths, severe splinting*
Individualized behavior: _____

Cry

0 = No cry/verbalization
1 = Moans or whimpering; occasional complaint;

Evidence

The results of pain assessment must be documented, acted upon, reassessed, and reevaluated to determine the effectiveness of interventions (1,6,17). Improved documentation can result in improved pain management (11,18). Studies demonstrate that pain is under-assessed and poorly documented resulting in children being under-medicated and/or their pain being poorly managed (19). Regular pain evaluation can contribute to the safety and efficacy of management of acute pain (20).

Children's self-report of pain is regarded as the gold standard and in most circumstances it is the preferred approach. However, it needs to be

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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).

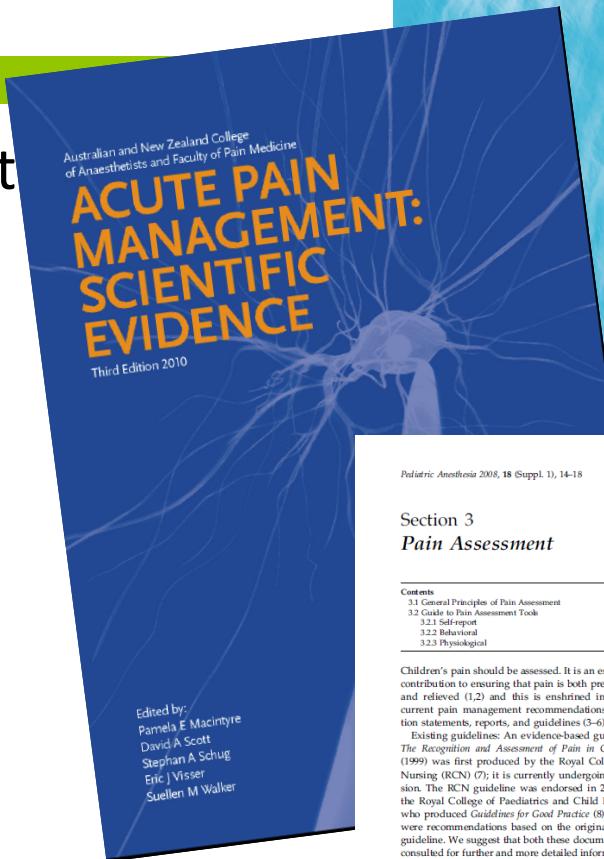
Children with PCN and pain

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



doi:10.1111/j.1460-9592.2008.02429.x

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Children's pain should be assessed. It is an essential contribution to ensuring that pain is both prevented and relieved (1,2) and this is enshrined in many current pain management recommendations, position statements, reports, and guidelines (3-6).
In 1999, the Royal College of Children's Physicians published 'An Evidence-based Guideline: The Recognition and Assessment of Pain in Children' (1999) was first produced by the Royal College of Nursing (RCN) (7); it is currently undergoing revision. The RCN guideline was endorsed in 2001 by the Royal College of Paediatrics and Child Health, who produced 'Guidelines for Good Practice' (8) which were recommendations based on the original RCN guideline. We suggest that both those documents be consulted for further and more detailed information; the evidence and recommendations presented here are intended to support and supplement this existing guidance.

3.1 General principles of pain assessment

Good pain assessment contributes to the prevention and/or early recognition of pain as well as the effective management of pain (1). There are three fundamental approaches to pain assessment in children:

1. Self-report: measuring expressed experience of pain.
2. Observational/behavioral: measuring behavioral distress associated with pain, or measuring the perceived experience of pain by parent or carer report.
3. Physiological: primarily measuring physiological arousal consequent to pain.

As self-report is the only truly direct measure of pain it is often considered the 'gold standard' of measurement, however, for developmental reasons

self-report may be difficult or impossible in some children and therefore a proxy measure must be used. For pain to be measured as accurately as possible the principles underpinning assessment at different developmental ages and in different settings must be appreciated.

Good practice point
In order to assess pain, effective communication should occur between the child (whenever feasible), their family or carers, and the professionals in the multidisciplinary team.

