

Shared Decision Making in Pediatrics

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Outline

- Introductions
- What is SDM
 - Unique aspects within pediatrics
 - When done well
 - Reality
- Your Experience
- Research evidence
- Decision Aids
 - Features
 - Examples
 - Discussion
- Design a DA



Work Life: Pediatric Psychologist

- "Address the psychological aspects of illness, injury, and promotion of health behaviors in children, adolescents, and families in a pediatric health setting."
 - Consultation/Liaison Service

Research focus







Family (aka hobbies)







Research Foundation



BRIEF REPORT

Transgenerational Effects of Posttraumatic Stress Disorder in Babies of Mothers Exposed to the World Trade Center Attacks during Pregnancy

Rachel Yehuda, Stephanie Mulherin Engel, Sarah R. Brand, Jonathan Seckl, Sue M. Marcus, and Gertrud S. Berkowitz

Journal of Traumatic Stress, Vol. 24, No. 4, August 2011, pp. 399-404 (© 2011)

Do Adolescent Offspring of Women with PTSD Experience Higher Levels of Chronic and Episodic Stress?





Impact of Clinical Work

Support Care Cancer (2017) 25:769–774 DOI 10.1007/s00520-016-3458-x

ORIGINAL ARTICLE

Communication preferences of pediatric cancer patients: talking about prognosis and their future life





JOURNAL OF PSYCHOSOCIAL ONCOLOGY http://dx.doi.org/10.1080/07347332.2017.1307894



ARTICLE

Preparing youth with cancer for amputation: A systematic review

Caitlyn A. Loucas, BA^a, Sarah R. Brand, PhD^{a,b}, Sima Zadeh Bedoya, PsyD^c, Anna C. Muriel, MD, MPH^{a,b}, and Lori Wiener, PhD^c



Why is This Issue Worth Discussing?

- Ana 12 y/o girl with a sacral Ewings Sarcoma
 - Decision needed about local control (radiation vs surgery)
 - Survival outcomes were relatively equal
 - Each option had possible morbidity
- Questions from the team and parents:
 - What information should they give Ana
 - To what extent (and how) should they include her in the decision making process.
- Minimal empirical literature



Introductions – Who is in the Room?

- Name
- Professional identity what would you like us to know about you and your work?
- Why are you interested in this topic/what do you hope to gain over the next 90 minutes?





Shared Decision Making (SDM)

- Key attribute of person/family centered care
- Patients and clinicians both share information
- A treatment plan is jointly determined between the patient and the provider
 - Use of decision aids (DA)
- Promotes patient knowledge, more accurate risk perception, patient-physician relationship quality, and patient satisfaction

Barry & Levitan, 2012. N Engl J Med



Shared Decision Making within Pediatrics

- SDM and DA have not been routinely implemented in the pediatric setting...(because it is complex).
- Evolving developmental context impacts ability to participate
- Adapting model to the child-parent-physician triad.
- Parents have legal decision making power
 Majority of research is focused on parents.
- Emphasis on SDM by the American Academy of Pediatrics and Institute of Medicine.
- Children and adolescents have varying desires for involvement and this does not always correspond with their parents' preferences of involving them.

Lipstein et al. (2012). *Med Decis Making*; Wyatt et al. (2015). *Acad Pediatr;* Kelly et al. (2016). *Pedi Blood Cancer*



When Done Well, SMD can:

- Communicate the important role patients play in their own care.
- Inclusion can:
 - Decrease anxiety
 - Increase sense of value and control
 - Improve communication
 - Increase engagement

Angst et al. (1996). J of Fam Nurs; McCabe (1996). J of Pedi Psych;
Moore, et al. (2010). J of Clin Nurs; Miller, V. (2009). Families, Systems, & Health;
Ruggeri et al. (2014). PloS One; Sawyer et al. (2005). Med J Aust



Reality: Not the Standard of Care

 Children are often relegated to non-participant status and routinely excluded from medical conversations.

 Actions of parents and healthcare professionals may inhibit a child's efforts to participate in medical conversations

Van Dulmen (1998). Pediatrics; Runeson et al. (2002). Int J Nurs Prac



In Your Experience, What are the Barriers and Facilitators to Regularly Implementing SDM in Pediatrics?

Decision Level – Related to the decision itself

Approach Level - Related to the approach used, materials provided

Adopter Level – HCPs, parents, children

Relational Level – Interpersonal interactions and process between HCP, parents, children.

Practice Level – Practice Environment





Barriers and facilitators of pediatric shared decision-making: a systematic review

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Abstract

Background: Shared decision-making (SDM) is rarely implemented in pediatric practice. Pediatric health decision-making differs from that of adult practice. Yet, little is known about the factors that influence the implementation of pediatric shared decision-making (SDM). We synthesized pediatric SDM barriers and facilitators from the perspectives of healthcare providers (HCP), parents, children, and observers (i.e., persons who evaluated the SDM process, but were not directly involved).

Methods: We conducted a systematic review guided by the Ottawa Model of Research Use (OMRU). We searched MEDLINE, EMBASE, Cochrane Library, CINAHL, PubMed, and PsycINFO (inception to March 2017) and included studies that reported dinical pediatric SDM barriers and/or facilitators from the perspective of HCPs, parents, children, and/or observers. We considered all or no comparison groups and included all study designs reporting original data. Content analysis was used to synthesize barriers and facilitators and categorized them according to the OMRU levels (i.e., decision, innovation, adopters, relational, and environment) and participant types (i.e., HCP, parents, children, and observers). We used the Mixed Methods Appraisal Tool to appraise study quality.

