STRATEGIES TO IMPROVE THE PAIN CARE OF CHILDREN IN HOSPITAL: THE CHILDKIND INITIATIVE

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Conflict of Interest Disclosure

• Conflicts of Interest for ALL listed contributors.
  • Neil L. Schechter – No conflict of interest
  • Renee C. B. Manworren – No conflict of interest

A conflict of interest is a particular financial or non-financial circumstance that might compromise, or appear to compromise, professional judgment. Anything that fits this should be included. Examples are owning stock in a company whose product is being evaluated, being a consultant or employee of a company whose product is being evaluated, etc.

• Taken in part from “On Being a Scientist: Responsible Conduct in Research”, National Academies Press. 1995.

Objectives

• Review the history and current status of pain management in children
• Analyze the gap from knowledge to clinical translation to prevent relief of children’s pain
• Discuss efforts to promote organizational sensitivity to pain and institutional commitments to pain management
• Describe the need, evolution, 5 principles, and criteria for ChildKind International accreditation
History of Pain Control in Children

- Hospitalized children
- Newborns
- Procedure pain

Pain in Hospitalized children

- Swafford (1968) – Children don’t feel pain; no need to treat it
- 1970s – Eland reviewed charts of 25 postop children (ages 4-8) – mixed diagnoses such as neck mass excision, palate repair, nephrectomy, traumatic amputation and 25 adults
  - Children: 12 received analgesia, 24 doses in total half opioid
  - Adults – 372 opioid, 299 NSAIDs
- Mid 80s – Mather, Beyer, Schechter
  - Significant disparity between adult and child dosing
  - PRN interpreted as “as little as possible”; disparity between adult and child dosing
- Cancer pain – both disease and procedure pain minimally addressed
Pain in the Newborn

- Infants (voiceless); depending on discipline, over 20% of clinicians thought infants did not feel pain
- Intraoperative anesthesia often not used and postop analgesia, non-existent
- Pain of procedures (arterial sticks, chest tube insertions, circumcisions, heel sticks) rarely considered despite frequency of occurrence
- Barker and Rutter 1995 - 54 newborns in NICU between 3 and 10 days - 3000 procedures
Procedure Pain

- Procedures major source of distress in children, particularly those with chronic disease; often more painful than the disease itself
- Procedures often required physical restraint
- BMA/BMB, laceration repair, debridement usually done with minimal local anesthesia/sedation
- When analgesia/anesthesia used
  - No uniform approach
  - Agents used often unsafe (DPT cocktail) or inadequate (chloral hydrate)

Pediatric Sedation in the Eighties

4 Sizes to Fit All Ages

- Newborn Small Size
- Regular Size
- Large Size
- Extra-Large Size

30 years ago...

- Postoperative pain management was an afterthought
- Management of disease related pain was inadequate
- Newborn pain and procedure pain was typically ignored
- Procedure pain was minimally addressed
Why?

- Essentially no research on pain in children
- Difficulties of assessment
- Ethical constraints
- Lack of financial incentives
- No information in text books (Rana - 1987 examination of top 10 pediatric textbooks [over 12,000 pages, less than 1 page on pain]
- Persistence of myths which minimized children’s experience of pain
  - Children don’t feel pain
  - Analgesics are too strong

What changed?

- Recognition of short and long term consequences of inadequate analgesia
- Anand – dramatic increase in stress hormones in newborns undergoing surgery w/o anesthesia
- Fitzgerald – multiple painful procedures change the way in which the nervous system responds to future pain
- Taddio - Increased distress at 4 and 6 month immunization in infants circumcised without anesthesia
- Inadequate anesthesia during bone marrow aspiration predicts increased pain during subsequent marrows despite adequate anesthesia

Consequences of Painful Procedures

Pain Scores in Children < 8 yr.
Which led to...

- Outpouring of editorials in major journals demanding better pain care
- Which led to...

30 years of Pediatric Pain Research

- Understanding of how pain is interpreted and transmitted in the nervous system
- Progress in understanding the safety, efficacy, dose response, pharmacogenomics and clinical outcomes of analgesics and anesthetics in neonates, infants, and children.
- Multi-factorial nature of pain and the development of multidisciplinary teams
- Development of successful behavioral and physical strategies for chronic pain
- Ability to assess pain and treat the overwhelming majority of pain problems in children regardless of age and cognitive ability

Yet...