Recommendations
No individual measure can be broadly recommended for pain assessment across all children or all contexts: Grade B (9,10)

Children's self-report of their pain, is the preferred approach: Grade B (9)

Children's pain should be assessed, documented, and appropriate action taken as this contributes to prevention and relief of pain: Grade D (1,11)

Healthcare professionals and parents/carers should receive information, education, and training in pain assessment: Grade D (12,13)

There is little evidence to recommend the clinical use of physiological measures alone to measure pain: Grade D (14,15)

Evidence
The results of pain assessment must be documented, acted upon, reassessed, and reevaluated to determine the effectiveness of interventions (1,16,17). Improved documentation can result in improved pain management (11,18). Studies demonstrate that pain is under-assessed and poorly documented resulting in children being under-medicated and/or their pain being poorly managed (19). Regular pain evaluation can contribute to the safety and efficacy of management of acute pain (20).

Children's self-report of pain is regarded as the gold standard and in most circumstances it is the preferred approach. However, it needs to be

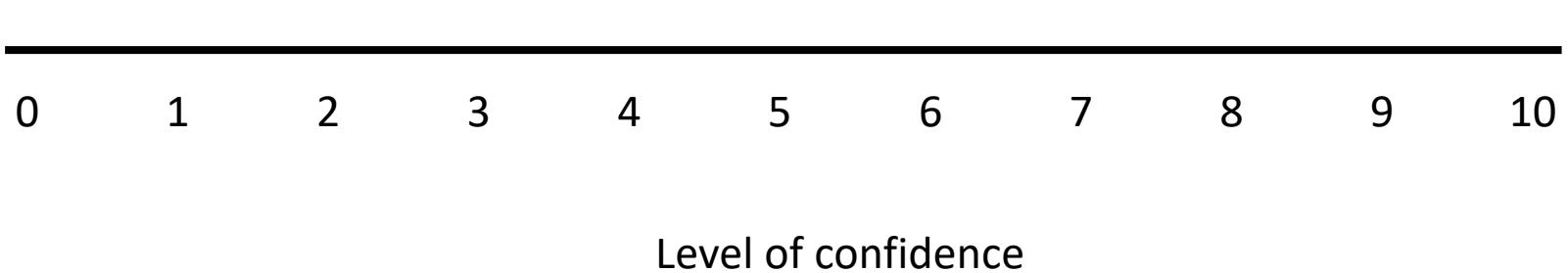
Pain assessment

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?



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)

http://www.britishpainsociety.org/book_apa_part1.pdf

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 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**
 - ▣ **NCCPC-R** (Non-Communicating Children's Pain Checklist): intended for 3-18 year olds (Breau et al. 2000; Breau et al. 2001; Breau et al. 2002; Breau et al. 2003)
 - ▣ **PPP** (The Paediatric Pain Profile): intended for 1-18 year olds (Hunt et al. 2004)
- **Post operative pain**
 - ▣ **NCCPC-PV** (Non-Communicating Children's Pain Checklist- Postoperative Version): intended for 3-19 year olds (Breau et al. 2002).
 - ▣ **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**
 - ▣ **PPPM** (Parents Post operative Pain Measure): (Chambers et al. 1996; Chambers et al 2003; Finley et al 2003)

