Supplemental Information

SUPPLEMENTAL INFORMATION 1: WEB SITES/RESOURCES FOR PROFESSIONALS AND FAMILIES FOR SDM ASSISTANCE

Sample General SDM Resources

- AHRQ treatment options publication list: http://www.ahrq.gov/professionals/clinicians-providers/partnership/assets/hcp-ehc_publists.pdf
- Autism Science Foundation: http://autismsciencefoundation/sites/default/files/Autism%20Toolkits.pdf; handouts about services toolkits, continuing education
- Autism Speaks: https://autismspeaks.org/family-services/tool-kits; multiple toolkits, especially Guide to Providing Feedback to Families, Managing Comorbid Medical Conditions, First Concern Action toolkit, and others
- Family Voices: http://www.familyvoices.org/work/family_care; SDM and family-centered care
- Ottawa Decision Aids: https://decisionaid.ohri.ca/decoids.html
- Patient SDM (Policies and Programs To Improve Wisconsin’s Health): http://whatworksforhealth.wisc.edu/program.php?t1=22&t2=17&t3=30&id=59

Sample Resources for Strategies to Support Discussions With Families

Ask, Tell, Ask

- Centre for Collaboration, Motivation, and Innovation: https://www.youtube.com/watch?v=cTwektQpxUg
- Medical Oncology Communication Skills Training Learning Module: https://depts.washington.edu/oncotalk/learn/modules/Modules_01.pdf
- Queen’s University Undergraduate Blog, “Get to the point with Ask-Tell-Ask feedback”: https://meds.queensu.ca/blog/undergraduate/?p=2298

Health Literacy


Minimal Feedback

- Accreditation Council for Graduate Medical Education format: http://www.acgme.org/Portals/0/PDFs/2015%20AEC/ Presentations/ses039.pdf

Teach-Back

- Toolkit for training and/or clinical use: http://www.teachbacktraining.org/
SUPPLEMENTAL INFORMATION 2: CLINICAL CASE EXAMPLES (REAL NAMES ARE NOT USED)

Case 1: “Jackie” (Complementary and Alternative Medical Treatments and Autism Spectrum Disorder)

Jackie is a 2.75-y-old female who has been followed by her pediatrician since birth. She has a history of language delay and did not seem to respond to overtures by her older sister. At her 18-month visit, she failed the Modified Checklist for Autism in Toddlers, Revised (M-CHAT/R), and when her pediatrician brought her back for the follow-up interview the failure persisted. She was referred for developmental pediatric evaluation and was diagnosed with autism spectrum disorder at 30 months. Her parents do not question the diagnosis but are confused about what treatments they should pursue, because they want to make sure “no stone is left unturned.” They have worked with early intervention and a behavior therapist and have developed a comprehensive home-based program, which includes working with a special educator, a behavior therapist (to implement an intensive behavioral program), a speech/language therapist, and an occupational therapist (to work on sensory issues).

Jackie’s parents have searched the Internet extensively and identified some treatments that they want to consider for their daughter. They have attended a number of parent support group meetings in their community and have additional ideas from other parents about treatments they might want to pursue. They bring a list of the possible treatments for discussion with their pediatrician, including the gluten-/casein-free diet, dietary supplements (eg, high-dose multivitamins and minerals and others), and equine therapy.

Example SDM Process With the Pediatrician and Family

In this case, the child and family are well known to the pediatric practice and the child was recently (<6 months ago) diagnosed with autism spectrum disorder. The parents are uncertain about what treatments for Jackie would be good and have returned for follow-up, which provides a good opportunity for a reciprocal discussion using principles of SDM to facilitate the parents deciding and pursuing treatment of Jackie.

Equality of Primary Partners

- “Would you like to talk about treatments you are using for Jackie and other treatments that you are considering?”
- “I see you brought a list of possible treatments; I would be glad to talk to you about their possible benefits or harm so that you can make the best choices for treatment for Jackie.”

Checking Knowledge

- “Where did you learn about these treatments?”
  - On the Internet? Specific Web sites for autism treatments?
  - From friends and family?
  - Other sources (eg, handouts from early intervention)?
- “What did these sources suggest are the benefits of these treatments?”
- “Did anyone (or site) mention any possible harm?”

