Shared Decision Making in Pediatric Otolaryngology: The Pinnacle of Patient-Centered Care?

Paul Hong, MD, MSc, FRCSC
CHSOR Seminar, Baltimore
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Disclosure

• I have no actual or potential conflict of interest in relation to this presentation
Perspective

Shared Decision Making — The Pinnacle of Patient-Centered Care

Michael J. Barry, M.D., and Susan Edgman-Levitan, P.A.
Shared Decision Making\textsuperscript{1,2}

• Provider and patient work together
• Share information about
  – Treatment options/outcomes
  – Values/preferences
• Work toward a consensus about the preferred treatment
Patient Values/Preferences

Angelina Jolie undergoes double mastectomy
By Ed Payne, CNN
updated 8:09 AM EDT, Thu May 16, 2013

Empowered patient: Angelina Jolie
Patient Values/Preferences

GOSSIP

Melissa Etheridge: Angelina Jolie's double mastectomy was a 'fearful choice,' not 'brave'

The singer, who herself battled breast cancer, questioned Jolie's decision to get preventative surgery.

Comments (77)

BY MARGARET EBY / NEW YORK DAILY NEWS

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Grey zones of clinical practice: some limits to evidence-based medicine

C David Naylor

• Medical decisions: black, white or gray
  – 24-44% potential medical intervention for which evidence was either absent or contradictory
  – 9-32% actual practice decisions were reported to be equivocal
Uncertainty in Medicine

- Minimalism vs intervention based on inference/experience
- Decision making guided by non-evidence factors
- Confusion between opinion and evidence
Evidence of the Problem

Medical Practice Variation
40 Years of Research
Documenting Inconsistent Care

The DECISIONS Study
A Portrait of How Americans Make Common Medical Decisions
Shared Decision Making

• Middle ground between “nanny-knows-best” paternalism and rampant consumerism
  – “Meeting of experts”
• Crux of patient-centered care
Benefits for Patients

- Shared decision making can\textsuperscript{1-4}
  - Reduce decisional conflict/regret
  - Improve experience of care
  - Improve adherence to treatment plan
Benefits for Health Systems

• Shared decision making may\textsuperscript{10-12}
  – Improve quality of care
  – Increase patient satisfaction
  – Reduce unnecessary variations practice and costs
HR3590 Section 936
Program to Facilitate Shared Decision Making

To facilitate collaborative process between patients and providers .. and to incorporate patient preferences and values into medical plan
Shared decision making is at the core of ethical, patient-centered care.
41 parents interviewed 2 weeks after consultation
93% wanted more information about surgery, risks/benefits of treatment options
93% used Internet to obtain medical information
Technology-based mode of information deliver

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• 34/126 (26%) had significant decisional conflict
• Parent ratings of shared decision making negatively correlated to decisional conflict and regret
• Decisional regret positively correlated to decisional conflict
Parental Decision Making in Pediatric Otoplasty: The Role of Shared Decision Making in Parental Decisional Conflict and Decisional Regret

Paul Hong, MD; Ayala Y. Gorodzinsky, PhD; Benjamin A. Taylor, MD; Jill MacLaren Chorney, PhD
Parents who had significant decisional conflict felt less autonomous and less related/connected to others.

They also had significantly more negative emotions and fewer positive emotions.
• 126 parent-surgeon interaction videotaped
• Wide variability in degree of parental involvement
• No correlation between parents’ perception of shared decision making and observed behaviour
Research Summary

• Parents who thought themselves to be more involved in the decision making process made better decisions

• How do we increase shared decision making in our practice?
Decision Support Tools

• Decision aids
  – Information about condition
  – Treatment options; risks and benefits
  – Values clarification

• Multiple formats
  – Paper-based, video, website, app
Decision Aids

Decision aids for people facing health treatment or screening decisions (Review)


International Patient Decision Aid Standards (IPDAS) Collaboration
IPDAS Framework