Research Study

Informing practice

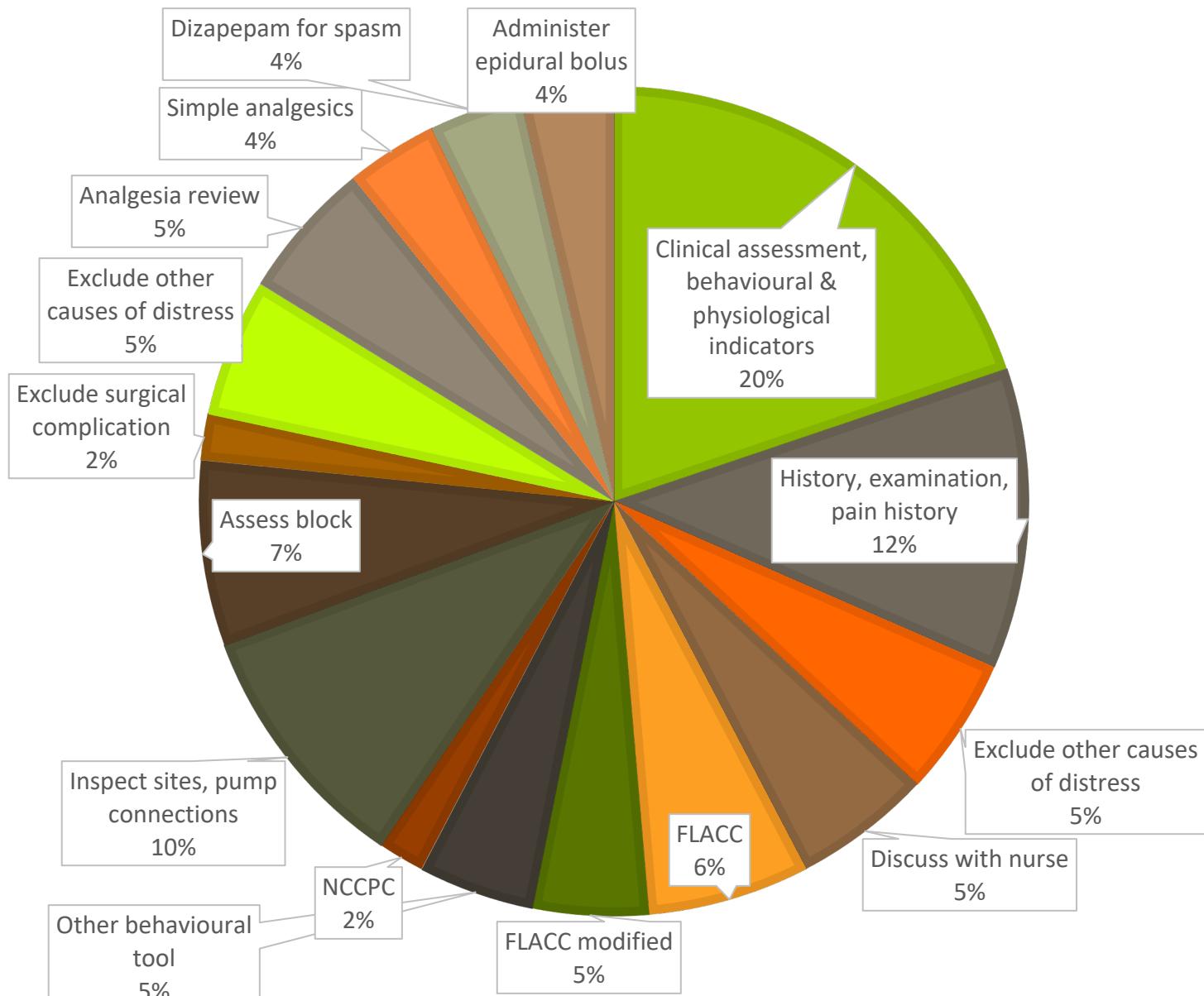
Anaesthetists' views of managing children's pain post-surgery

Joan Simons *Faculty of Wellbeing, Education and Language Studies, The Open University, Milton Keynes, UK*
Bernie Carter *Faculty of Health and Social Care, Edge Hill University, Ormskirk, UK*
Jennie Craske *Department of Anaesthetics, Alder Hey Children's NHS Foundation Trust, Liverpool, UK*
Sarah Parry *Pain Team, Bristol Royal Hospital for Children, Bristol, UK*
Sally Coles *Pain Team, Birmingham Children's Hospital NHS Foundation Trust, Birmingham, UK*
Michelle Bennett *Pain Team, Queen's Medical Centre Campus, Nottingham University Hospitals NHS Trust, Nottingham, UK*