Checking on Values (Early Preferences)

- “What do you think about what you have heard/read?”
- “Have other family members (friends and others) given you opinions about treatments?”
- Describe options and benefits, risks, expectations: “I have information about some of these treatments and would be glad to talk about their pluses and minuses and your expectations.”
- “What form of information would you prefer (handout, Web page, other)?”
**Decision Support/Moving to a Decision**

- “What are your thoughts about the treatments we have talked about?”
- “Do you need more time to think about the treatments?”
- “Can we give you more sources of information?”
- “Do you have more questions?”
- “How would you like to proceed?”

**Review**

- “We can talk more at the next visit, or set up an earlier visit to discuss.”

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**Case 2: “Miguel” (Spastic Cerebral Palsy, Intellectual Disability, and Perceived Pain From Hip)**

Miguel is a 10-y-old boy, born to first-generation immigrant parents and the third of 4 children in the household. After a stormy intensive care nursery course after premature birth (30 wk), Miguel now demonstrates communication and cognitive delays; his mobility has been increasingly via wheelchair over the past 2 y. He underwent selective dorsal rhizotomy 6 y ago and is still receiving baclofen for spasticity in his lower extremities. For approximately 6 mo, the family perceives Miguel’s intermittent fussing, hip flexion posturing, and apparent pain to be related to his left hip subluxation (previously documented on radiography).

The family is looking for guidance as they are confused by conflicting recommendations. The physician prescribing the baclofen has encouraged the family to pursue surgical open reduction of the hip; 1 orthopedist readily agreed to go forward; a second surgeon expressed hesitancy to go forward as a first-step intervention. The family has regularly prayed that Miguel will gain relief with increased baclofen and ibuprofen. To date, they have seen no changes. Presently, Miguel, who communicates nonverbally and with great limitations, has had increasing bowel incontinence as the family has noted resistance from him when they attempt to transfer him onto the toilet.

The extended family, who has always been an advocate for Miguel, expresses competing concerns: they want to provide Miguel with pain relief, but they are uncertain about and somewhat anxious over potential adverse outcomes of another surgical endeavor. They would like to know what you would do if Miguel were your child.

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**Example SDM Process With the Pediatrician and Family**

In this case, the request for consultation demonstrates that the parents have concerns about decisions that are being requested by medical staff. By history and joint appearance for consultation, active involvement of both, and the grandparents, is noted.

Pediatrician: “Well. I’ve had the chance to look over the reports from the specialists you’ve seen. I can understand how you might feel uncertain as to the ‘next step.’” [Open-ended questions allow for statements/questions that can help direct further discussion.]

Family: “It seems like we had no choice but surgery. Then the second surgeon said we didn’t have to do surgery right now. We just want the best for Miguel.”

Pediatrician: “So, tell me—what are the 3 top questions or concerns you have right now?” [Reinforces partnership: sets forth family preferences, and gives insight into role(s) for pediatrician. Acknowledges concerns and decisions that are “in play.”]

Family: “Will the surgery make the pain go away? Will it get worse if we do nothing? What could go wrong based on what we decide?”

Pediatrician: “Tell me about the pain. How is it now? Why do you think it comes from the hip?” [Helps with better sense of family’s understanding and expectations; entry into treatment options, risks, benefits.]

Family: “We see him crying and he pulls his leg up and doesn’t want to straighten it for a while.”
Pediatrician: “Miguel doesn’t like it when you move him to the toilet. How are his bowel movements with all this going on?” [Begin to explore alternative or adjunctive processes that may be significant and may offer options for interventions that would inform decisions.]

Family: “He’s had worse constipation for months now.”

Pediatrician: “He’s been taking a fair amount of ibuprofen and increased baclofen doses.” [Open-ended statement helps get sense of where family is with present treatments.]

Family: “They said he is on the very highest dose of baclofen. We’ve been reading about side effects from ibuprofen, but we think maybe it helps a little sometimes.”

Pediatrician: “You mentioned side effects or adverse outcomes. Are there specific concerns?” [Transitioning to “option talk.” Checking knowledge before discussing first decision.]

Family: “Well, it takes him so long to ‘bounce back’ after a big procedure. What are the main concerns we should be focused on?”

Pediatrician: “There are several reasonable considerations: lack of pain relief after the procedure; potential loss of daily care routines, with need for rehabilitation; infection from the surgery; slow wound healing if adequate nutrition cannot be assured; avascular necrosis of the femoral bone is infrequent but should be listed. Have you heard about these?” [Consolidating and summarizing.]