• Decision aids
  – Identified scope of tool
  – Established steering committee
  – Conducted needs assessment
  – Conducted scoping review of evidence
  – Conducted pilot study
  – Gained iterative feedback
Decision aid prototype development for parents considering adenotonsillectomy for their children with sleep disordered breathing

Erin Maguire¹, Paul Hong¹,²,³,⁷*, Krista Ritchie²,⁴, Jeremy Meier⁵, Karen Archibald² and Jill Chorney¹,²,⁶
Surgical Risks

Surgery may resolve your child's symptoms, but it is not without some risks. These are the most commonly reported risks for this surgery and how often they occur:

- **Pain**: About 75% of children have significant pain on the first day after surgery.
- **Bleeding**: About 3.5% of children will have bleeding after surgery.
- **General anesthesia**: About 0.002% of children wake up during anesthesia.
- **Readmission**: About 4% of children are readmitted to hospital because of vomiting, pain, or fever.
- **Adenoid re-growth**: About 0.5% of children have their adenoids grow back.
- **Blood transfusion**: About 0.02% of children will need a blood transfusion.

This pamphlet can help you and your child's surgeon talk about treatment options and work together to decide on the option that is right for you and your child.

May, 2015

CHSORM Seminar
**Watching & Waiting**

**How your child’s symptoms may change if choosing to watch and wait:**

- **Snoring and breathing problems during sleep**
  - Using nasal spray can cut the number of breathing problems during sleep by half (50%)
  - Snoring and breathing problems may or may not change over time

- **Energy level and behaviour**
  - 20-30% of children who have OSA may have significant attention problems
  - Problems with daytime energy (too much or too little), sleep, and irritability may or may not change over time

- **School performance**
  - School performance may decrease due to poor sleep quality

- **Nasal/mouth breathing**
  - Difficulties breathing through the nose or open mouth breathing may or may not change over time

- **Growth**
  - Growth problems may or may not change over time

- **Eating**
  - Appetite may or may not change over time

**Surgery**

**How your child’s symptoms may change if choosing surgery:**

- Surgery stops snoring and breathing problems during sleep for 60% to 60% of children
- Surgery can be less effective for children who are overweight

- **50% of children no longer have significant attention problems after surgery**
- **Daytime energy, sleep, and irritability may be improved**

**Values**

Use the questions below to think about what matters to you in this decision:

- Taking time off work for my child’s surgery would be difficult
- Not being physically active (e.g., play, sports) for 7-10 days would be difficult for my child
- I am confident that my child will be able to successfully cope with the surgery
- I am worried about symptoms getting worse
- I am worried about the risks of surgery
SURGICAL RISKS

Surgery may resolve your child’s symptoms, but it is not without some risks. These are the most commonly reported risks for this surgery and how often they occur in a population of 100 children:

PAIN
About 75% will have significant pain on the first day after surgery

ADENOIDS RE-GROWTH
About 0.5% have their adenoids grow back

READMISSION
About 4% are readmitted to the hospital because of complications

BLOOD TRANSFUSION
About 0.02% will need a blood transfusion

BLEEDING
About 3.5% have bleeding after surgery that requires readmission and some children needing further surgery

GENERAL ANESTHESIA
About 0.002% will wake up during anesthesia

For more information regarding Tonsillectomy & Adenoidectomy surgery, or to check out our online decision aid module, visit:

www.insertwebsitehere.com

Making a Decision about Tonsillectomy & Adenoidectomy

Obstructive Sleep Apnea (OSA)

Additional resources:

- Lorem Ipsum webpage: www.insertwebsitehere.com
- Lorem Ipsum webpage: www.insertwebsitehere.com

This pamphlet can help you and your child’s surgeon talk about treatment options and work together to decide on the option that is right for you and your child.
**What is Obstructive Sleep Apnea (OSA)?**
Tonsils and adenoids are tissues that sit at the back of the throat and inside the nose. They can become large and cause problems with breathing when children are asleep.

**How is OSA treated?**
OSA is sometimes treated by watching and waiting and sometimes by surgery.

**What is watching and waiting?**
Watching and waiting means that you will monitor your child's symptoms and follow up with your doctor. Sometimes watching and waiting includes using a medication your doctor has prescribed.