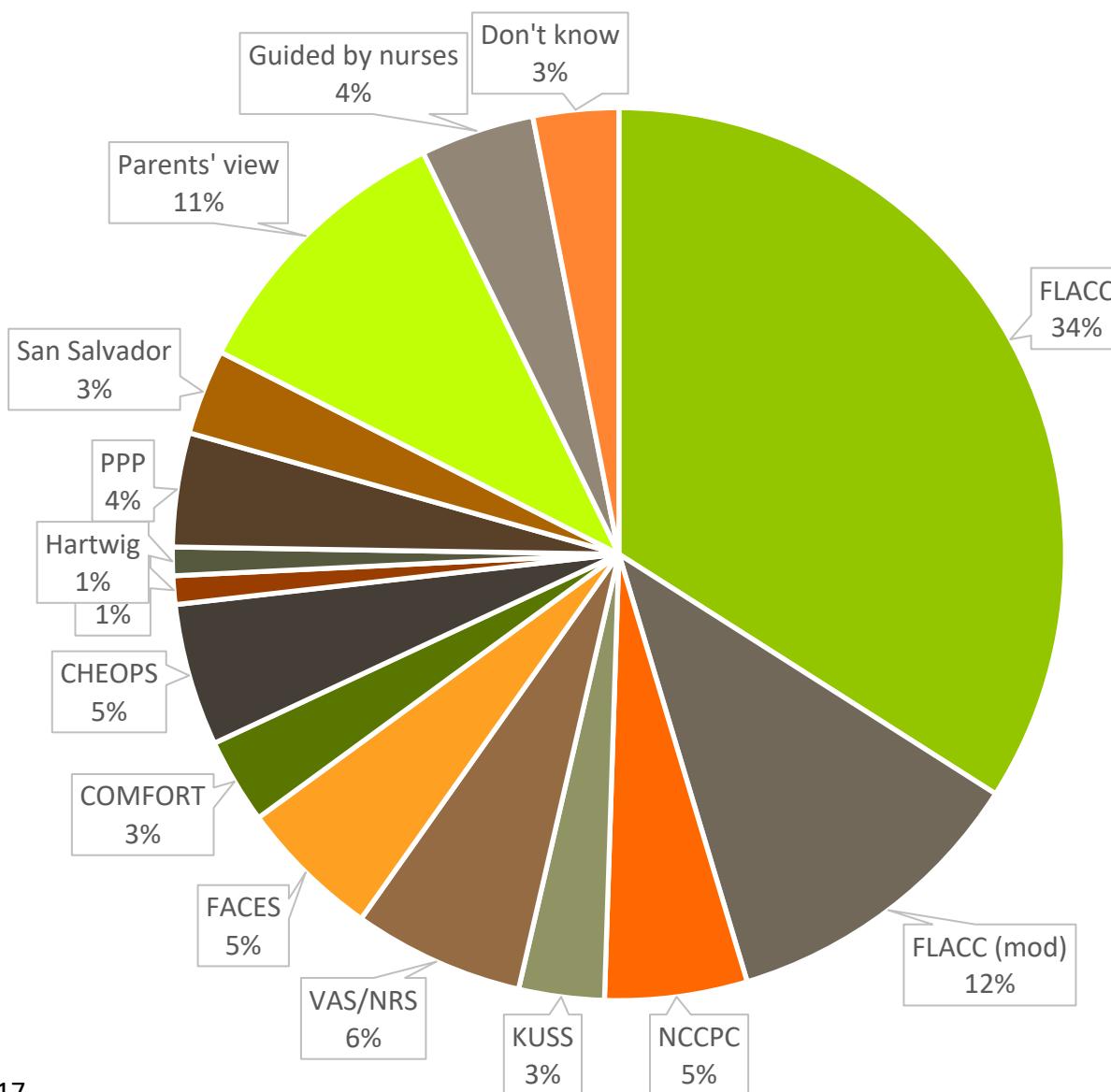
Pain News
2017, Vol 15(4) 181–184
© The British Pain Society 2017
SAGE

- ▣ 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)

