Parents' involvement in pain assessment and management – the Whys

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A journey of pain - and pain relief

This morning...
- Current issues with parental involvement in 3 different contexts
  - Primary care
  - Acute and post-op care
  - NICU care
- Organizational level opportunities for improvement

This afternoon...
- Implementing effective practices for parent engagement in these settings

Parent involvement in the care of children with pain

- What involvement do parents want?
- Can they do it?
- How should they do it?
- What is the effect on children’s pain expression?
- What is the effect on the quality of pain care?
- How can hospital staff help (or hinder)?

Why is pain prevention so important?

“each individual learns the application of the word [pain] through experiences related to injury in early life”  IASP 1979

How often do children receive injections?

- Minimum 5 injections in the first year
- Up to 20 injections by school entry (Canada)
- Up to 5 in 1 visit (USA)
- NOT counting flu shots
- NOT counting additional vaccines if underlying medical condition

Adverse effects of injection pain

- Anticipatory fear at future procedures and healthcare avoidance
  - Poorer adherence to immunization schedules
  - Refusal to seek dental care, health checks
- Reduced effectiveness of comfort and analgesics
- Difficulty in carrying out procedures
- Sensitization due to changes in how the nervous system processes pain
- Needle phobia (10%)
  - Median onset 5.5 yrs
Parents worry about knowing when children …

Have pain from injury?

Have pain from illness?

Are tired or grumpy?

How parents think about young children’s pain

Parents believe children’s pain communication...
- becomes more sophisticated with age
- serves multiple purposes
  - expression of physical/emotional distress
  - pursuit of various personal goals: pain relief, elicitation of emotional support, attention seeking, activity avoidance or continuation, avoidance of embarrassment, reprimand and treatment
  - manipulation of interpersonal relationships: sibling rivalry and family relationships
- is sometimes suppressed for positive self-presentation (i.e. appear brave)

How parents think about young children’s pain

Parents have difficulty interpreting their children’s pain behaviors
- children’s developmental level and communication skills
- their own beliefs about pain and illness
Parents sometimes know their children are in pain but they struggle to identify the cause
- ‘My husband always think it’s the worst, if it’s a headache…he’s like “MENINGITIS!” and I’m like no, it’s fine, so we argue about it.”

How parents think about young children’s pain

- Parents have difficulty in deciding when it was appropriate to give medicine to their children
- They worry about the effects of giving medicine too often and when unnecessary
- They also worry about their child suffering when they had the means to make them feel better

How parents think about young children’s pain

- Parents feel their concerns about their children’s pain are not always listened to by general practitioners
- ‘I just think you know when something’s not right, I find a lot of times if you go to GPs they don’t listen, they palm you off because you’re not a doctor, they should listen’
Parents don’t always know how best to help…

It hurt. I screamed and cried. Mummy smacked me. Nurse scratched me with the needle. I got a sticker. (Boy, 3 years)

Children and young people’s views about injections, RCPCH, 2005

Partnering with parents to prevent vaccine injection pain

We can do better than this…

What about parents of hospitalized children?

Parents are not as involved as they want to be…

• Feel helplessness
  Worry about pain is associated with high parental stress
• Feel child comfort should be their role
• Source of conflict with hospital staff
  • On general wards
  • In critical care units


Nurses’ views of parent involvement

• They did not discuss involvement with parents: “So she probably demonstrated how much she wanted to be involved without actually obviously saying it.”

• They expected parents to approach them with concerns “She hasn’t voiced any concerns to me.”

