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.

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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

duplicate with conflict resolution by consensus (KW, JD, GP, BL, NA).

We broadly defined SDM as the process of involving patients or their caregivers/surrogates in medical decision making with clinicians. As such, methods or approaches (including tools) designed to facilitate involvement in the process of medical decision making involving patients <18 years of age, their parents, or both and reported in English were eligible for inclusion. For interventions applied (or potentially applied) to both pediatric and adult patients, we determined eligibility on the basis of their applicability to a general pediatric population. We did not limit by study design, outcomes reported, or the presence of comparator groups, and we explicitly included unstudied interventions. We excluded studies on antenatal/perinatal care and research participation decisions. We did not restrict on the basis of the degree of clinical equipoise involved in each decision, as no standardized approach exists to measure equipoise.

Multiple Studies of One Intervention

All reports of the same intervention (or very similar iterations of the same intervention) were initially evaluated separately. Descriptive characteristics of interventions (eg, target audience) were combined and reported at the intervention level, but outcome data (eg, effect on knowledge) were kept separate and reported at the study level. When outcomes were reported separately by participant in the same study (eg, child and parent), these outcomes were reported and analyzed separately in meta-analysis; therefore, some studies appear more than once in forest plots.

Data Extraction

Coauthors working independently (KW, NA, BL) performed data extraction in duplicate using a predesigned electronic extraction form. Items extracted included intervention name, author, institution, clinical scenario, format, targeted user or users, timing of intervention in relation to clinical encounter, free-text description of intervention, and outcomes measured. Although all SDM interventions ostensibly extend to target the clinician, the patient, and their parents, we classified only the most immediate target(s) (ie, who is receiving the intervention) under "targeted user." Thus, clinician training interventions were classified as targeting the clinician only. Given the anticipated heterogeneity and qualitative nature of reported outcomes, much of the extraction took the form of free-text input with conflicts resolved by consensus.

Risk of Bias Assessment

Risk of bias assessment was performed independently in duplicate (KW, BL) for RCTs, non-RCTs, and controlled before–after studies using the 9-item Cochrane Collaboration suggested risk of bias criteria.[17] Conflicts were resolved by consensus with clarification from a senior member of the study team (AL).

Publication Bias

We intended to create funnel plots and perform the Egger regression test[22] on quantitative results to assess for publication bias; however, the small number of quantitative studies reporting similar outcomes and high heterogeneity precluded the generation of meaningful funnel plots.[23]

Statistical Analyses

We performed meta-analyses of the consistently reported quantitative outcomes (satisfaction, decisional conflict, and knowledge). The DerSimonian and Laird random-effects method was used to combine standardized mean difference (SMD).[24] Two-tailed P values of $<.05$ were considered significant. We used I^2 to assess heterogeneity across the studies, in which $I^2 > 50\%$ suggests high heterogeneity,[25] but researchers' clinical judgment was also used to assess suitability for inclusion in meta-analysis in the event of high heterogeneity. This allowed us to provide the best available estimate of effect while acknowledging that inferences made using this estimate are limited by unexplained heterogeneity. All statistical analyses were conducted by Stata version 12.1 (StataCorp, College Station, Tex, USA).

Results

Description of Pediatric SDM Interventions

The results of the search, eligibility assessment, and number of references included are outlined in Figure 1. The database search resulted in 1652 references, and the environmental scan resulted in 53 references, all of which we assessed for eligibility. Sixty-one references meeting eligibility criteria were retained for inclusion in the systematic review. Because 11 citations reported results related to 4 unique interventions,[14,26–35] we therefore report on 54 unique interventions (Fig. 1).

We summarize the included references in Online Appendix 2. We found 12 included citations in the database search, 35 in the environmental scan, 7 in duplicate through the database search and environmental scan, 6 in references of references, and 1 in duplicate through references of references and the environmental scan.

The number of citations increased dramatically after 2010 (n = 17 from 1983 to 2009; n = 35 from 2010 to 2013) (Fig. 2). The most common clinical scenarios were immunization (8 interventions: 3 were on human papilloma virus immunization, 2 were on measles, mumps, and rubella immunization, and 3 were on other immunizations or were nonspecific), attention-deficit/hyperactivity disorder (5 interventions), and acute respiratory tract infection (5 interventions).

Interventions utilized a variety of formats. Eighteen interventions were electronic only, with 14 of these published by the same organization;[55–57,65–69,75–80] 16 were paper based; 4 consisted of live sessions; and 16 included a combination of the aforementioned formats or were in a different format.