Pediatrician: “That is a lot of talking! Does this make sense? Is it too much information?” [Allows response to family’s questions/preferences. Gives permission to stop and let family digest amount of material in front of them. Sets the stage for prioritizing choices in anticipation of decisions.]

Family: “No, this is good. That really helped. So where do we go from here?”

Pediatrician: “With the information you’ve shared, this is how I would summarize where we are:

- the pain seems not to be optimally managed with the present medications;
- movement of the hip seems to cause Miguel to “tighten up” and resist the attempts;
- the spasticity remains an ongoing contributor to discomfort, and spasticity may well continue even after a surgery;
- constipation could be creating abdominal pain; flexion of the hip might worsen the abdominal discomfort but be perceived as “hip pain” rather than “abdominal pain”;
- the constipation may be a result of Miguel’s hesitancy to transfer and use the toilet as he previously did;
- given the radiograph description of the hip, we have a question of whether a trial of a more specific nonsteroidal medication would be in order;
- if Miguel’s limitation of hip movement is either mechanically driven or pain driven, perhaps an injection of an antiinflammatory and an anesthetic into the joint (under sedation) could help differentiate between the two;
- we could always continue our present course and continue to monitor for several months.”

“What am I leaving out?” [Sets up action plan priorities and preferences. Sets up family and physician to begin negotiation and agreements on decisions for action.]

Family: “We can’t think of anything else. It doesn’t sound like we have to decide on surgery right now, but it sounds like we need to prepare for it. We need to address the constipation, the spasticity, the pain control and we’d like to start there. The idea of a trial injection for comparison before-and-after makes sense; how and when should we do this?”

Pediatrician: “We can set priorities for investigating by tackling constipation, spasticity management, and pain control in quick, stepwise fashion. After monitoring for a short period (several weeks), we can reassess the decision for a trial injection.”

Pediatrician: “I know you’ve asked me what I would do if Miguel were my son. This is what I would do: work through the process as we’ve begun; be aware of the possible contributors to Miguel’s pain; consider each with our plan; and feel confident in the information we gather as we go. Would you like to speak to the doctors you’ve seen and tell them about our conversation, or would you like me to have those conversations and report back to you?”

Family: “If you could, that would be helpful.”
Case 3: “Katie” (Intellectual Disability and Increasing Obesity)

The parents of a 5-y-old girl requested a time for consultation with the pediatrician. Katie was first evaluated at 11 mo of age for possible Prader-Willi syndrome because of her low tone, accelerating weight gain, and generalized developmental delay. Multiple diagnostic tests for Prader-Willi syndrome were negative. She continues to grow at >98th percentile weight and >75th percentile height. Now, she shows frontal bossing, midfacial dysmorphisms, and small hands with distal tapering fingers. She shows expressive and receptive language delays. Recently, updated genetic studies revealed a 16p11.2 deletion that encompassed the SH2B1 gene (implicated in obesity). Attempts at weight control have been frustrating.

The parents share their concerns about the following: Katie’s present body size, the likelihood of increased challenges as she gains body habitus, and continued lags in cognition and communication. The family searched resources and came upon both medical and surgical options to slow her growth trajectory. They are considering possible interventions for Katie and as a solution for her family/caregivers over the coming years. The parents now seek the pediatrician’s guidance because they have had friends and family members express strong opinions both for and against several of the options. Their “search of articles” about the treatment options revealed variable medical and editorial opinions.

Example SDM Process With the Pediatrician and Family

In this case, the request for consultation demonstrates that the parents have identified that a decision needs to be made. By joint request and joint appearance for consultation, both have an active level of involvement.

“So, you’ve given this some thought already. Are there questions/concerns that either of you have—jointly or individually?” [Equality of primary partners.]

“I hear your concerns, questions; are there other family members or “players” who are involved in this particular subject?” [Equality/prioritization of all “players.”]

“Tell me about the options you’ve heard or read about. Are you aware of others that we might discuss?” [Equality of partners including pediatrician.]

“Given the options we’ve discussed, what is your understanding of the risks/benefits of each?” [Information sharing.]