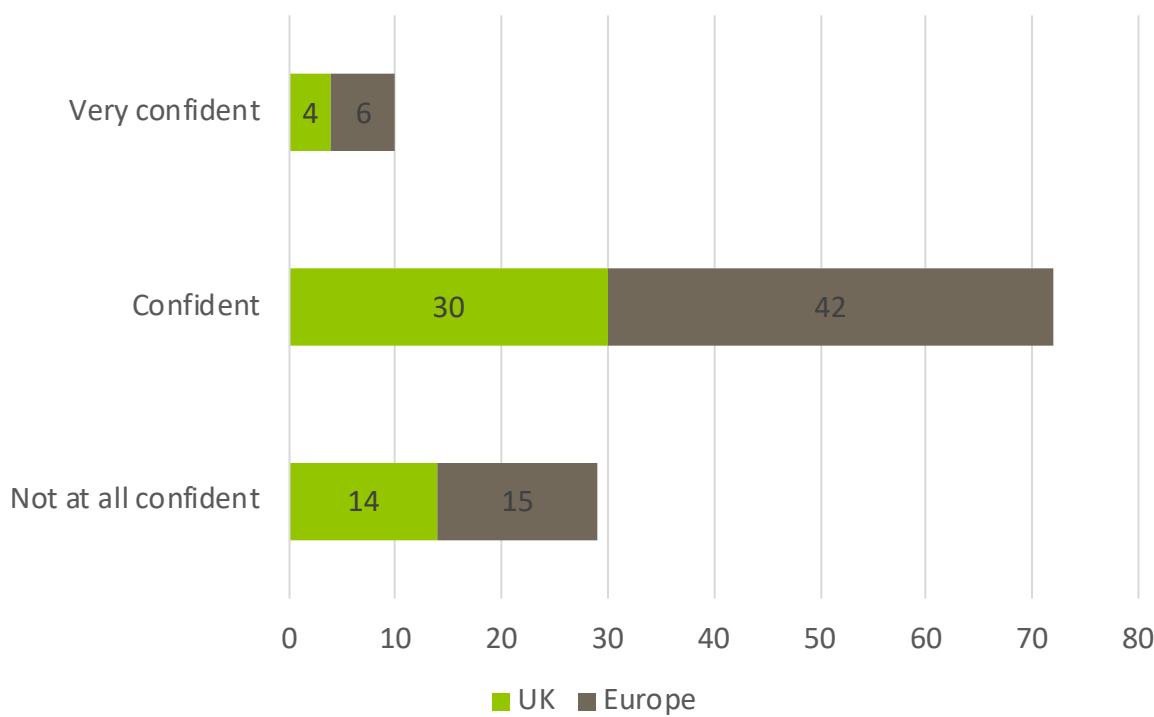
Q17 How would you assess Ruby's pain?



Q19 What pain assessment tool or tools would you use, if any, to assess Ruby's pain?



Q20: How confident would you be in assessing Ruby's pain?



Revised FLACC (revisions in italic)

FLACC-R

- ❑ 5 item scale
 - Face
 - Legs
 - Activity
 - Cry
 - Consolability
- ❑ Each item rated 0-2
- ❑ Total score 0-10

Face

0 = No particular expression or smile
1 = Occasional grimace/frown; withdrawn or disinterested; *appears sad or worried*
2 = Consistent grimace or frown; frequent/constant quivering chin, clenched jaw; *distressed-looking face; expression of fright or panic*
Individualized behavior: _____

Legs

0 = Normal position or relaxed; *usual tone & motion to limbs*
1 = Uneasy, restless, tense; *occasional tremors*
2 = Kicking, or legs drawn up; *marked increase in spasticity, constant tremors or jerking*
Individualized behavior: _____

Activity

0 = Lying quietly, normal position, moves easily; *Regular, rhythmic respirations*
1 = Squirming, shifting back and forth, *tense or guarded movements; mildly agitated (e.g. head back and forth, aggression); shallow, splinting respirations, intermittent sighs.*
2 = Arched, rigid or jerking; *severe agitation; head banging; shivering (not rigors); breath holding, gasping or sharp intake of breaths, severe splinting*
Individualized behavior: _____

Cry

0 = No cry/verbalization
1 = Moans or whimpers; occasional complaint; *occasional verbal outburst or grunt*
2 = Crying steadily, screams or sobs, frequent complaints; *repeated outbursts, constant grunting*
Individualized behavior: _____

Consolability

0 = Content and relaxed
1 = Reassured by occasional touching, hugging or being talked to. Distractable.
2 = Difficult to console or comfort; *pushing away caregiver, resisting care or comfort measures*
Individualized behavior: _____

NCCPC-R

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

Non-communicating Children's Pain Checklist – Revised (NCCPC-R)

NAME:	UNIT/FILE #:	DATE:	(dd/mm/yy)	
OBSERVER:	START TIME:	AM/PM	STOP TIME:	AM/PM

How often has this child shown these behaviours in the last 2 hours? Please circle a number for each item. If an item does not apply to this child (for example, this child does not eat solid food or cannot reach with his/her hands), then indicate "not applicable" for that item.

0 = NOT AT ALL 1 = JUST A LITTLE 2 = FAIRLY OFTEN 3 = VERY OFTEN NA = NOT APPLICABLE

I. Vocal
1. Moaning, whining, whimpering (fairly soft).....
2. Crying (moderately loud).....
3. Scream (loudly, very loud).....
4. A specific sound or word for pain (e.g., a word, cry or type of laugh).....

