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## The promise of shared decision-making in paediatrics

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On one end of the spectrum of decision-making in medicine is paternalism, in which the clinician formulates and communicates the treatment plan to the family. At the other end is informed choice, in which the family decides after gathering information from the clinician or other sources. Situated between these extremes, shared decision-making (SDM) involves the clinician explaining the medical evidence for different options and family members discussing these options in the context of their personal values. With both the medical evidence and personal values delineated, the clinician and family jointly determine the treatment plan. SDM is especially helpful for clinical situations with multiple evidence-based options and when variation exists in how families weigh their risks and benefits.

Based on findings primarily from adult healthcare, researchers and policymakers, including the Institute of Medicine and the World Health Organization, have focused increasing attention on SDM. SDM is supported by studies that have repeatedly found that improving provider-patient communication is directly linked to satisfaction, adherence and health outcomes. Because socio-cultural differences between clinicians and patients may impair communication and decision-making if not addressed, explicitly discussing values in the context of medical decisions is also likely to improve care for minority groups underrepresented in the health professions.

In the United States, the 2010 health care reform law marks an unprecedented move towards three elements that are essential for SDM: transparency, consumer protection and evidenced-based medicine, achieved through an investment in comparative effectiveness research. The law establishes a federal programme to promote the implementation of SDM and facilitate the creation and dissemination of patient decision aids – validated tools to promote SDM by helping families learn about the risks and benefits of treatment. This provision also encourages that decisions be made in the context of families' personal values.

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None.

In addition to action on the federal level, states have also recognized the potential benefits of SDM. In 2007, Washington became the first state to enact a law that provides enhanced legal protection to doctors practicing SDM as means of obtaining informed consent. The law also requires a demonstration project to assess the effects of SDM on preference-sensitive conditions such as chronic back pain. Other states are considering similar legislation.

European countries are also encouraging increased patient involvement in medical decision-making. These efforts range from a national program in the Netherlands that develops and publishes patient decision aids on a government website to judicial rulings in France that have strengthened a patient's right to information. Overall, the legislative action supporting SDM underscores its emergent international importance.

Despite this growing prominence, relatively little attention has focused on SDM in paediatrics. A review of the decision support needs of parents found that parents are interested in participating in decision-making and desire information and support when evaluating options (1). Other work demonstrated that communication skills training for paediatric clinicians may improve behavioural health outcomes, especially for children from minority groups (2). Few studies have explicitly examined SDM. In one, more than 70% of parents expressed an interest in being involved in SDM for otitis media (3). In response to scenarios presented by that research team, parental involvement was associated with both improved satisfaction with otitis media care and decreased antibiotic use. More broadly, national guidelines for paediatric conditions such as attention deficit hyperactivity disorder (ADHD) and asthma have increasingly prioritized the involvement of the patient and family (4,5). The optimal implementation of these guidelines depends upon continued work to understand how best to integrate the patient, family and clinician as partners in decision-making.

Decision aids have been developed to help clinicians implement SDM in clinical practice; however, these are largely focused on adult conditions. A consensus set of internationally endorsed criteria is available to guide their creation (6). Of particular importance, meta-analyses of randomized trials of decision aids have shown that these tools improve the quality of health care decisions and reduce the overuse of options that patients do not value (7). Paediatric clinicians may benefit from the growing, but still small, group of paediatric decision aids that address such topics as ADHD, birth control, depression, diabetes, enuresis, headaches, smoking cessation, thyroid disease, tonsillitis, warts and weight control (8).

## CHALLENGES TO IMPLEMENTING SDM IN PAEDIATRICS

Despite these promising results, many barriers remain to implementing SDM in paediatrics. The following paragraphs highlight some challenges that warrant increased attention from clinicians, researchers and policymakers.

For parents to be effective partners in decision-making, they should be able to understand the medical evidence. However, research on adult literacy suggests that 90 million U.S. adults have basic or below-basic literacy skills and that 110 million have basic or poor numerical/quantitative skills. Of particular concern, low literacy and numeracy skills have been associated with less health knowledge, poor health behaviours and worse outcomes (9). Even with education from clinicians, certain families may still be unable to understand the medical evidence and apply it to potentially life-changing decisions. To practice SDM in this setting while effectively providing evidence-based care, clinicians need tools such as decision aids, as well as reimbursement structures that allow adequate time for education and explanation. In this context, SDM should be considered a key component of well-coordinated care (10). In addition, given recent evidence of the importance of telephone care to SDM, efforts to foster SDM may also benefit from interventions that improve ongoing

communication between families at home and paediatric offices through health information technology (11).

In addition to cognitive and logistic challenges to effective partnership, certain families may simply be uncomfortable with participation in health care decision-making. For certain individuals, paternalism is expected in health care. A participatory approach may be seen as 'bad' medicine. Participating in health decisions may also be emotionally difficult for some families. Given high levels of stress among parents of children with special healthcare needs, participation may be perceived as an added or unmanageable burden for some. To successfully practice SDM, paediatric clinicians will have to be especially attentive to the need to directly provide emotional support or refer families to parent support groups or counsellors. Clinicians need to understand that some parents will make a decision intended to minimize their guilt should their child not do well on their chosen treatment plan.