**What does the surgery involve?**
Surgery involves removing the tonsils and adenoids while the child is under general anesthesia (asleep). The surgery is about an hour long. Most children recover after surgery around 14 days.

Other symptoms you may not have thought of that can be a part of obstructive sleep apnea:
- Odd sleeping positions
- Moving around during sleep
- Bedwetting
- Teeth grinding
- Night sweats
- Night terrors
- Sleepwalking
- Loud snoring or changes in breathing

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**How your child's symptoms may change:**

<table>
<thead>
<tr>
<th>WATCHING &amp; WAITING</th>
<th>SURGERY</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Snoring and breathing problems during sleep</strong></td>
<td></td>
</tr>
<tr>
<td>Snoring and breathing problems may or may not change over time</td>
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<tr>
<td>Appetite may or may not change over time</td>
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</tbody>
</table>

- Surgery stops snoring and breathing problems during sleep for up to 80% of children
- Surgery can be less effective for children who are overweight or obese
- 50% of children no longer have significant attention problems after surgery
- Daytime energy, sleep, and irritability may be improved
- Some children (especially under 6 years old) may have a small growth spurt after treatment
- Changes in ability to breathe through the nose and less open-mouth breathing may be addressed with treatment
- School performance may show an improvement (10%) with treatment
- Food preference and ability to eat different textures may show an improvement with treatment

*Depending on your child’s health and treatment plan, there may be some changes over time including improvement for your child in the marked areas.*

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**SURVEY**

Use the questions below to think about what matters to you in this decision.

- Taking time off work for my child’s surgery would be difficult.
- Not being physically active (e.g. play, sports) for 7 to 10 days would be difficult for my child.
- I am confident that my child will be able to successfully cope with the surgery.
- I am worried about the current severity of my child’s symptoms.
- I am worried about my child’s symptoms getting worse.
- I am worried about the risks of surgery for my child.
- I am worried about my child taking pain medication after the surgery.
Making a Decision About Tonsillectomy & Adenoidectomy
Obstructive Sleep Apnea (OSA)

This site can help you and your child's surgeon talk about treatment options and work together to decide on the option that is right for you and your child.

1. OPTIONS
   How your child's symptoms may change.

2. WHAT MATTERS
   Think about what matters to you in this decision.

3. SURGICAL RISKS
   Statistics to consider.

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### How your child’s symptoms may change

<table>
<thead>
<tr>
<th>SNORING AND BREATHING PROBLEMS DURING SLEEP</th>
<th>WATCHING &amp; WAITING</th>
<th>SURGERY</th>
</tr>
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</table>
| ![Snoring Icon]                             | - Snoring and breathing problems may or may not change over time  
  - Using prescribed medication can cut the number of breathing problems during sleep by half (50%) | - Surgery stops snoring and breathing problems during sleep for up to 80% of children  
  - Surgery can be less effective for children who are overweight or obese | |

| ENERGY LEVEL AND BEHAVIOUR | | |
|-----------------------------| | |
| ![Energy Icon]              | - 20-30% of children who have OSA may have significant attention problems  
  - Problems with daytime energy (too much or too little), sleep, and irritability may or may not change over time | - 50% of children no longer have significant attention problems after surgery  
  - Daytime energy, sleep, and irritability may be improved |

| GROWTH | | |
|--------| | |
| ![Growth Icon] | - Growth problems may or may not change over time | - Some children (especially under 6 years old) may have a small growth |

| SCHOOL PERFORMANCE | | |
|--------------------| | |
| ![School Icon]     | - School performance may decrease due to poor sleep quality | - School performance may show an improvement up to 10% |

Regardless of your decision, these things may or may not change.
What Matters

Use the questions below to think about what matters to you in this decision.
The bar on the right will help show which decision you’re leaning more toward.

