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# Do surgeons and patients/parents value shared decision-making in pediatric surgery? A systematic review

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ABSTRACT

*Background:* Shared decision-making (SDM) is touted as the preferred approach to clinical counseling. However, few data exist regarding whether patients prefer SDM over surgeon-guided discussions for complex surgical decision-making. Even fewer data exist regarding surgeon preferences. Such issues may be especially pronounced in pediatric surgery given the complex decision-making triad between patients/parents and surgeons. The objective of this systematic review was to evaluate patient/parent and surgeon attitudes toward SDM in pediatric surgery.

*Methods:* A systematic review of English language articles in Medline, EMBASE, and Cochrane databases was performed. Inclusion and exclusion criteria were predefined. Text screening and data abstraction were performed by two investigators.

*Results:* Seven thousand five hundred eighty-four articles were screened. Title/abstract review excluded 7544 articles, and full-text review excluded four articles. Thirty-six articles were identified as addressing patient/parent or surgeon preferences toward SDM in pediatric surgery. Subspecialties included Otolaryngology (33%), General Surgery (30%), Plastics (14%), Cardiac (11%), Urology (8%), Neurosurgery (6%), Orthopedics (6%), and Gynecology (3%). Most studies (94%) evaluated elective/nonurgent procedures. The majority (97%) concentrated on patient/parent preferences, whereas only 22% addressed surgeon preferences. Eleven percent of studies found that surgeons favored SDM, and 73% demonstrated that patients/parents favored SDM.

*Conclusions:* Despite recommendations that SDM is the preferred approach to clinical counseling, our systematic literature review shows that few studies evaluate patient/parent and surgeon attitudes toward SDM in pediatric surgery. Of these studies, very few focus on complex, urgent/emergent decision-making. Further research is needed to understand whether patients/parents, as well as surgeons, may prefer a more surgeon-guided approach to decision-making, especially when surgery is complex or taking place in urgent/emergent settings.



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## Introduction

Over the past several decades, shared decision-making (SDM) has been increasingly touted as the preferred approach to clinical counseling about treatment decisions.[1] SDM is a process by which physicians and patients work together to develop mutually decided on care plans that incorporate evidence-based standards of care as well as patient's values, goals, and preferences.[2,3] As described by Charles *et al.*,[4] truly collaborative decision-making requires shared information between patient and physician, active involvement of both parties in the process of generating a treatment plan, and an eventual agreement between the physician and patient regarding the plan to be implemented.

Much of the implicit acceptance of SDM stems from suggestions that SDM improves quality of care and reduces health care costs.[5,6] Such claims have prompted the integration of SDM into health policy.[5] Specifically, the Patient Protection and Affordable Care Act as well as the Health Care and Education Reconciliation Act of 2010 have targeted SDM as a key tool in health care delivery system reform efforts, and multiple organizations—including the Robert Wood Johnson Foundation, the Foundation for Informed Medical Decision Making, and the National Institutes of Health—have developed funding opportunities to investigate the value of SDM.[5]

Despite such enthusiasm for SDM, relatively few data exist regarding patient and physician preferences toward this approach to patient care.[2,7] In fact, some studies have determined that patients may not prefer to be heavily involved in medical decision-making. For example, Strull *et al.*[8] demonstrated that 80% of patients preferred to have their physicians make decisions about their care, whereas only 19% of patients preferred SDM. Furthermore, Elkin *et al.*[9] showed that only 44% of patients with colorectal cancer wanted to be informed of their prognosis, 52% of patients preferred to have a passive role in decision-making, and 25% of patients preferred their physician make the final decision regarding the treatment plan. Data regarding physician preferences toward SDM are even more sparse than those evaluating patient preferences. In one of the largest reviews of physician attitudes toward SDM, Pollard *et al.*[7] identified 43 articles which demonstrated that physician acceptance of SDM varied depending on the clinical situation. Physicians supported SDM in situations where strong evidence for one procedure as opposed to another did not exist or where evidenced-based clinical guidelines did not favor a given treatment option. Physicians also favored SDM in non-emergent settings where patients were willing and able to participate fully and when treatment options were likely to have a significant effect on the patient's life, such as in decisions to withhold or withdraw life-sustaining treatment. However, although physicians stated their support of SDM in certain clinical settings, they were not always likely to use this approach in clinical practice.[7]

The inconsistent support for SDM by both patients and physicians has prompted some to question whether patients truly prefer the opportunity to be heavily involved in the decision-making process or whether they would instead prefer a more physician-guided approach to decision-making.[10] Presumably, increased physician guidance may offer patients some relief from the burden, conflict, and regret that can be associated with medical decision-making.[10] One may also question whether physicians believe SDM is really the most efficacious approach to decision-making or whether patient encounters would be more beneficial if increased guidance from the physician were expected.

Concerns about the appropriateness of SDM may be particularly pronounced in surgical decision-making, especially when considering emergent, highly complex operations that may be associated with a high risk of mortality or significant morbidity. Overall, very few data exist in the surgical literature regarding patient and surgeon attitudes toward SDM during surgical decision-making. In one of the larger, more recent studies in the field, Boss *et al.*[2] offer an extensive literature review of articles related to SDM in elective surgical cases performed between 1990 and 2015. They found only 24 published articles, with only four of those articles specifically addressing physician or patient perspectives. Notably, only two articles in this review addressed pediatric surgery.[2] The issue of SDM may be even more challenging in pediatric surgery given the complex decision-making triad that exists between patients, parents, and surgeons. Increased understanding of the perceived value of SDM for both patients and surgeons will help elucidate the most efficacious approach to surgical counseling. To gain a better understanding of the available literature regarding this issue we conducted a systematic review of articles that addressed patient/parent or surgeon attitudes toward SDM in pediatric surgery.

## Materials and methods

### *Literature search*

We followed the Preferred Reporting Items for Systematic Reviews and Meta-analyses guidelines and systematically searched Medline (1964-present), EMBASE (1947-present), and Cochrane (from inception) databases for studies that evaluated surgeon and patient/parent preferences toward SDM in pediatric surgery.[11] The search strategy was developed in conjunction with a medical librarian. The Medline search was conducted on April 4, 2017, and the EMBASE and Cochrane searches were conducted on May 9, 2017. This review was limited to English language, peer-reviewed, published literature, and publication bias was not assessed. Detailed search strategies are outlined in Appendix 1.

### *Inclusion and exclusion criteria*

Inclusion and exclusion criteria were defined a priori. Articles were included if they specifically investigated attitudes of surgeons or patients/parents toward SDM in pediatric surgery. Articles in the following categories were excluded: reviews, letters to the editor, editorials, suggested models of care, patient education handouts, decision-making tools, animal studies, or articles without accessible full text.