- Kozlowski (US), 2014 – 40% of postop children had “mod to severe” pain
- Karling (Sweden), 2002 – 23% postop patients in pain; 31% patients with non-postop pain
- Stevens (Canada), 2012 – survey of 32 units in 8 pediatric hosp – 3822 children surveyed over 24 h – 33% mod to severe pain
- Carbajal (France), 2008 – Infants averaged 16 painful + stressful procedures daily during first 14 days in NICU, rarely with analgesia (153 tracheal aspirations, 95 heelsticks in 14 days)
- Marked variation in approach to invasive procedures; 28X more likely to receive opioids in one NICU than another
- Finley (Thailand), 2007 – 81% of hospitalized children
Where are we now?

- Despite:
  - Recognition of short and long term negative consequences
  - Enormous increase in research on pain in children
  - Dramatic change in attitude and improvement in clinical care
  - Parental wishes
    - Ammendorp, 2005
      - Parents of 300 children queried regarding priorities and satisfaction with hospitalization
      - Of 36 categories, "pain" had greatest gap between priority and satisfaction

There remains.....

- Significant inter and intra institutional variability persists
- Smaller but significant number of children (around 25%) still experience unnecessary pain
- Although limited data on LMIC, by extrapolation from adult data, significant pain problems are common
What can help?

Despite gaps in knowledge, multiple streams of evidence suggest that if available information was uniformly applied, the overall burden of pain that children experience would diminish significantly.

“For nearly thirty years I have studied the reasons for inadequate management of postoperative pain, and they remain the same….inadequate or improper application of available information and therapies is certainly the most important reason for inadequate postoperative pain relief”

John Bonica, 1990

Traditional Strategies to Foster and Maintain Change

- Education
- Guidelines and protocols
- Quality Improvement


**Educational Strategies**

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**Passive Medical Education**

- Grand Rounds/lectures/CME
- Multiple studies demonstrate lack of impact of sporadic lectures on practice behavior*
- Some effect if lectures are perceived as directly relevant or if in repeated series


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**Active Medical Education**

- Case based instruction
- Small Group Instruction
- Instruction at the site of care
  - On rounds in hospital
  - In office through educational outreach ("academic detailing")
Educational Outreach: “Academic Detailing”

- Cochrane report – most effective educational strategy
- Small group interactive instruction in office setting
- Technique
  - Go to offices and survey to identify current knowledge and practice patterns
  - Define clear educational objectives
  - Establish credibility through non-profit organization
  - Develop interactive interesting educational program to be administered in office
  - Positive reinforcement through FU visit
- Labor intensive and expensive

Injection Protection Project

- Academic detailing to address injection pain
- Develop “best practices” model for injection pain reduction through consensus meeting
- Develop teaching materials based on those practices
- Visit offices
  - Identify impediments to change
  - Teach techniques
  - Supply materials
- Survey practices at prior, 1, and 6 months

*Schechter NL et al. Pediatrics 2010;126:e1514-21

Results: Providers

![Graph showing practice changes in providers over time with statistical significance](image)
Consumer Education

- Brochures/information for patients discussing the availability of pain management
- Signage throughout hospital asserting the “right to pain relief”
- Articles in lay publications (parenting magazines)

Summary of Educational Strategies

- Traditional passive continuing professional education strategies (single isolated lecture) not usually effective at changing behavior
- If frequently reinforced and occurring at site of care more effective
- Active strategies such as educational outreach, case based instruction, small groups much more effective
- Education of consumers may facilitate provider change
- Multifaceted educational models with at least 3 components – 71% success rate
- Education only part of overall plan to produce institutional change

Guidelines*

- “Best practices” based available research developed by multiple governmental, non-governmental and professional societies (WHO, AHRQ, APS, ASPMN)
- Limited impact on practice
  - Lack of awareness of guidelines
  - Lack of agreement with guidelines (Disagree with or distrust national experts)
  - Guidelines difficult to use/ Focus on knowledge and not practice
  - Inertia – not ready for change
  - Lack of relevance to local community or office conditions
  - Non-clinical factors – facility, finances, resources
- Use of local “needs assessment” documenting problems may make use of guidelines more acceptable

### Guidelines*

- ASPMN guidelines for assessing patients with limited abilities to communicate (2007 & 2011)
- ASPMN guidelines for range orders
- ASPMN Neonatal circumcision guidelines
- APS post-operative guidelines (2015)
- APS principles of analgesia (newly released)

### Adherence to Guidelines*

- National Institute for Clinical Excellence (NICE) established in England to "improve standards of care for patients and reduce inequalities in access to innovative treatments"
- Produced a series of evidence informed guidelines
- Selected 12 “tracer guidelines” to investigate adherence

* Sheldon et al. What’s the evidence that NICE guidance has been implemented. BMJ 2004;329:1-8.