- Taking time off work for my child’s surgery would be difficult
- Not being physically active (e.g. play, sports) for 14 days would be difficult for my child.
- I am confident that my child will be able to successfully cope with the surgery.
- I am worried about the current severity of my child’s symptoms.
- I am worried about my child’s symptoms getting worse.
- I am worried about the risks of surgery for my child.
- I am worried about my child taking pain medication after the surgery.

Strongly DISAGREE

Strongly AGREE
Surgical Risks

Surgery may resolve your child's symptoms, but it is not without some risks. These are the most commonly reported risks for this surgery and how often they occur:

PAIN
- Adenoid re-growth
- Readmission
- Blood transfusion
- Bleeding
- General anesthesia

Pain

75%

About 75% (75 in 100) will have significant pain on the first day after surgery.
Pilot Trial of Decision Aid

• To assess usability and feasibility
• 2 sites (Halifax, Salt Lake City)
  – 6 surgeons
  – 100 parents randomized to receive decision aid or not
• Results
  – No difference between groups
Pilot Trial of Decision Aid

• Why?
  – Surgeons did not spend time using decision aid
  – Parents did not have enough time to read decision aid

• SDM was not occurring with/out decision aid
• MD attitudes towards SDM vary by specialty
• MD support use of SDM in situations where patient desires to be involved in decision making process (not when unwilling)
• SDM thought as a way to convince patients to agree to their preferred treatment option
• Confusion between SDM and information transfer
Barriers and facilitators to implementing shared decision-making in clinical practice: Update of a systematic review of health professionals’ perceptions

France Légaré a,b,*, Stéphane Ratté a, Karine Gravel a, Ian D. Graham c,d

• Perceived barriers
  – Time constraints, lack of applicability due to patient characteristics and clinical situation

• Perceived facilitators
  – Provider motivation, positive impact on clinical process and patient outcomes
Perceived Barriers-HCP

• Current decision making process is fine
  – We are already doing SDM
  – Information overload
• How to account for variation in practice
Limited use of SDM in pediatrics

Child and adolescent patients had little role in decision making

- Most sat quietly during visit except to answer social questions or questions about their symptoms
Providers rarely elicited information from parents; nor did many parents volunteer information about their goals and preferences.

Providers gave verbal information, answer questions and offer recommendations; information exchange was mostly unidirectional.
Why Not?

• Discussing options is not embedded in the attitudes or communication skills of MD
• Learned sequence of short clinic visit
  – History
  – Physical exam
  – Diagnosis
  – Treatment
Why Not?

• Difficult to learn (and not taught)
  – Change involves attitude, effort, time
• Patient/Family dynamics
  – Different expectations across cultures, social, age groups, 2 caregivers
The Salzburg Statement on Shared Decision Making

In December 2010, 58 people from 18 countries attended a Salzburg Global Seminar to consider the role patients can and should play in healthcare decisions. Those listed below have agreed a statement that calls on patients and clinicians to work together to be co-producers of health.

We call on clinicians to:
- Recognise that they have an ethical imperative to share important decisions with patients
- Stimulate a two-way flow of information and encourage patients to ask questions, explain their circumstances, and express their personal preferences
- Provide accurate information about options and the uncertainties, benefits, and harms of treatment in line with best practice for risk communication
- Tailor information to individual patient needs and allow them sufficient time to consider their options
  Acknowledge that most decisions do not have to be taken immediately, and give patients and their families the resources and help to reach decisions.

We call on clinicians, researchers, editors, journalists, and others to:
- Ensure that the information they provide is clear, evidence-based, and up to date and that conflicts of interest are declared.

