Strategies to Optimize Patient and Family Satisfaction and Decrease Decisional Regret

Disclosure

Dr. Sandberg was awarded a contract from the Patient Centered Outcomes Research Institute (PCORI 1360). This multisite project that involves the input of provider specialists from multiple disciplines, representatives of DSD patient support/advocacy organizations and parents of affected children, will deliver a web-based decision support tool.
Objectives

- Understand the background, process, and importance of shared decision making.
  - Why is it important to patients?
  - Why is important to providers?
- Learn about decisional conflict, decisional regret, and how decision support tools affect treatment choice and satisfaction.
- Learn how to use a new decision support tool for DSD conditions.
- Anticipate and understand the benefits and challenges to implementation of shared decision making.

Definitions

- **Shared decision making (SDM)** is a collaborative process that allows patients and their providers to make health care decisions together, taking into account the best scientific evidence available, as well as the patient’s values and preferences.
  - It is a *subset of informed decision making*

Definitions

- **Decisional Regret**: A negative conscious and emotional reaction to personal past acts, decisions, or behaviors
- **Decisional conflict**: Personal uncertainty of which course of action to take when options involve risk, regret, or challenge to life values
Why is this so important?
- Decisional regret impacts our patients
- Decisional regret impacts their parents
- Decisional regret impacts us

Regret and Consequences for Providers
- Most common scenarios for regret:
  - Perceived lack of control in patient care
  - Loss of therapeutic adherence
  - Patient’s condition worsening unexpectedly
  - Committed errors
  - Sense that patient’s dignity was not respected.
  - More severe consequences for the patient.
- Regret may lead to 2 types of consequences
  - Changes in clinical practices
  - Negative impact on health care professionals’ own health and quality of life.
    - Sleep disorders
    - Attention deficits


How do we measure decisional conflict?

SURE Test version for clinical practice

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The SURE Test © O’Connor and Legard. 2008.
Decision Regret Scale

Lorenzo et al. J Urol 2014

Decisional Regret

Distal hypospadias repair

- Decisional regret is associated with
  - Postoperative complications (OR 14.7)
  - Parental desire to avoid circumcision (OR 7.4)
  - Preoperative decisional conflict (OR 1.06)

Lorenzo et al. J Urol 2014
Why is this important for our patients and parents with DSD conditions?

For many 46 XY,DSD partially androgenized females after feminization surgery, dissatisfaction levels are high—
- With function of the surgical result (47.1%)
- With clitoral arousal (47.4%)
- With overall sex life (37.5%)
- With desire (70.6%)
- With dyspareunia (66.3%)

Kehler B et al. J Clin Endocrinol Metab. 2012

Why are decision support tools helpful with DSD conditions?

- Uncertainty and multiple options
  - Best time to intervene is not clear
  - Optimal surgical approach may not be clear
  - Gender identity may not be clear
- Long term outcomes are uncertain
  - Uncertainty about optimal timing
  - Uncertainty about long term sexual function
  - Tumor risk is unclear
- Family values differ
- The child may not be able to give assent or informed consent
- There is limited time in clinic

What are Patient Decision Aids?

- Patient decision aids are tools designed to help people participate in decision making about health care options.
- They provide evidence-based information on the underlying condition, treatment options, and benefits, harms, and uncertainties.
- They help patients clarify and communicate the personal values.
- They allow patients and families time to review the surgical intervention as well as other more conservative options

Elwyn G et al. BMJ 2006
Why are the benefits?

- Greater knowledge
- Lower decisional conflict related to feeling uninformed
- Less decisional conflict related to feeling unclear about personal values
- Stimulate people to take a more active role in decision making
- Reduced proportion of people who remained undecided
- Positive effect on patient-practitioner communication
- Reduced the number of people of choosing major elective invasive surgery in favor of more conservative options
- Improve accurate risk perceptions when probabilities are included in decision aids

Stacey D. Cochrane Review. 2014

What are the unknowns?

Decision aids were no better for:
- Satisfaction with decision making
- Anxiety
- Health outcomes

Inconclusive:
- May increase consultation length
- May not impact continuation of treatment
- Resource use

Stacey D. Cochrane Review. 2014

Uses in Gynecology

- Contraception tools
- Prolapse
- Breast cancer
- Fibroids

Prenatal Genetic Testing

- Women were less likely to have invasive diagnostic testing (6.9% vs 12.3%; odds ratio [OR], 0.45 [95% CI, 0.25-0.80])
- More likely to forgo testing altogether (25.6% vs 20.4%; OR, 3.30 [95% CI, 1.43-7.64])
- Higher knowledge scores (9.4 vs 8.8 on a 15-point scale; mean group difference, 0.62 [95% CI, 0.34-1.31])
- More likely to correctly estimate the amniocentesis-related miscarriage risk (73.8% vs 59.0%; OR, 1.95 [95% CI, 1.39-2.75])
- Significant differences did not emerge in decisional conflict or regret.

Kupperman M et al. JAMA 2014

Fibroids

- Mailed DVD and brochure about fibroid treatment to 300 women
- Intervention group reported
  - Higher knowledge scores
  - Knew more treatment options
  - Felt more satisfied with their decision
  - Reported more consistency with their values

Solberg LI et al. Med Decis Making 2010

"OK, all those in favour of delegating decision-making, shrug your shoulders"
How do we do this?

- Set the stage and develop an appropriate team
- Establish preferences for information and roles in decision making
- Perceive and address emotions
- Define concerns and values
- Identify options and present evidence
- Share responsibility for making a decision


Web Based Decision Support Tool

Facilitators and Barriers to Implementation

- **Facilitators:**
  - Financial incentives
  - Physician buy-in crucial
- **Barriers:**
  - Competing demands and time pressures were persistent barriers
  - The effect of decision aids on length of consultation varied from 8 minutes shorter to 23 minutes longer
  - Adjusting the tool for low literacy

Uy V et al. Health Expect 2014
Stacy et al. Cochrane Review 2014
Questions?

References

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