The majority (n = 34, 63%) of interventions targeted parents alone, while 4 (7%) targeted the pediatric patient alone, 3 (6%) targeted the clinician alone, and 14 (26%) targeted more than one party, with the most frequently targeted dyad being the patient and parent (n = 6, 11%). The

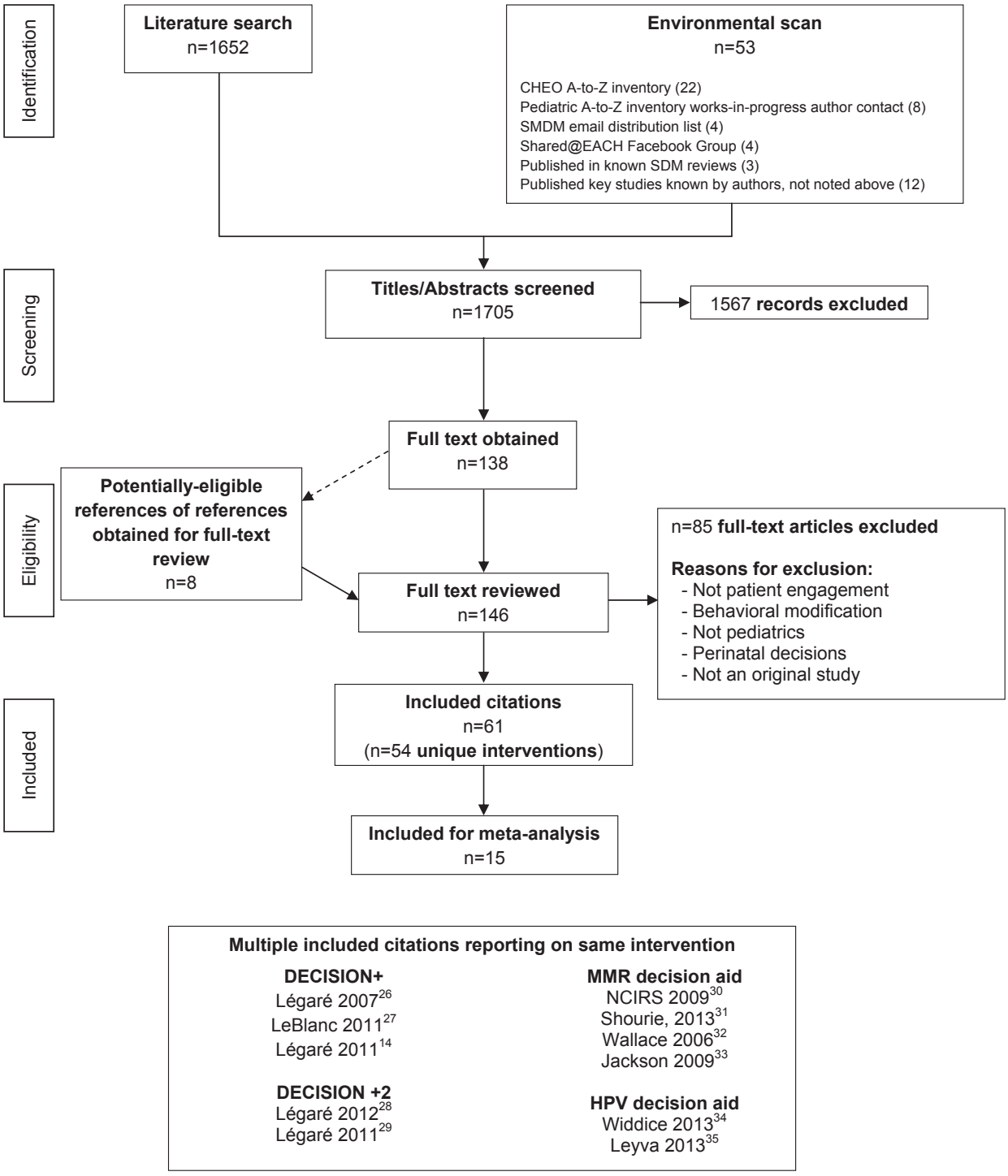


Figure 1. *Flowchart.*

patient, parent, and clinician triad was targeted by only 3 interventions (6%). In total, 14 (26%) targeted the pediatric patient with or without other parties.