• They were unaware of parents’ reluctance to do so: ‘They’d tell you, they wouldn’t sit there.’ Simons et al 2001

Parents can be your most effective intervention

• Parents
  – Brief training
  – Reduction in parental anxiety – or no worse
  – More satisfied
• Children
  – Less discomfort
  – Often less distress
  – More satisfied
• Staff
  – Doctors more anxious
  – No difference in performance
How BIG is the problem of Postoperative Pain
• In the US, about 2 million undergo surgery each year
• Children can suffer persistent physical and psychological problems as a result
• Behaviour changes: attention seeking, temper tantrums, sleep disturbances, eating problems, social withdrawal
• Emotional responses: anxiety, fear, depression, separation anxiety
• Problems may continue 4 weeks or more following discharge from hospital (Kain et al 1996; Kotiniemi et al 1997; Stargatt et al 2006; Karling et al 2007)

Risk factors for poor pain coping
– higher child or parent state anxiety pre-surgery
– withdrawn temperament
– younger age
– previous negative experiences
– induction procedure
– pain and other symptoms
– staying over night

Preparing parents/children is drug-sparing for day case surgery
Preparing parents to take an active role in their child’s preparation for surgery:
¬ Parent/child anxiety in holding area
¬ Child anxiety at induction equal to midazolam
¬ Emergence delirium
¬ Recovery room analgesia
¬ Recovery room length of stay
¬ Post-hospital behavior problems

Pain and behavior changes following surgery
• Children 2 to 12 yrws
• Admitted for urology (34%), ENT (30%) or general (36%) surgery
• Inpatient or day case surgery under general anaesthesia at 3 London hospitals

Parents search for information
• 93% parents reported receiving information about their child’s surgery prior to admission
  – 78% leaflets
  – 41% discussion
  – 2% video
• 32% did additional information searching
  – 85% of these parents used the internet

Pain and behavior changes following surgery

Power et al 2012

Power et al 2012
Pain and behavior changes following surgery

Table 4 Overall predictors for problematic behaviour at the end of week 2

<table>
<thead>
<tr>
<th>Predictor</th>
<th>OR</th>
<th>95% CI</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child temperamental liability (5-25 EASI)</td>
<td>0.63</td>
<td>0.469 to 0.848</td>
<td>0.002</td>
</tr>
<tr>
<td>Parent baseline anxiety (20-90 STAI)</td>
<td>1.10</td>
<td>1.027 to 1.168</td>
<td>0.006</td>
</tr>
<tr>
<td>Child pre-operative anxiety (0-100 mYPAS)</td>
<td>1.11</td>
<td>1.027 to 1.189</td>
<td>0.007</td>
</tr>
<tr>
<td>Pain experienced during last medical procedure (yes vs no)</td>
<td>8.21</td>
<td>1.890 to 35.646</td>
<td>0.005</td>
</tr>
</tbody>
</table>

EASI, Emotionally Activity Sensitivity and Impulsivity Instrument; mYPAS, modified Yale Pre-operative Anxiety Scale; STAI, State Trait Anxiety Inventory.

Parent concerns about their child after cardiac surgery

“**I am worried that he is uncomfortable and in pain. Seeing him in pain and being uncomfortable is difficult.**”

“**Not being able to pick him up and cuddle him to tell him it will be ok.**”

Franck et al 2010

Involving parents improves parent/child N/ICU outcomes

- Helping parents to be more active in psychosocial support of children
  - Maternal mental health problems up to 1 year later
  - Child behaviour problems

Melnyk et al., 2004, 2007

Preparing parents/children for pain care at home after surgery

Parental concern and distress about infant pain

Parents’ perceptions of their infant’s pain experience in the NICU

*Ghayrat, Sh., Linde-Sanderson, Simon-Koboth, Mary Lynch”*
Infant pain is stressful for parents
They:

• Are aware of infant pain
• Worry about pain - associated with higher parent distress
• ...Want more information/involvement in infant comfort

Parents have worries about infant pain

Franck et al., 2004

Parents’ worries about infant pain

• Higher parental stress scores associated with:
  - Belief that their baby experienced more pain
  - More worries about pain/pain management
  - Dissatisfaction with pain information they received
  - Controlling for state anxiety and overall satisfaction with care...
• Parents who preferred not to be present during procedures were more anxious

Franck et al., 2004

Early infant pain may alter interactions between child and parent

• Former NICU preterm children (9–14 yr) during experimental pain task
  - showed more distress
  - were more likely to elicit solicitous maternal responses to pain
• Maternal behaviors reinforced children’s pain responses
• Proposed mechanism
  - Perception by mother of failure to protect from pain in the NICU


Why should we do more to help parents get involved?