II. Social
5. Not communicating, cranky, irritable, unhappy.....
6. Loss of appetite with others, who eat.....
7. Seeking comfort or physical closeness.....
8. Being difficult to distract, not able to satisfy or pacify.....

III. Facial
9. A furrowed brow.....
10. A change in eye, including squinting of eyes, eyes opened wide, eyes frowning.....
11. Tightening of mouth, not smiling.....
12. Lips puckering up, tight, pouting, or quivering.....
13. Clenching or grinding teeth, chewing or thrusting tongue out.....

IV. Activity
14. Not moving, less active, quiet.....
15. Jumping around, agitated, fidgety.....

V. Body and Limbs
16. Floppy.....
17. Stiff, spastic, tense, rigid.....
18. Guarding or reaching part of the body that hurts.....
19. Protecting, favoring or guarding part of the body that hurts.....
20. Resisting touch, pulling away from touch, or being sensitive to touch.....
21. Moving the body in a specific way to show pain (e.g. head back, arms down, curls up, etc.).....

VI. Physiological
22. Shivering.....
23. Choking, vomit, puke.....
24. Sweating, perspiring.....
25. Constipation.....
26. Sharp intake of breath, gasping.....
27. Breath holding.....

VII. Eating/Sleeping
28. Eating less, not interested in food.....
29. Insomnia.....
30. Decrease in sleep.....

SCORE SUMMARY:
Category: I II III IV V VI VII TOTAL
Score:



This profile belongs to _____

<http://www.pprofile.org.uk>

Paediatric Pain Profile

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

Instructions and guidance for use



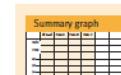
The pain history

This part of the profile asks about your child's history of pain. It provides space to write about your child's experience with pain as an infant, during surgery or from injuries, or pains that have occurred due to your child's illness or disability. Knowing how your child has coped with pain and injury in the past can help to guide how pain is managed in the present.



Baseline assessments

In this section we ask you to describe on the pain profile your child's behaviour when they are 1) at their best or 'on a good day' and 2) if your child has any current or recurring pains. Using the pain profiles you just circle the number that best describes how much your child is like the item in the left hand column. There are sheets to describe your child's most troublesome pain (Pain A) and up to two other pains (Pains B and C). Then transfer the numbers you have circled to the right hand column of each profile and add up the totals. The total scores can then be plotted by placing a cross in the shaded area on the Summary Graph.



Summary Graph

The baseline assessments provide a comparison for any further assessments you need to make in the future.

Paediatric Pain Profile



Ongoing pain assessments

You can use the Pain Profile

– ongoing pain assessments sheets to make assessments at any time that suits you, for instance if you need to record your child's behaviour or if you are monitoring your child's response to a treatment. The scores can be transferred to the Summary Graph and/or the Assessments, actions and outcomes page.



Assessments, actions and outcomes

Using this sheet you can describe the actions that have been taken to relieve your child's pain and your child's response. It is often a good idea to use the profile again after the intervention to see and record if the action has been effective in relieving the pain.



Talking to professionals about your child's pain

Some pains can be quite troublesome and difficult to relieve. You might like to talk to your doctor or another health professional about your child's pain. It might be helpful to show them your child's Profile. Ask them if they would like to write something on the professional's page about your child's pain problem.

Paediatric Pain Profile

Baseline assessments

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

Is your child like this? (Tick applicable box) 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? (Tick applicable box)