Most (n = 30, 57%) interventions were designed for use only before the clinical encounter. Sixteen (30%) were designed for use only during the clinical encounter, and 7 (13%) were designed for use before and/or during the clinical encounter.

When considered according to study design, 28 (52%) of the interventions were formally evaluated: 10 in RCTs, 5 in non-RCTs, 6 in pre/post studies, 1 in pre/post study and RCT, 4 in single-arm studies, and 2 in other study designs.

Reported Outcomes

Satisfaction was the most frequently reported outcome measured of patients and parents (13 studies), followed by decisional conflict[87] (10 studies) and knowledge (7 studies). Satisfaction was measured using a variety of non-standardized scales. Decisional conflict was measured using the Decisional Conflict Scale.[87] The scale measures perceptions of uncertainty and attempts to identify

modifiable factors (eg, feeling uninformed, feeling unclear about personal values, feeling unsupported in decision making) contributing to the feeling of uncertainty. It also measures perceptions of effective decision making. Knowledge was assessed as percentage of questions correctly answered. The remaining outcomes tended to be specific to the clinical context and are outlined in Online Appendix 3. Only one study[73] reported the OPTION instrument,[88] a widely accepted measure of patient involvement by the clinician.

Six studies[46,47,50,59,64,81] reported satisfaction in sufficient detail for inclusion in meta-analysis, which showed a nonsignificant trend toward improved satisfaction with SDM interventions (SMD 0.37, 95% confidence interval [CI] −0.04 to 0.78, $P = .08$, Fig. 3A).

Nine studies reported decisional conflict in sufficient detail for inclusion in meta-analysis.[14,28,31,33,34,54,58,73,81] One study reporting on DECISION+[14] and another reporting on DECISION+2[28] assessed decisional conflict but reported combined results for pediatric and adult patients. We contacted the study authors who provided pediatric-specific decisional conflict results which we used in the meta-analysis. Meta-analysis showed significant reduction in decisional conflict with SDM interventions (SMD −1.20, 95% CI −2.01 to −0.40, $P = .003$, Fig. 3B). We noted that one study showed several fold greater reduction in decisional conflict than other studies.[31] After verification of data extraction, we performed sensitivity analysis excluding this study from the analysis, and the result remained significant (forest plot not shown; SMD −0.43, 95% CI −0.76 to −0.10, $P = .01$).

Six studies[33,34,41,54,58,73] reported knowledge in sufficient detail for inclusion in meta-analysis. In studies where knowledge was reported separately as intervention-specific knowledge and general knowledge, only intervention-specific knowledge was used for consistency. Meta-analysis showed significant improvement of knowledge with SDM interventions (SMD 1.21, 95% CI 0.26 to 2.17, $P = .013$, Fig. 3C).

Year of Publication

When plotted over time, the cumulative number of included references sharply increased after 2010 (Fig. 2).

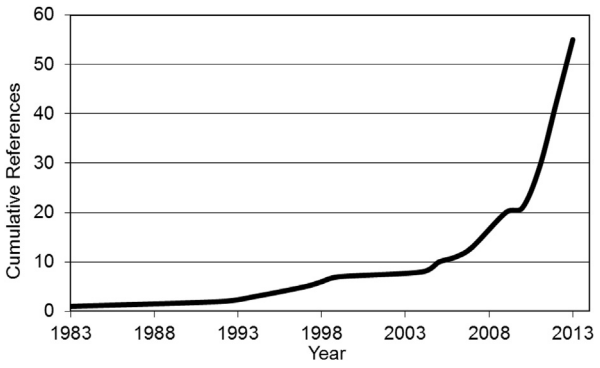


Figure 2. *Cumulative references over time.*

The Healthwise online decision support tools were a significant portion of the included references and were classified by year of most recent update (and not year of initial publication, as this information was not readily available). Because this had the potential to skew the publication dates to later dates, these references were excluded for a sensitivity analysis, which revealed a similar-appearing graph also showing a sharp increase in references after 2010 (data not shown).

Risk of Bias

We detail risk of bias assessments for RCTs, non-RCTs, and pre/post studies using Cochrane risk of bias criteria[17] in Online Appendix 4 and demonstrate them graphically in Online Appendix 5. Some components of the risk of bias assessment could not be evaluated in pre/post studies as the patient/caregiver served as his or her own control; thus, these were not included in the generation of the figure. Lack of adequate blinding was the most common source of bias but was unfeasible in most cases, given the nature of the interventions.