“With those options (with their pluses and minuses), what are your expectations

• for Katie in the short-term (medications/possible surgeries/dietary changes/etc);
• for Katie in the long-term: potential long-term health/quality-of-life considerations;
• of responses you might get from medical/family/community individuals as to the ethical, medical, functional impacts of these decisions?” [Benefits, risks, understanding, expectations.]

“So, [Mom], what are your thoughts? [Dad], what about you, any questions, concerns?” [Benefits, risks, understanding, expectations.]

“So, the options—as I understand them—include those you’ve outlined. One option is that of taking no specific intervention right now; that option leaves us with questions of health management and care. There are other options I can describe if you’d like. Keep in mind, some of the options we talk about today are irreversible medically.” [Open-ended statement allows preferences to emerge.]

“It sounds like some of what we’ve discussed has left you with some concerns:

• potential effects from an endocrine aspect;
• potential effects related to bone health and nutrition;
• some of the potential surgeries have inherent risks (anesthesia, hospitalization, and others)” [Begins negotiation and entry into shared decision.]

“I know you’ve asked me what I would do if Katie were my daughter. This is what I would do:

• recognize this is not a situation of immediate emergency; I would take advantage of the time available to reflect and regroup; I would sleep on this for a night or so;
I would go into this decision knowing that there is no single “right number” here; I would become comfortable and confident knowing I’ve looked at all angles;

I would visit with those central to the decision, then I would sit down at least once more to jointly map out our specific next steps.” [Listening, supportive health team.]

SUPPLEMENTAL RESOURCES: CASE 1


SUPPLEMENTAL RESOURCES: CASE 2


SUPPLEMENTAL RESOURCES: CASE 3


*Pediatrics*

Kalichman MA. Growth attenuation will not solve the problem. [Comment on Allen DB, Kappy M, Diekema D, Fost N. Special article: growth-attenuation therapy: principles for practice. Pediatrics. 2009;123(6):1556–1561.] [Published online June 18, 2009.]

*Pediatrics*


*Pediatrics*


The 9-item Shared Decision Making Questionnaire (SDM-Q-9)

*Example* Please indicate which health complaint/problem/illness the consultation was about:

*Example* Please indicate which decision was made:

Nine statements related to the decision-making in your consultation are listed below. For each statement please indicate how much you agree or disagree.

1. **My doctor made clear that a decision needs to be made.**
   - completely disagree
   - strongly disagree
   - somewhat disagree
   - somewhat agree
   - strongly agree
   - completely agree

2. **My doctor wanted to know exactly how I want to be involved in making the decision.**
   - completely disagree
   - strongly disagree
   - somewhat disagree
   - somewhat agree
   - strongly agree
   - completely agree

3. **My doctor told me that there are different options for treating my medical condition.**
   - completely disagree
   - strongly disagree
   - somewhat disagree
   - somewhat agree
   - strongly agree
   - completely agree

4. **My doctor precisely explained the advantages and disadvantages of the treatment options.**
   - completely disagree
   - strongly disagree
   - somewhat disagree
   - somewhat agree
   - strongly agree
   - completely agree

5. **My doctor helped me understand all the information.**
   - completely disagree
   - strongly disagree
   - somewhat disagree
   - somewhat agree
   - strongly agree
   - completely agree

6. **My doctor asked me which treatment option I prefer.**
   - completely disagree
   - strongly disagree
   - somewhat disagree
   - somewhat agree
   - strongly agree
   - completely agree

7. **My doctor and I thoroughly weighed the different treatment options.**
   - completely disagree
   - strongly disagree
   - somewhat disagree
   - somewhat agree
   - strongly agree
   - completely agree

8. **My doctor and I selected a treatment option together.**
   - completely disagree
   - strongly disagree
   - somewhat disagree
   - somewhat agree
   - strongly agree
   - completely agree

9. **My doctor and I reached an agreement on how to proceed.**
   - completely disagree
   - strongly disagree
   - somewhat disagree
   - somewhat agree
   - strongly agree
   - completely agree

**SUPPLEMENTAL FIGURE 2**
**SUPPLEMENTAL TABLE 5 Tools for Promotion and Measurement of SDM**

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<th>Tool</th>
<th>Rating Source</th>
<th>Notes</th>
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<td>9-Item Shared Decision Making Questionnaire&lt;sup&gt;b&lt;/sup&gt;</td>
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<td>Patient rating</td>
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AHRQ, Agency for Healthcare Research and Quality.