In addition to overcoming challenges for effectively including families as partners in decision-making and care, efforts to bolster SDM will also need to ensure that clinicians are comfortable with this process. This is especially important because studies of deliberation in paediatrics suggest that passive participation by families is common in acute paediatric encounters (12). In many settings, clinicians may not be trained to effectively engage parents as partners in decision-making. Concern has been expressed about physician's quantitative limitations, specifically the ability to apply mathematical concepts to the practice of medicine (13,14). This skill set is essential for two prerequisites of SDM: practicing evidence-based medicine and communicating information about risk and prognosis in a way that can easily be understood. Given these concerns and a historic lack of emphasis on this area in medical training, policymakers and medical educators have highlighted the need to enhance clinician training in communicating medical evidence, risks and benefits to families (15,16).

Shared decision-making in paediatrics is also unique because of the challenge of integrating children as well as parents and the clinician. With increasing age and cognitive maturity, children better understand the purpose, risks and benefits of treatment. Children's perspectives on treatment may also differ from their parents. More broadly, guidance from the American Academy of Pediatrics Committee on Bioethics recommends that children participate in decision-making to the greatest extent possible (17). However, children, especially those of younger age and of less educated parents, are less likely to participate in clinical encounters. These results suggest the importance of research to develop better approaches to engage children in decision-making.

## CONCLUSION

Delivering high quality healthcare depends upon optimizing decision-making. SDM represents what we consider the ideal decision-making approach for many paediatric conditions with multiple evidence-based treatments. However, challenges to implementing SDM in paediatric practice include limited parental health literacy and numeracy, the need for paediatric decision aids, the need for emotional supports for parents, a lack of clinician training in the use of decision aids and SDM and the need for better approaches to integrate the child into this process. Paediatric researchers and advocates for families should increasingly focus on developing optimal strategies to overcome these barriers to SDM.

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## Biographies



## References

1. Jackson C, Cheater FM, Reid I. A systematic review of decision support needs of parents making child health decisions. *Health Expect*. 2008; 11:232–251. [PubMed: 18816320]
2. Wissow LS, Gadomski A, Roter D, Larson S, Brown J, Zachary C, et al. Improving child and parent mental health in primary care: a cluster-randomized trial of communication skills training. *Pediatrics*. 2008; 121:266–275. [PubMed: 18245417]
3. Merenstein D, Diener-West M, Krist A, Pinneger M, Cooper LA. An assessment of the shared-decision model in parents of children with acute otitis media. *Pediatrics*. 2005; 116:1267–1275. [PubMed: 16322146]
4. American Academy of Pediatrics, Subcommittee on Attention Deficit/Hyperactivity Disorder and Committee on Quality Improvement. Clinical practice guideline: treatment of the school-aged child with attention-deficit/hyperactivity disorder. *Pediatrics*. 2001; 108:1033–1044. [PubMed: 11581465]
5. U.S. Department of Health and Human Services. [accessed on August 2, 2010] Guidelines for the diagnosis and management of asthma. National Heart Lung and Blood Institute. 2007. Available at: <http://www.nhlbi.nih.gov/guidelines/asthma/index.htm>
6. O'Connor AM, Stacey D, Barry MJ, Col NF, Eden KB, Entwistle V, et al. Do patient decision aids meet effectiveness criteria of the International Patient Decision Aid Standards Collaboration? A systematic review and meta-analysis. *Med Decis Making*. 2007; 27:554–574. [PubMed: 17873255]
7. O'Connor AM, Bennett CL, Stacey D, Barry M, Col NF, Eden KB, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*. 2009; CD001431. [PubMed: 19588325]
8. The Childrens Hospital of Eastern Ontario. Decision Services. Available at: <http://www.cheo.on.ca/en/decisionaids>.
9. Rothman RL, Yin HS, Mulvaney S, Co JP, Homer C, Lannon C. Health literacy and quality: focus on chronic illness care and patient safety. *Pediatrics*. 2009; 124(Suppl. 3):S315–S326. [PubMed: 19861486]
10. Fiks AG, Leslie L. Partnership in the treatment of childhood mental health problems: a pediatric perspective. *School Ment Health*. 2010; 2:93–101. [PubMed: 20694177]
11. Fiks AG, Localio AR, Alessandrini EA, Asch DA, Guevara JP. Shared decision-making in pediatrics: a national perspective. *Pediatrics*. 2010; 126:306–314. [PubMed: 20624804]
12. Cox ED, Smith MA, Brown RL. Evaluating deliberation in pediatric primary care. *Pediatrics*. 2007; 120:e68–e77. [PubMed: 17606551]

13. Gigerenzer G, Gaissmaier W, Kurz-Milcke E, Schwartz LM, Woloshin S. Helping doctors and patients make sense of health statistics. *Psychol Sci Public Interest*. 2007; 8:53–96.
14. Rao G. Physician numeracy: essential skills for practicing evidence-based medicine. *Fam Med*. 2008; 40:354–358. [PubMed: 18465286]
15. Levinson W, Lesser CS, Epstein RM. Developing physician communication skills for patient-centered care. *Health Aff (Millwood)*. 2010; 29:1310–1318. [PubMed: 20606179]
16. Accreditation Council for Graduate Medical Education. Common Program Requirements. Available at: <http://www.acgme.org/outcome/comp/compFullasp>.
17. Bartholome WG. Informed consent, parental permission, and assent in pediatric practice. *Pediatrics*. 1995; 96:981–982. [PubMed: 7478854]