### Features associated with high compliance with Guidelines

- Commitment to managing process of implementation
- Identification of lead clinician
- Proactive assessment of local costs and implications
- Responsibility for funding and implementation vested locally
- Strong clinical governance appropriately resourced
- Involvement of clinicians in the guideline process
- Targeted audit of non-compliance
Quality Improvement Activities

• Audit and feedback is often cornerstone (Giving individuals information about how their practices or pt outcomes compare with internal or external standard)
• Moderately successful at producing some change in specific behaviors*
• Reasons for failure include
  • No immediate opportunity to use feedback which often comes significantly after the fact
  • No penalty for not responding to feedback
• Satisfaction is poor indicator of quality (often high satisfaction despite high pain)


Figure 1

Combination Approaches

- Am Alliance for Cancer Pain Initiatives study (JPSM 2006;31:248-61)
  - education and QI in 113 health care facilities
  - modest decreases in pain but % of patients in severe pain still high
  - increased pain assessment and documentation, increased non-pharm
  - no improvement in patient pain outcomes
- STOP Project in Germany (Zernikow et al. EJPain 2008;12:819-33)
  - Longitudinal, nationwide, multi-center pediatric quality improvement study by German Society of Ped Hem/Dis
c  - Outcome – significant increase in knowledge and change in practice
  - Neither parents nor patients sensed improvement

Then what does work?

- Individual initiatives are sustainable if part of an institutional commitment to pain relief
- Pain relief is “institutionalized”
  - Core value similar to confidentiality and safety; part of institutional culture and “fabric of care”
  - Pain management is everyone’s responsibility; not just pain service; comfort measures used by all personnel during all patient encounters
  - Poorly managed pain is out of context in the institution and stands out

Support for Importance of Culture Change

- Twycross 2010; Dowden, 2008
- Bruce and Franck – survey identified organizational culture as barrier
- Jordan Marsh et al. (2004) – sustained change resulted from:
  - Linked pain control to strategic plan
  - Standardized policies
  - Extensive education
  - Weekly rounds
  - Leadership buy in and role modeling
History of “Institutionalizing” Pain Relief

• 1990: Mitchell Max (Improving outcomes of analgesic treatment: Is education enough?); proposed making pain “visible” and suggested the need for a broader approach
• Ferrell (1995) reported on the development of an institutional commitment to pain at a cancer hospital
• Summarized by Dahl (Building an institutional commitment to pain, 2000)
• Multiple pediatric institutions in the US have developed pain initiatives which emphasize institutional commitment

Elements of “Institutionalized”* pain treatment

• Interdisciplinary work group with administrative mandate for change
• Uniform standards for pain assessment
• Explicit policies and procedures
• Clearly defined accountability
• Easy access to pain information
• Patients and families are informed and actively involved in care
• Ongoing routinized education for staff
• Ongoing audit process

How to begin

- Survey present practice in selected areas – compare to benchmarks
- Identify impediments to change
- Get buy in from appropriate stakeholders empowered to make change
- Establish “Pain Council” consisting of individuals from different disciplines should monitor change and develop institutional action plan – not Pain Service
- Identify “champions” in different disciplines - Physicians should not be solely responsible
- Develop local evidence-based protocol, ongoing educational initiatives, and quality audits

How to Foster Institutional Commitment

- Stick
  - Regulatory Mandate
    - Joint Commission in U.S.
    - Canadian Council on Hospital Accreditation
  - Litigation
  - Legal Statute
    - California – mandated referral, mandated education, mechanism to follow undertreatment
    - Australia – “legal right to receive relief from pain and suffering to the maximum extent possible”
    - Human Rights violation – UN Convention on Rights of the Child
The Problem with the stick...

*If you use laws to direct people and punishments to control them, they will merely try to evade the punishments and will have no sense of shame. But if by virtue you guide them, and by rites you control them, there will be a sense of shame and of right.*

- Analects of Confucius

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A Potential Carrot

[www.childkindinternational.org](http://www.childkindinternational.org)

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What is ChildKind?

- An organization conceived by the Special Interest Group on Pain in Childhood of the International Association for the Study of Pain as a strategy to reduce pain in children by formally recognizing healthcare facilities that have made an institutional commitment to providing pain relief
- If a hospital can provide evidence that it has made such a commitment and has in place policies, protocols, quality audits, and ongoing educational activities that address pain, it can apply for designation as "A ChildKind Hospital"
What is Childkind?

