Shared Decision Making in Pediatrics: A Systematic Review and Meta-analysis

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ABSTRACT

BACKGROUND: Little is known about the impact of interventions to support shared decision making (SDM) with pediatric patients.
OBJECTIVES: To summarize the efficacy of SDM interventions in pediatrics on patient-centered outcomes.
DATA SOURCES: We searched Ovid Medline, Ovid Embase, Ovid Cochrane Library, Web of Science, Scopus, and Ovid PsycInfo from database inception to December 30, 2013, and performed an environmental scan.
STUDY ELIGIBILITY CRITERIA: We included interventions designed to engage pediatric patients, parents, or both in a medical decision, regardless of study design or reported outcomes.
STUDY APPRAISAL AND SYNTHESIS METHODS: We reviewed all studies in duplicate for inclusion, data extraction, and risk of bias assessment. Meta-analysis was performed on 3 outcomes: knowledge, decisional conflict, and satisfaction.
RESULTS: Sixty-one citations describing 54 interventions met eligibility criteria. Fifteen studies reported outcomes such that they were eligible for inclusion in meta-analysis. Heterogeneity across studies was high. Meta-analysis revealed SDM interventions significantly improved knowledge (standardized mean difference [SMD] 1.21, 95% confidence interval [CI] 0.26 to 2.17, $P = .01$) and reduced decisional conflict (SMD −1.20, 95% CI −2.01 to −0.40, $P = .003$). Interventions showed a nonsignificant trend toward increased satisfaction (SMD 0.37, 95% CI −0.04 to 0.78, $P = .08$).
LIMITATIONS: Included studies were heterogeneous in nature, including their conceptions of SDM.
CONCLUSIONS AND IMPLICATIONS OF KEY FINDINGS: A limited evidence base suggests that pediatric SDM interventions improve knowledge and decisional conflict, but their impact on other outcomes is unclear.
SYSTEMATIC REVIEW REGISTRATION NUMBER: PROSPERO CRD42013004761 (http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42013004761).

KEYWORDS: adolescent; child; child, preschool; decision aids; decision making; decision making, shared; decision support techniques; infant; infant, newborn; pediatrics

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WHAT THIS SYSTEMATIC REVIEW ADDS

- Shared decision making (SDM) is an emerging trend in pediatrics, although most interventions have not been rigorously studied.
- A limited evidence base suggests that SDM techniques may improve knowledge and decrease decisional conflict, but we did not observe these techniques to improve satisfaction.
- Currently available SDM interventions often fail to engage children in medical decisions.

HOW TO USE This Systematic Review

- Clinicians who care for children may choose to engage patients and families in SDM, but they should use available interventions cautiously, as many of these interventions have not been well studied and their use cannot yet be completely justified as an evidence-based practice.
- Many interventions are accessible online for providers to use with their patients and their families, although many of these have not been formally studied for their efficacy.

A RELATIVELY RECENT focus on patient and family engagement has led to interest in shared decision making (SDM) among clinicians who care for children ("children" will be used herein to refer collectively to infants, children, and adolescents aged from birth to 18 years old).[1] SDM aims to engage patients and clinicians in a partnership to make medical decisions that are supported by the best available evidence and aligned with patient's values, preferences, and treatment goals.[2–5] A reasonable extension of this idea to pediatrics would include involvement of parents ("parents" will be used herein to refer to biological parents, legal guardians, or other caregivers with medical decision-making responsibilities). Groups including the American Academy of Pediatrics and United Nations advocate for involvement of children and parents in decision making.[6–10]

SDM in pediatrics raises unique challenges in that parents and other caregivers (eg, grandparents, stepparents, siblings) may also have a vested interest in the decision and bring different personal values or preferences into the equation.[11,12] Moreover, children are involved in decision making on a spectrum that evolves as they age and mature.[1,11,12] One challenge not addressed by the adult literature in SDM is how to empower children and adolescents to become engaged and informed medical decision makers.

SDM is often implemented through the use of decision aids (DAs), which are tools designed to facilitate SDM. However, clinicians, patients and families may engage in SDM without the use of DAs. The largest systematic review of DAs included 115 randomized controlled trials (RCTs) and found that they improved patient engagement, choice of options consistent with personal values, and knowledge transfer.[13] However, only one of these studies,[14] conducted in a family practice setting, included children, making it difficult to generalize these results to pediatrics.

Clinicians who care for children and are interested in implementing SDM in practice lack a comprehensive review of the field that summarizes the tools and techniques available to them, as well as their effects. Thus, we aimed to systematically review pediatric SDM interventions and summarize their reported effects on patient-centered outcomes through meta-analysis.

METHODS

STUDY PROTOCOL

We previously published the study protocol as an open access article[15] and registered the systematic review in Prospero (CRD42013004761; http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42013004761). We briefly describe the methods herein as well as changes that occurred during the review process.

CHANGES IN THE REVIEW PROCESS

The original protocol proposed contacting all primary study authors for verification of extracted data.[15] However, given substantial agreement between data extractors after one round of conflict resolution, the study team unanimously agreed to forego verification of extracted information with the exception of if a member of the study team were to question the accuracy of extracted data. We proceeded in this manner because of limited resources for author contact, which often requires multiple follow-up contacts for those who do not respond, and the anticipated low yield of this process. In no case was the accuracy of extracted data questioned such that this procedure became necessary.

The original protocol also called for using the 6-item Cochrane Risk of Bias tool[16] to evaluate RCTs but did not indicate a means by which to assess the quality of non-RCTs and controlled before–after studies.[15] After discovering a number of non-RCTs and controlled before–after studies that were eligible for inclusion, the study team agreed to utilize the expanded 9-item risk of bias tool suggested by the Cochrane Collaboration with these study designs.[17] To permit comparison between studies and be more thorough, RCTs were also evaluated using the 9-item tool.

Initial literature scoping suggested that the limited number of studies available may preclude a quantitative analysis and that therefore a metanarrative approach may be most appropriate for reporting the results.[18] However, because sufficient data were extracted for quantitative analysis, a traditional meta-analytic approach was taken for quantitative outcomes, as outlined in the protocol.[15]

SEARCHING PROCESS

We searched Ovid Medline, Ovid Embase, Ovid Cochrane Library, Web of Science, Scopus, and Ovid PsycInfo from database inception to December 30, 2013. A librarian (PE) experienced in systematic reviews on methods of patient engagement conducted the search (Online Appendix 1).

We also performed an environmental scan to include online DAs not found in the database indexed literature and unpublished studies. The environmental scan began by reviewing a systematic review of RCTs of DAs[13] and a narrative review of pediatric decision making[11] and compiling a list of studies that were known to the authors. We consulted a Facebook group of SDM experts[19] as well as an email distribution list from the Society for Medical Decision Making,[20] reviewed the Children's Hospital of Eastern Ontario A-to-Z inventory of online pediatric DAs,[21] and conducted informal networking to identify additional citations for consideration.

We scanned the references of all articles that reached the full-text review stage for additional citations that potentially met inclusion criteria, and we obtained the full text of these citations to further determine inclusion eligibility.

SELECTION AND APPRAISAL OF DOCUMENTS

All titles and abstracts of references identified through the database-indexed literature search and environmental scan were independently assessed in duplicate for inclusion (KW, JD, GP, BL, NA) using DistillerSR (Evidence Partners, Ottawa, Canada). We evaluated any item that did not include an abstract in its entirety during this stage. We obtained full text of all references identified by at least one reviewer as potentially eligible for inclusion. Full-text citations were then independently assessed for inclusion in