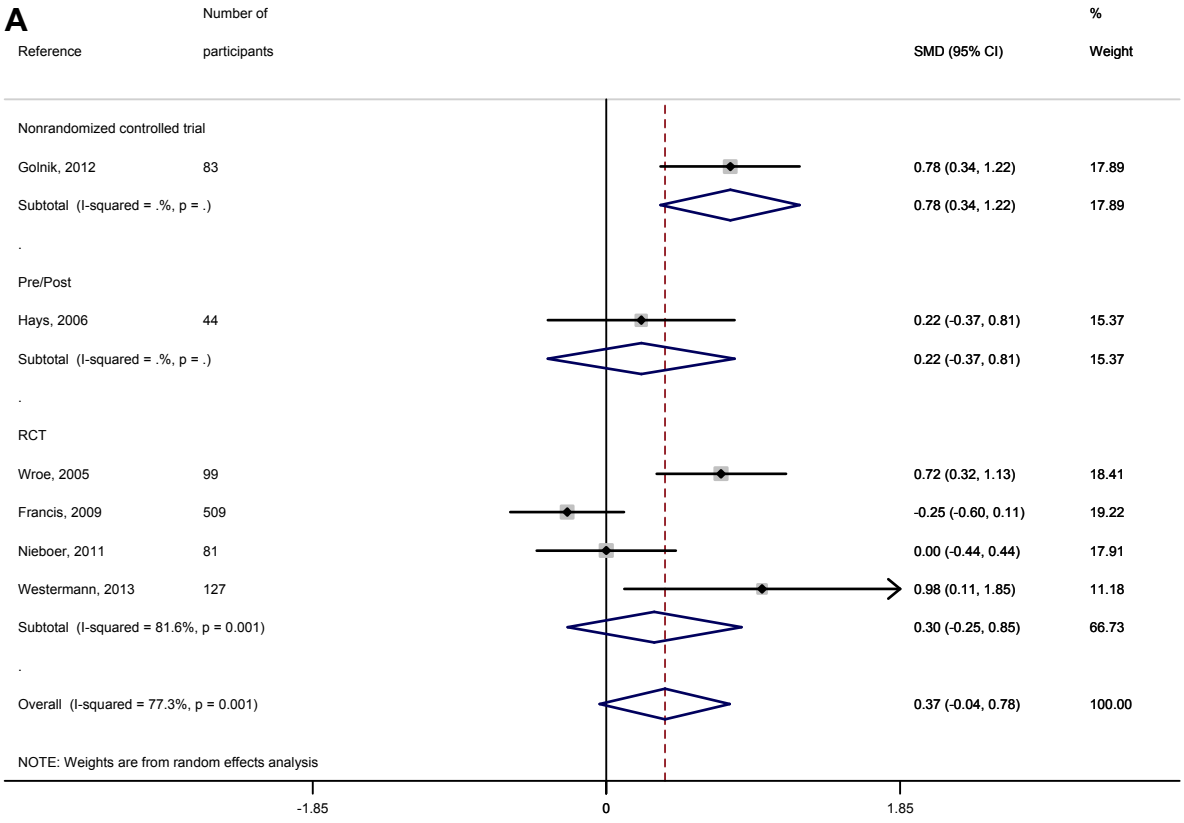
Discussion

Summary of Findings

SDM in pediatrics remains poorly defined. In particular, the relative roles of the pediatric patient and their parent have not been clarified. A number of SDM interventions have been developed for pediatrics, but only approximately half of these interventions were formally studied. This may be in part because the environmental scan generated the majority of the included references, many of which were online resources, and thus by their nature were not formally studied. Moreover, less than half of those that were formally studied were evaluated in RCTs. Many of the reviewed studies were small quality improvement or pilot projects with poor methodological rigor, often lacking a control group. Risk of bias in these studies was largely high or unclear. When outcomes were reported, they were often inconsistent between studies and tended to be specific to the clinical context. Our meta-analyses must be interpreted cautiously in the context of these limitations.

The small number of SDM interventions in pediatrics that were studied had inconsistent effects on key patient-centered outcomes. When considered in meta-analysis, SDM interventions significantly increased parent knowledge and decreased decisional conflict. Although not statistically significant, the effect of SDM interventions on satisfaction appeared to be favorable. Therefore, these interventions appear to have favorable effects, but further research with more rigorous study designs and consistent outcome reporting is needed to fully understand their impact and factors that make them effective.