- Based on the highly successful WHO/UNICEF Baby Friendly initiative to promote breast feeding – 15,000 Baby Friendly Hospitals
- Award is independent of level of institutional resource; goal is to develop a standardized approach and commitment to pain management

What is Childkind?

- Maintains resource library currently being updated that offers policies, protocols and educational programs so that lack of access to up-to-date information will not preclude the provision of appropriate pain relief.

Evolution of ChildKind

- Concept introduced at Vancouver ISPP meeting and endorsed by the SIG Executive Council
- Organizational meeting held at Rockefeller Foundation Study Center in Bellagio, Italy with support from the Mayday Fund
- 20 participants from 14 countries with WHO representation
- Development of Childkind principles and process
- Accrual of endorsements, piloting and 1st awards
- 2016 - Open to all NA
- 2017 – Open to all facilities
Childkind Hospitals
• Presently 5 Childkind hospitals
• 2 others have applied and pending site visits
• 5 others are developing applications

Endorsements
• Childkind is endorsed by 10 international professional organizations

The 5 ChildKind Principles
• Presence of a facility-wide written policy on pain prevention, assessment, and management endorsed by hospital administration
• Comprehensive and on-going education for staff and patients
• Documentation that pain is assessed using a developmentally appropriate process and recorded
• Creation of and access to specific evidence-informed protocols for pain management including pharmacologic, psychological and physical methods
• Use of a regular institutional self-monitoring quality program
Criteria for ChildKind Accreditation

Principle 1: Institutional commitment to pain prevention, assessment, and management
Presence of a facility-wide, evidence informed written policy on pain prevention, assessment, and management

- **Essential elements:**
  - Organizational commitment as evidenced by organization CEO, president or other senior administrator
  - Inherent in the fabric of the institution
  - Reflected in core values, strategic plan, policies, procedures and/or charter
  - Visible
  - Accessible
  - Integral to the care of the child

Criteria for ChildKind Accreditation

Principle 2: Ongoing education and awareness of pain
Comprehensive and ongoing education and awareness programs for all staff, students/trainees, patients and their caregivers

- **Defining criteria:**
  - Ongoing
  - Inclusive of all professional healthcare providers
  - Multi-modal approaches to pain education (e.g. verbal, written, web-based)
  - Consideration of learning styles
  - Family education that is linguistically and culturally appropriate

Criteria for Childkind Certification

- **Principle 3: Pain Assessment**
  All children have pain assessed using an evidence-informed, developmentally-appropriate process and recorded in the patient record

- **Defining Criteria**
  - Available and visible
  - Evidence-informed and current
  - Multi-modal approaches to pain education (e.g. verbal, written, web-based)
  - Consideration of multiple care providers’ learning styles
Criteria for ChildKind Accreditation
Principle 4: Protocols, procedures, guidelines
There are specific, evidence-informed, protocols, procedures and guidelines for pain prevention and management including pharmacologic, psychologic, and physical methods.
Defining Criteria:
• Current
• Evidence-informed
• Available
• Accessible

Criteria for ChildKind Accreditation
Principle 5: Self-monitoring and Quality improvement
There is a regular institution self-monitoring program of the ChildKind principles and criteria
Defining Criteria:
• Regular review of policies, procedures, and pain practices
• Framework of continuous quality improvement

Why ChildKind Certification is valuable?
• Offers a visible manifestation of institutional commitment to children’s comfort as a core foundational value
• Promotes pride in hospital staff members to work in an institution that has received international recognition for humane care.
• Evidence to consumers that institution has made commitment to improving the quality of patient experience
• Evidence to hospital-accrediting organizations that pain criterion for accreditation is addressed
Why is ChildKind certification valuable?

• Provides an organization:
  • A structured process to evaluate current practices
  • Ability to benchmark against other similar institutions
  • Technical assistance to improve the quality of the care they provide
  • Links to a community of likeminded colleagues who learn from each other and share similar values

Chicago, The first ChildKind City

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Summary

• Enormous progress in both research and clinical aspects of pediatric pain
• The burden of pain that children suffer in hospital could be further reduced if current knowledge was uniformly applied
• Typical strategies such as education, guidelines, and audits to change practice are more likely to be successful if they are part of an overall comprehensive institutional commitment to pain relief
• The ChildKind initiative encourages institutions to make such a commitment, helps them to do so, and recognizes them once they have
Although the world is full of suffering, it is also full of the overcoming of it

Helen Keller