



Shared clinician–patient decision-making about treatment of pediatric asthma: what do we know and how can we use it?

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Purpose of review

Shared decision-making (SDM) is an emerging field that promises to improve healthcare. We aim to explore the concept of SDM, how it has been studied or applied in the treatment of asthma, and how it might be implemented to improve adherence and outcomes in pediatric asthma.

Recent findings

Healthcare providers often fail to involve their patients in clinical decision-making by not presenting all available options, associated risks and benefits, in light of the patient's values, preferences, concerns, lifestyle, and perceived barriers to following various treatment regimens. It has been argued that SDM is preferable to a clinician-controlled approach and may improve patient outcomes (increase satisfaction with care, reduce decisional conflict and decisional regret, improve health-related quality of life, and increase decision-specific knowledge). This may be especially important in managing chronic conditions in which adherence to treatment regimen may increase if the patient was actively involved in the decision-making. In pediatrics, the decision process is further complicated by the clinician–parent(s)–child interaction. We found no studies on how to effectively involve and communicate with children at different developmental levels, or how to coalesce the parent and child's perspective to work as a unit.

Summary

SDM has the promise to improve satisfaction with disease management, treatment adherence and patient-centered outcomes in pediatric asthma, but further research is needed to determine its effectiveness and to establish guidelines on how to implement SDM in the clinical setting and incorporate the input and preferences of all stakeholders' perspectives.

Keywords

asthma, children, education, shared decision-making

INTRODUCTION: HISTORY OF SHARED DECISION-MAKING AND KEY CONCEPTS

The foundational processes underlying clinical care are transforming. In the past, these processes were dominated by the physician. Today, care aims to be patient-centered, based on a partnership between healthcare provider and patient and incorporating the patient's unique characteristics and preferences into treatment decisions [1]. It is postulated that this approach will improve the quality of medical care [2]. Patients' rights to involvement in their healthcare have recently been codified through new legislation – most notably in the Affordable Care Act of 2010 – which has specifically designated patients' engagement in 'shared decision-making (SDM)' as a central

component of high-quality, patient-centered care (Pub. L No. 11-148 Sec. 3506).

The term SDM was first used in 1982 by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research describing a process based on mutual respect and partnership that aims to help patients in

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KEY POINTS

- SDM has the promise to improve patient-centered outcomes.
- SDM may be useful in the management of chronic diseases to promote treatment regimen adherence.
- There is a need for studies applying an SDM approach in the pediatric population.
- There is lack of guidelines on how to involve a child in the decision-making process or how to incorporate the parent(s)' and child's input and preferences into the treatment decision.

receiving the care they prefer [3]. Since the issuance of this report, a number of scholars have offered conceptual definitions of SDM [1,4–7]. A systematic review of the literature indicates that SDM is a complex, ongoing process that includes several steps [8]. First, it is generally agreed that SDM in the clinical context should begin with a definition and explanation of the problem to be addressed, followed by a presentation of the clinical options available and their associated benefits, risks and

costs, elicitation of the patient's values and preferences, and education and discussion to ensure the patient's understanding of the different options in relation to their values and preferences, and the likelihood that various options will accomplish the patient's goals [3,9]. Finally, a decision is negotiated, often subject to revision depending on the patient's response to and experience with the treatment, or else explicitly deferred to allow further deliberation [3]. Charles and Gafni [1,4] have provided a useful definition of the characteristics of SDM, as shown in Table 1, and this definition has the advantage that it works well for both treatments that are one-time or irreversible and delivered by the clinician (e.g. between two types of surgery or between surgery and other treatment options) and those decisions that occur on an ongoing basis in the management of a chronic disease such as asthma. It is this definition that undergirds the use of the term in this review.

WHAT ARE THE PROBLEMS, AND WHAT IS THE SHARED DECISION-MAKING PROMISE?

Clinical practice has been historically dominated by a paternalistic physician-centered decision-making

Table 1. Definition of shared decision-making

Basic features of SDM	
SDM requires that both the clinician and patient:	
Are involved in the decision-making process	
Share information with each other	
Take steps to participate in the decision process by expressing treatment preferences	
Agree on the treatment to implement	
SDM information exchange ^a	
Patient → Clinician (information needed from the patient)	Patient ← Clinician (information that needs to be given to the patient)
Disease history and knowledge; past treatment experience	Nature of the disease and rationale for various treatments
Perception of how well or poorly the patient's disease is controlled	How well controlled the patient's disease is by medical criteria – understanding patients' disease status is critical to patient's/parent's understanding of:
How their disease affects the patient's daily life	The relevance of different treatment options
Goals: What the patient would most like to change about their disease or its treatment	The need, and the possibility, for improvement in asthma control
Preferences: Which features of the regimen matter most/least to the patient:	Treatment options:
Effectiveness (disease control)	Existing treatment alternatives for environmental control and pharmacotherapy
Side-effects, risks, other properties	How do different medications work?
Cost	What are the benefits and risks/side-effects?
Convenience	How are they administered?
	The clinician's perspective on various treatment options:
	Effectiveness
	Ability to satisfy the patient's goals and preferences