We call on patients to:
- Speak up about their concerns, questions, and what’s important to them
- Recognise that they have a right to be equal participants in their care
- Seek and use high-quality health information.
Patients and Families

• Do patients/parents know that they should be participating in decision making?
  – Some prefer not to
  – Even if they do, they don’t
  – Preconceived notions
    • Information from internet and others
    • Mind already made up
Do We Know What Patients Want?\textsuperscript{6}

### Top Three Goals and Concerns for Breast Cancer Decisions

<table>
<thead>
<tr>
<th>Condition: Goal</th>
<th>Pat</th>
<th>Prov</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keep your breast?</td>
<td>7%</td>
<td>71%</td>
<td>P\textless{}0.01</td>
</tr>
<tr>
<td>Live as long as possible?</td>
<td>59%</td>
<td>96%</td>
<td>P=0.01</td>
</tr>
<tr>
<td>Look natural without clothes</td>
<td>33%</td>
<td>80%</td>
<td>P=0.05</td>
</tr>
<tr>
<td>Avoid using prosthesis</td>
<td>33%</td>
<td>0%</td>
<td>P\textless{}0.01</td>
</tr>
</tbody>
</table>
Patients and Families

• Little patient participation
  – Low SES and racial/ethnic minority groups
  – Less activation (ability and inclination to manage health)

• Improve patient participation
  – Increase quality of care
  – Reduce health inequalities
Patients and Families

• Highly activated patients
  – Take more responsibility
  – Acquire more knowledge/skills
  – Improved decision making

• Less activated patients may not benefit from SDM or decision aids
• Activating interventions to help prepare low SES patients
• Interventions (decision aid, patient activation intervention) directed at increasing engagement is useful for less activated patients
How to Implement SDM?

• Need awareness and training
  – Are we ready?
  – We don’t even realize we are not doing it well?
  – Does SDM training work?
Free shared decision making course offered (CME)
Mostly general practitioners and internists signed up
94% had positive attitudes
Does SDM Training Work?

Family Decision Services
Helping Families Make Tough Healthcare Decisions

About Family Decision Services

CHEO believes the highest quality of care includes a patient- and family-centred approach to care. We recognize and respect the expertise and continuous role of the family in their child or youth’s life. Families are key members of the health care team at CHEO. While health care professionals are experts on health and disease, families are the experts on their child and what matters most to their family. When information is shared, children and families receive the care that is best for them.
CHEO SDM Training

• Trained > 200 staff
• Outcomes promising for the training
  – Increased self-efficacy
  – High satisfaction
• But-very few trained staff are using SDM in practice
Implementation Research

• Although talk about patient centered care is ubiquitous, there is a great challenge to turn this rhetoric into routine clinical practice
More than just “barriers”
Current system supports the “normal process”
Systems level/structural change needed
Focus not just on providers (patients, managers, policy makers)
What Will Make a Difference?

• Society
  – Consumerist society with better informed patients
  – Movement away paternalism
• Regulatory pressures
• Reimbursement/quality improvement
• Trends in medical education
• Decision support tools
Twelve myths about shared decision making

France Légaré a,b,*, Philippe Thompson-Leduc a

1. SDM is a fad—it will pass

3. Not everyone wants SDM
   - SDM difficult for vulnerable patient populations
   - They may benefit the most from SDM
4. Not everyone is good at SDM
5. SDM takes too much time
7. We are already doing SDM
8. SDM is easy! A tool will do

9. SDM is not compatible with clinical practice guidelines
Components of Patient Engagement in Pediatric Surgical Care

Cognitive Dimension
(What the patient and family thinks and knows)
- Logistical Information (When, where to arrive)
- What is normal before, during and after surgery
- Attitudes about pain and pain medication

Behavioral Dimension
(What the patient and family does)
- Communicate with healthcare providers
- Assess and manage pain (pharmacological and nonpharmacological strategies)
- Identify and respond to adverse events
- Administer medication
- Ensure adequate hydration

Emotional Dimension
(What the patient and family feels)
- Self-efficacy
- Confidence
- Manage emotions including anxiety, fear, stress, fatigue
Conclusion

• SDM is feasible, suitable and adequate means to approach clinical encounter in the 21st century

• Current debate about SDM should not deter stakeholders from pursuing its scaling up across the healthcare continuum
Conclusion

• Transitioning to a SDM approach may require organizational change, financial inputs, potential revision to medical school training, as well as alteration to MDs practice

• Implementation strategies are needed

• Future research of SDM and healthcare utilization needed
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Thank You!
References