No pain Mild pain Moderate pain Severe pain Very severe pain

Completed by _____

Date _____

Paediatric Pain Profile

Baseline assessments

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 _____

Paediatric Pain Profile

Baseline assessments

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

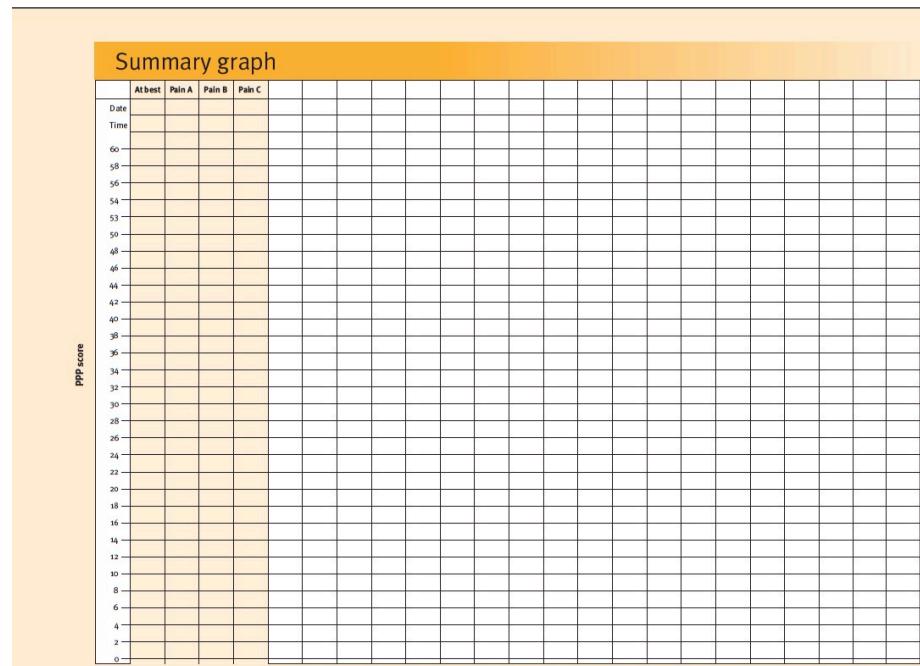
When my child has this pain, he or she...	Not at all	A little	Quite a lot	A great deal	Score
Is cheerful	3	2	1	0	
Is sociable or responsive	3	2	1	0	
Appears withdrawn or depressed	0	1	2	3	
Cries /moans/groans / screams or whimpers	0	1	2	3	
Is hard to console or comfort	0	1	2	3	
Self-harms e.g. biting self or banging head	0	1	2	3	
Is reluctant to eat / difficult to feed	0	1	2	3	
Has disturbed sleep	0	1	2	3	
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Tends to touch or rub particular areas	0	1	2	3	
Resists being moved	0	1	2	3	
Pulls away or flinches when touched	0	1	2	3	
Twists and turns / tosses head / writhes or arches back	0	1	2	3	
Has involuntary or stereotypical movements / is jumpy / startles or has seizures	0	1	2	3	
					TOTAL

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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7



Research Study

Research Article

Navigating Uncertainty: Health Professionals' Knowledge, Skill, and Confidence in Assessing and Managing Pain in Children with Profound Cognitive Impairment

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³College of Health and Wellbeing, University of Central Lancashire, Preston, UK

Research Article

Developing a Sense of Knowing and Acquiring the Skills to Manage Pain in Children with Profound Cognitive Impairments: Mothers' Perspectives