Results: Of 20,008 identified citations, 79 were included. At each OMRU level, the most frequent barriers were features of the options (decision), poor quality information (innovation), parent/child emotional state (adopter), power relations (relational), and insufficient time (environment). The most frequent facilitators were low stake decisions (decision), good quality information (innovation), agreement with SDM (adopter), trust and respect (relational), and SDM tools/resources (environment). Across participant types, the most frequent barriers were insufficient time (HCPs), features of the options (parents), power imbalances (children), and HCP skill for SDM (observers). The most frequent facilitators were good quality information (HCP) and agreement with SDM (parents and children). There was no consistent facilitator category for observers. Overall, study quality was moderate with quantitative studies having the highest ratings and mixed-method studies having the lowest ratings.

Conclusions: Numerous diverse and interrelated factors influence SDM use in pediatric clinical practice. Our findings can be used to identify potential pediatric SDM barriers and facilitators, guide context-specific barrier and facilitator assessments, and inform interventions for implementing SDM in pediatric practice.

Trial Registration: PROSPERO CRD42015020527

Keywords: Implementation, Pediatrics, Shared decision-making, Barriers, Facilitators, Systematic review, Taxonomy, Ottawa Model of Research Use



Barriers

Facilitators

Decision Level

- Lack of options/ unacceptable alternative.
- Cost
- Lack of research evidence

- Lower stake decisions
 - HCPs
 - Children

Approach Level

- Poor quality of information/ inappropriate for children
- Requires to much time

- High quality information
- Information tailored to child's developmental level and parent's literacy



Barriers

Facilitators

Adopter Level

- Parent/child emotional state and health status
- HCP lack of skill
 - How/when to elicit and incorporate family values/ preferences
- Belief SDM is right thing to do and would improve outcomes.
- Child's older age

Relational Level

- Power imbalance
 - Physically excluding child
 - Child feeling intimidated
- HCP only providing one option or only giving information on preferred option.

Trust, respect in relationship

 Appreciation of others view point



Barriers

Facilitators

Environmental Level

- Insufficient time
- Clinic workflow

- SDM tools
- SDM resources



Decision Aids

- Tool designed to facilitate shared decision making and patient participation in health care decisions.
- Patient decision aids
 - Designed to be used by the patient prior to the clinical encounter.
- Encounter decision aids
 - Designed for use during the clinical encounter to support shared decision making conversations.



Features of Decision Aids

 Information about the clinical condition, options, and outcomes

Probabilities of outcomes (create realistic expectations)

Values clarifications

Information about other options



Example



Depression Medication Choice Decision Aid



ANTIDEPRESSANTS ARE MEDICINES TO TREAT DEPRESSION

Will they work for me?

Most people find a medicine that works; 6 out of 10 feel better with the first one they try.

How long before I feel better?

Most people need to take the medicine for 6 weeks to feel better.

Side Effects

Most people have at least one side effect; many side effects go away

but some people need to stop taking the medicine.

NEXT



Example





Bringing it Back to Ana

What Matters to Ana	Radiation	Surgery



Bringing it Back to Ana

	Radiation	Surgery
Being active	No significant impact	High impact immediately and long-term
Going to school	Daily treatment for six weeks but can be scheduled around school	Miss at least 4-6 weeks of school.
Feeling good	No significant impact	Pain, restriction in activity 4 weeks after surgery
Looking normal	No significant impact	Possible bowel/bladder dysfunction
Late effects (parents)	Secondary malignancy	Outlined above





What Matters to Me

- 1. You can call me Nicole, Nickie, or Nic.
- 2. I love doing crafts and playing in the playroom.
- 3. If my room is dark, I am trying to sleep. Please be quiet when you come in or come back later.
- 4. I like to listen when doctors talk with my mom.
- 5. Count to three before accessing my port.







Results: What Matters





Results: What Matters

Communication

- "Please ask if I want medical discussions inside or outside my room. I get nervous at times" – 13 F
- "All medical discussions outside of my room" 7 M
- "Introduce yourself. I like to know who you are and what you do" – 7 F

Delivery of care

- "I want the smallest dressing possible. I do not like the IV3000" 8 M
- "I need a family member present for med taking and dressing changes" – 14 F



Results: What Matters

- Knowing who they are as a person
 - "I am soft spoken and shy when I first meet someone. Please be patient and listen carefully" – 9 F
 - "I love dinosaurs and superheros. My favorite dinosaur is Indominus Rex and my favorite superheros are spiderman and ironman." 10 M





"Every day, in a 100 small ways, our children ask, 'Do you hear me? Do you see me? Do I matter?' Their behavior often reflects our response." ~ L.R. Knost

Review of Tools in Pediatrics

- Review tools on table
- What do you like, dislike?
- What are they missing?
- Can you imagine using them?





Design a Decision Aid

- What problem/issue do you want to address?
- Who is the tool meant for?
- What is the objective?
- What will it look like?
- What cool features will it have?







Thank You