Perhaps the most provocative and surprising finding of our review was that interventions rarely targeted patients (ie, children) but focused mainly on parents. Despite statements from the American Academy of Pediatrics and the United Nations affirming a child's right to express his or her views and be involved indecisions,[6,7,9] the SDM



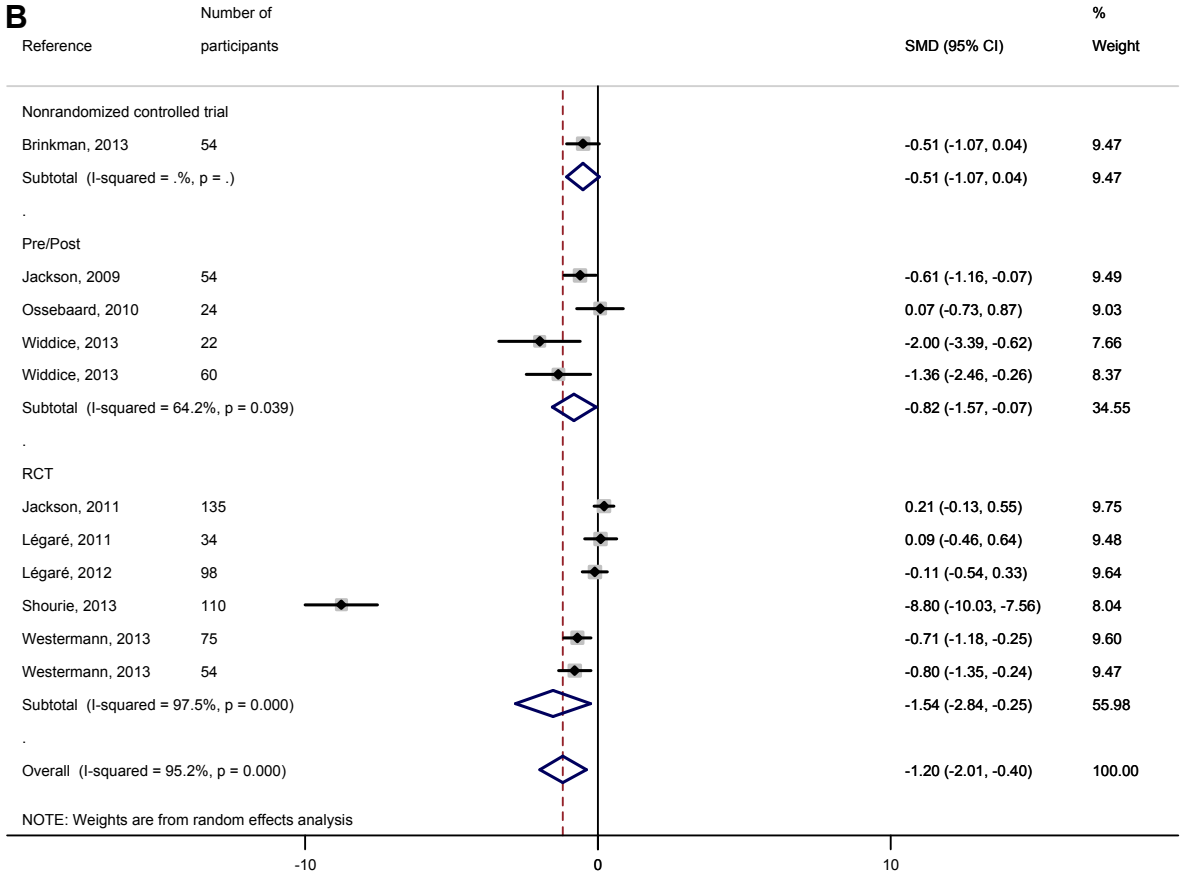


Figure 3. *Meta-analysis forest plots. (A) Satisfaction. (B) Decisional conflict. (C) Knowledge.*