Bernie Carter,¹ Janine Arnott,² Joan Simons,³ and Lucy Bray¹

¹Faculty of Health and Social Care, Edge Hill University, Ormskirk, UK

²School of Health and Well-Being, University of Central Lancashire, Preston, UK

³Faculty of Health and Social Care, The Open University, Milton Keynes, UK

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

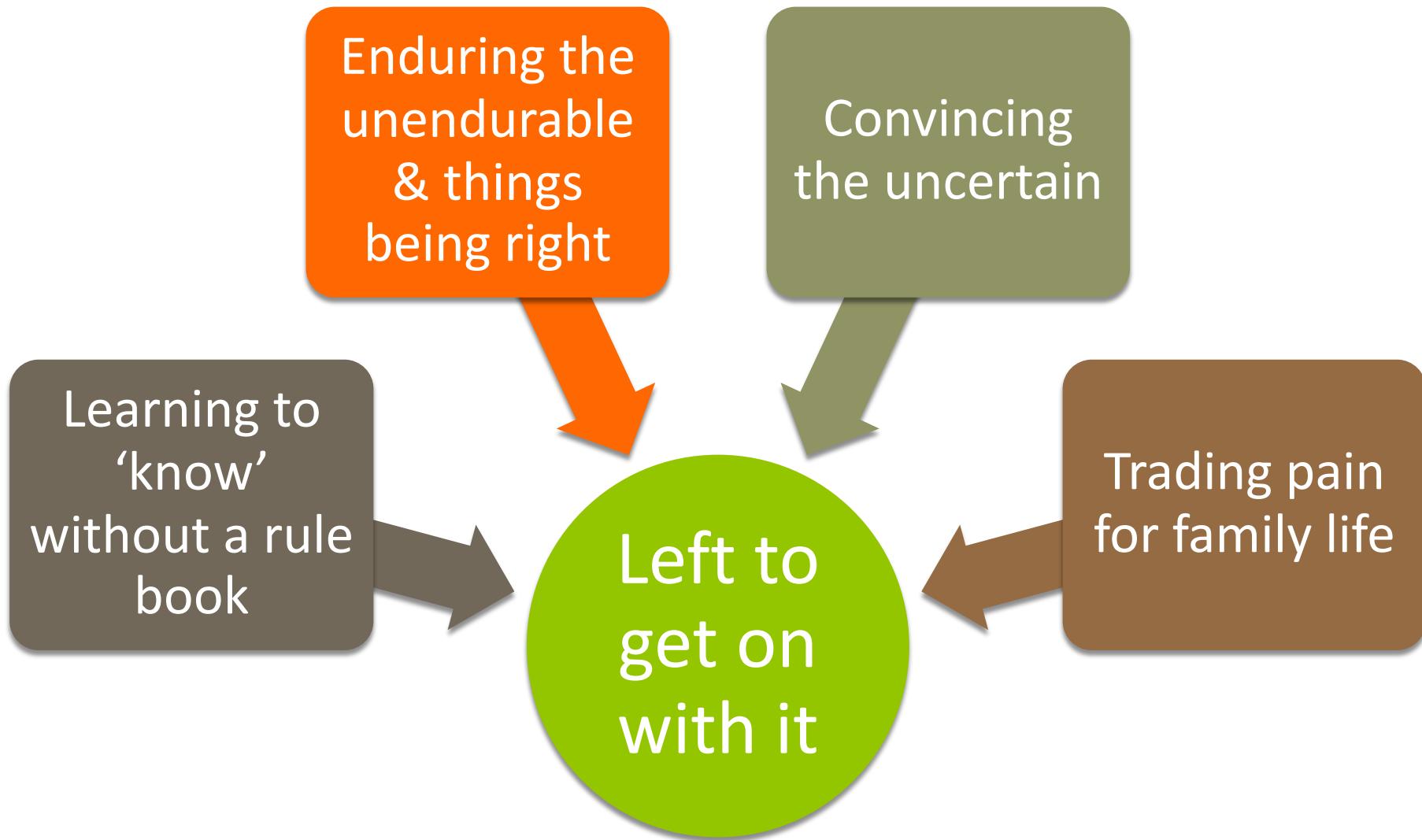
Exemplar survey data from 2 families

Family 1: Girl, 16 yrs

1. Comprehensive pain plan
2. Pain experienced: 6 out of 8 weeks
3. Pain sources: wisdom teeth, constipation, hip pain, period pain, headache, muscle spasm
4. Pain medicine given: paracetamol, diazepam, brufen, on top of regular pain meds given
5. Other actions – bath, massaging, positioning

Family 2: Boy, 13 yrs

1. Struggling with ongoing pain
2. Pain experienced: 8 out of 8 weeks
3. Pain sources: uncertain at times, abdominal, hip pain
4. Pain medicine given: paracetamol
5. Other actions – rubbing back and legs, positioning, new bed and wheelchair,



Learning to ‘know’ without a rule book

- 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”

Learning to ‘know’ without a guide

- 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”

Enduring persistent pain & things being right

- 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”

Convincing the uncertain

- 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”

Trading pain for family life

- 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 everythingto 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

Framing as
different and
teasing things
out

The settling
and unsettling
presence of
parents

Navigating
uncertainty;
deficits in
knowledge
and skills

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?

1 More education/training for anaesthetic staff

2 More education/training for nursing staff

3 Better education about pain scales for children/parents

4 Appropriate pain assessment tools at each bed

5 Pain scores assessed on regular basis

6 Pain scores documented

7 A dedicated pain service

8 Consistent use of an appropriate pain scale

9 Making pain assessment using an appropriate scale mandatory

10 Better communication between professionals

11 Better communication between professionals and parents

12 Pain is a higher priority within the institution

13 Clear policy for effective pain assessment

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.

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