• Self-regulatory theory: we regulate our behaviour based on expectations from experience and new information
  - Parents best able to help child integrate past w/ present
• Control theory: we regulate our environment through developed roles and routines
  - Parental role a reassuring, stable influence in an uncertain environment
• Emotional contagion theory: we transfer our emotional states (esp. anxiety) to others
  - Parent can model positive emotions and coping

Why should we do more to help parents get involved?

• To help us do a better job of pain assessment and management
Possible adverse effects of parental involvement in children’s pain management

- Increased parental burden
- Highly anxious people may feel worse
  - If previous bad experience, may be sensitised
  - High level of fear/arousal interferes with retention of information
  - May create sense of helplessness
- Staff burden
  - Workload
  - Performance anxiety
- Conflict between parents and staff

Why is parent involvement in hospitals sometimes ‘painful’?

Parent observes: subtle differences in individual child behavior
Clinician observes: deviations from population norms
Potential for conflict:
- Uncertainty about own or other’s expertise
- Failure to integrate all sources of knowledge

Partnering with parents to reduce infant pain in the NICU

And at home…

Prevention at the organizational level

The staff of Connecticut Children’s Medical Center is committed to being a place where the pain of medical treatment is controlled as much as possible. Although we may not be able to take away all of the pain, we will make every effort to reduce it. The idea is that this is a hospital where expert medical care and comfort go together. We call this: Comfort Central.

"We are creating a different kind of Emergency Department," said Dr. Pat Crocker, Medical Director of the Dell Children’s ED. "It's one that children want to come to, one that makes them feel welcome and cared for, one that is non-threatening and one that sets the standard for children’s care."

- Dell Children’s has implemented the following into the ED:
  - Consistent utilization of Pain Protocol
  - Use of Nitrous Oxide (a drug induced state with minimal sedation); Dell Children’s is the only hospital in Central Texas to offer this to medically appropriate patients
  - Anesthetic creams and sprays to numb area where injections are given or IVs are placed
  - Use of intranasal medications to reduce anxiety and fear by using age-appropriate techniques such as a kid-friendly, fish-shaped device
  - Utilization of "comfort positioning" during procedures; for example, allowing a child to sit in parent’s lap, which gives the child a greater sense of control

Our pledge to you and your child

If a painful treatment is necessary, every effort will be made to keep your child comfortable. Members of our pain management team are experts in helping children feel comfortable.

- We will help your child cope with discomfort by using relaxation techniques, sedatives, and/or pain medicine.
- Whenever the need for a blood sample is not an emergency, we will offer a special numbing cream one to two hours before blood is taken.
- If an intravenous (IV) line is needed, we will help your child relax, use a special numbing cream, or inject a numbing medicine. The IV may also be placed when your child already is sedated for a procedure or surgery.
- When it is best for your child, we will do procedures in a special treatment room so that your child feels safe in his or her own room and in the playroom.
- We will make every effort to give medicine in a pain free way. We will give your child medicine to swallow or through the IV. We do not give painful shots to help ease pain.
- We will check for pain often. We will respond quickly to reports of pain.
- We will measure your child’s pain based on his or her level of understanding. We will support parents in their role as part of our pain management team.
- We will give you information on how to prepare and support your child before, during and after a procedure or surgery. Most of the time, you will be able to be with your child.
- We will give you information about pain and pain management choices and work with you to develop a pain management plan.
- After the procedure or surgery, we will make every effort to keep your child comfortable using the pain management plan. If he or she is uncomfortable, we will change the plan until your child is comfortable.
Questions for you?

- Can you think of an instance where a child experienced preventable pain - and what could be done differently?
- What are the barriers in your organizations?
- What do you think would help?

Please remember...

- Procedures are never ‘routine’ for children and parents

  *When doctors give the shots, they don’t know how it feels: They say it’s not going to hurt, only because it doesn’t hurt them* (Lewis 1978)

Help parents become aware and involved

www.gosh.nhs.uk/paincontrolservice
Use your power!

What can YOU do to make YOUR Clinical Service a place where children receive the BEST pain prevention and treatment for all medical procedures?