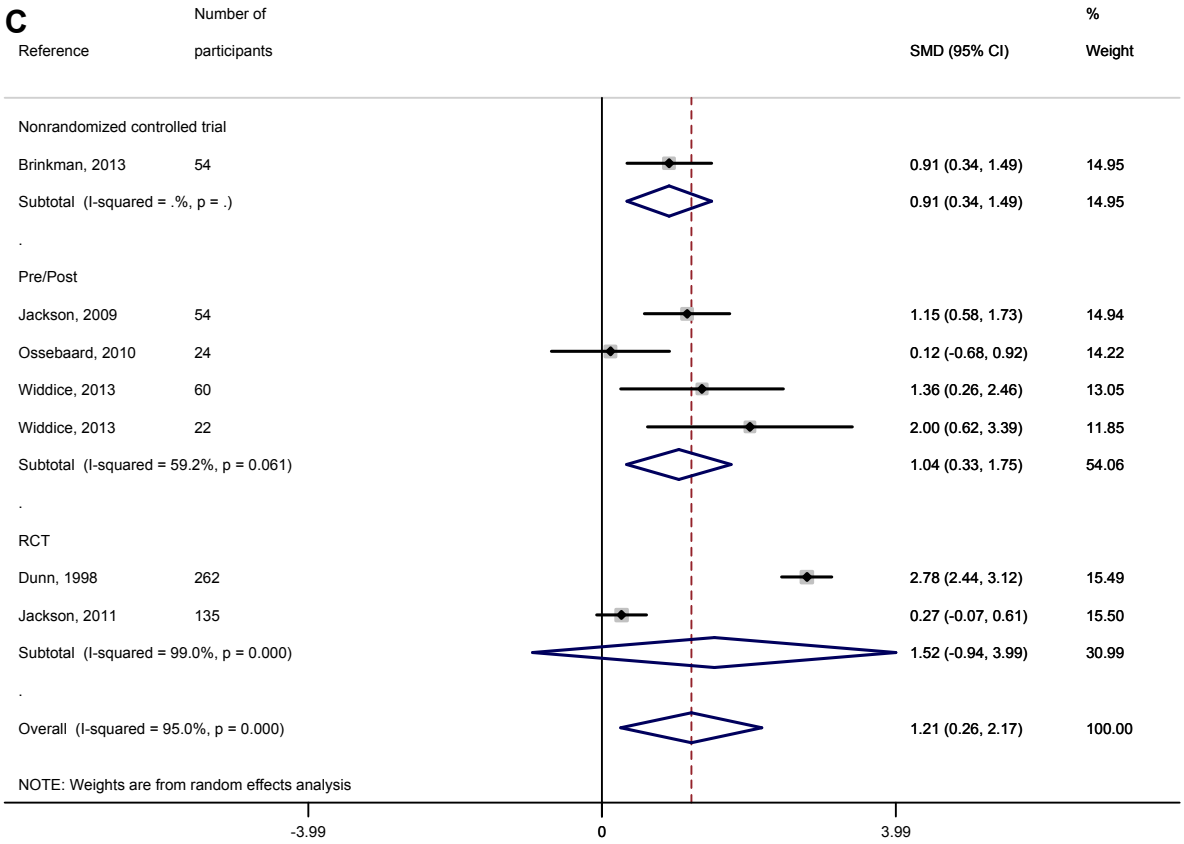


Figure 3. *(continued).*

interventions reviewed generally did not attempt to empower children with a voice, with only 7% of interventions targeting the pediatric patient alone and 19% targeting the pediatric patient with another party. This finding may be partly explained by the fact that many of the decisions did not lend themselves to involvement of the child because of age (eg, interventions regarding infant immunizations); however, it cannot be ignored that children were not directly targeted in many decisions they could arguably be capable of participating in. We invite the interested reader to judge which of these decisions children could reasonably participate in, as outlined in Online Appendix 2.

Children are capable of providing valuable insights into how they experience health and their care. How children participate in decisions depends on the child's level of development and maturation as well as the decision at hand.[12] Child involvement can take many forms, including expressing an opinion regarding the available options but not directly stating a choice, providing or withholding assent, collaborating with parents on decisions, and deciding autonomously.[89–91] Parents and providers should utilize judgment and empathy when deciding to what extent to engage children. Future DAs may consider developing separate components for parents and children, with the latter being more developmentally appropriate in order to better engage children. Because involving children in medical decisions may be something new and different for some parents, interventions may need to explicitly give parents permission to involve their children and reassure them that there is more than one reasonable option. In cases where multiple parties are engaged in decision making, triadic measurement tools are need for outcome measurement.

We observed an increase in the rate that pediatric SDM interventions have been developed in recent years, and indeed we have become aware of several articles that have been published or interventions that have been updated while the data for this report were being analyzed and the manuscript was being prepared, but these were not included because they were published after the literature search.[92–99]

Strengths and Limitations

Weaknesses of this study include that a majority of references were derived from the environmental scan, leaving the strong possibility of selection bias. The quantitative outcomes reported came from a minority of the included studies, and reporting bias could have influenced those results. Furthermore, assessment of risk of bias within the included studies revealed largely high or unclear risk of bias. There is no reference-standard measurement of the quality of SDM; therefore, whether improvements in the measurements included in our meta-analyses (knowledge, satisfaction, and decisional conflict) actually reflect improvements in SDM is unclear. Because our review included mostly DAs in addition to a limited number of other intervention types designed to promote SDM, it is unclear whether the results of the study apply equally to DAs and other interventions designed to promote SDM.

Inferences from the available research are further weakened by the general lack of independent assessment of the efficacy of decision support interventions, as most studies represent evaluations of interventions by their developers; however, in some cases potential bias was minimized by RCT design and trial registration. We did not include non-English-language reports, and extracted data were not verified with original study authors. We also did not assess individual DAs for the extent to which they met the International Patient Decision Aids Standards criteria.[100] The wide range of definitions of SDM we included in our review may have contributed to the observed heterogeneity in the quantitative analysis. We also pooled outcomes collected from both patients and parents, and a wide variety of clinical scenarios were considered, which may have further contributed to the observed heterogeneity. Despite high heterogeneity, meta-analysis was conducted in order to give readers the best available effect estimates, but readers should interpret these results with caution. Strengths include a systematic search strategy with strict inclusion criteria, broad and inclusive definition of SDM interventions with inclusion of studies of various designs, article selection and data extraction in duplicate, and comprehensive inclusion of gray literature (eg, online resources, unpublished interventions and studies) through an environmental scan.

Comparison With Existing Literature

A recent narrative review of pediatric decision making (not specifically SDM) summarized a number of studies, most of which qualitatively described the decision making process but did not offer specific interventions designed to guide the process.[11] Although these studies do not provide interventions that can be directly implemented, they do provide important insights, which can be adapted by clinicians and researchers, into how SDM can be facilitated. Key insights from this review included parents' desire to share in decision making with providers and the challenge of balancing their personal knowledge, emotions, and faith with their children's involvement in the decision.[11]

A recent systematic review by Feenstra et al[105] summarized 5 interventions[53,101–104] to support children's engagement in health-related decisions. In contrast to our review, theirs utilized a broader definition of health-related decisions to include behaviors such as sunscreen use[101] and substance use.[102,104] They also limited to published peer-reviewed studies and did not include interventions targeted to parents only. Similar to our study, they observed relatively few studied interventions, and when interventions were studied, outcomes were heterogeneous with risk of bias mostly high or unclear.[105]

Implications for Future Research

SDM researchers have traditionally focused on scenarios where there is clinical equipoise.[106] In these cases, there is no single, clearly "best" course of action from the provider's standpoint as a result of equivalence of options in most practical aspects, lack of evidence to suggest one option is clearly superior to others, or variability in which aspects of the options patients value most.[107] However, our review included interventions targeting decisions with less clinical equipoise, and these interventions were sometimes designed to persuade patients and parents toward a particular course of action that is widely accepted by the medical profession (eg, immunization). How these interventions fit with more traditional definitions of SDM[2–4] is unclear, but we would suggest that in cases where there is a clear standard of care, SDM may be less applicable than strategies such as motivational interviewing.

SDM researchers have traditionally focused much of their effort on development of DAs to facilitate SDM. However, our review has shown that pediatrics researchers have been progressive in their conception of SDM by developing some systems-based processes that do not rely on DAs to engage patients and their families. This is a key distinction because SDM should be understood not as tool but as a way of communicating and practicing. Because it is not feasible to develop a DA for every possible clinical scenario, provider skills training interventions[108] may provide a means to help clinicians implement SDM on a regular basis. Along these lines, we advocate that research should be focused on identifying strategies that effectively facilitate SDM in practice.

Conclusions

The research enterprise to promote SDM has left children behind. Not only are children often not involved in decisions, but interventions to engage patients and parents are often not rigorously studied. Although a limited evidence base suggests that SDM interventions improve parent knowledge and decisional conflict, further studies are needed to advance the science and practice of SDM in pediatrics.

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Supplementary Data

Supplementary data related to this article can be found at http://dx.doi.org/10.1016/j.acap.2015.03.011

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