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^abasic principle: both clinician and patient must have all this information and understand that it will be used to reach a treatment decision.

approach [10]. Healthcare providers often provide patients with insufficient information to make decisions about their treatment [11–13]. Providers and patients often lack the necessary communication skills or tools to engage in complex discussions of risks and benefits, and minimal standards of communication are not being met in clinical encounters [14,15]. Patients are often unaware that multiple treatments are available, and instead assume that the healthcare provider has chosen the only or the ‘best’ treatment available [16]. Even when providers engage their patients in discussions about the risks and benefits of healthcare options, the dialogue is often directive [17,18], and even in some consultations aimed at promoting SDM, providers tend to verbally dominate the conversation [19], rarely ask patients about their preferences for involvement in decision-making [20], and fail to effectively engage them in the process [21]. Targeting these issues, evidence suggests that SDM may increase satisfaction with care [22–25], reduce decisional conflict [26] and decisional regret, increase decision-specific knowledge [26], improve adherence to medication regimens [27–33], and improve health outcomes [28,34].

SDM may be particularly relevant in the management of chronic diseases, in which patients need to alter their lifestyle and re-evaluate decisions intermittently [35,36]. Failure to elicit and address patients’ individual circumstances, goals and preferences regarding their treatment may contribute to nonadherence [37]. Therefore, in the treatment of patients with chronic diseases such as asthma, SDM has both an ethical imperative (recognizing the right of the patient to have a voice in their treatment), and a practical rationale (recognizing that treatment outside the medical office is delivered, or not, by the patient).

SHARED DECISION-MAKING IN ASTHMA-RELATED APPROACHES

Existing behavioral and education interventions contain components that overlap with SDM. In particular, interventions promoting self-management of asthma educate the patients about their treatment regimen and promote an active role in the management of their disease [38]. Such interventions include physician education to improve physician–patient communication [39], clinic or school/community-based asthma education [40,41], interactive web-based platforms [42], and telephone counseling [43,44]. Systematic reviews of experimental evaluation of such interventions suggest improvements in patient self-management and clinician–patient communication skills; however,

effects on clinical outcomes and adherence are modest [45,46]. Researchers have failed to identify a clear set of practices that would substantially improve asthma treatment adherence [47,48] that may be related to a typical focus on education or otherwise motivating the patient to implement a regimen chosen for them by the physician [47–49]. Current asthma guidelines recommend that the patient’s, as well as the clinician’s, goals and preferences be considered and that patients be engaged, not only in the management of their asthma treatment, but also in treatment decision itself [50]. Published self-management approaches do not consistently engage the patient in treatment choice.

HOW HAS SHARED DECISION-MAKING BEEN APPLIED IN ASTHMA?

SDM research in asthma has been primarily conducted in adults. Surveys of factors influencing adherence suggest that asthma patients desire more control of their treatment regimen, suggesting openness to SDM [51]. A cross-sectional survey of asthma patients found a relationship between greater desire for involvement in decision-making and greater nonadherence to medication, suggesting that failing to address patients’ desire for involvement may contribute to nonadherence [52].

We identified three large studies (one RCT and two cohort studies) that have examined the association between SDM and both medication adherence and other health outcomes. The larger cohort study [53] in 808 women found that the existence of a negotiated treatment plan was associated with greater self-reported adherence to prescribed asthma medicines and (in women who used an oral steroids at baseline) with less need for oral steroids over 2 years, but was not related to fewer symptoms of asthma or reductions in urgent healthcare use in the sample as a whole. A second cohort study in 324 women over 2 years, compared women who reported a negotiated treatment plan at baseline, 12 and 24 months. Those who reported a negotiated treatment plan at more time points reported higher adherence and satisfaction with their care [54*]. Importantly, a ‘negotiated treatment plan’ in both studies referred to having what is commonly referred to as an asthma action plan that had been worked out with the patient’s physician. It is not clear that the regular controller medication regimen in the plan was arrived at by a shared decision process as defined here.

A three-arm, multisite RCT in 612 adults with poorly controlled asthma also provides evidence of the impact of SDM on asthma adherence and outcomes [28]. In this study, participants were

randomly assigned to receive either 1) an SDM intervention that included evaluation of the patient's asthma control, patient education, a discussion of the patient's goals and preferences, comparison of treatment options, and a process for evaluating treatment options in light of the patient's goals and preferences so as to arrive at a mutually acceptable decision; 2) usual medical care (no intervention); or 3) a 'clinician decision-making' (CDM) intervention (active control condition), which included the same assessment of asthma control and provision of asthma education as occurred in the SDM intervention, but not a discussion of the patient's goals and preferences or comparison of treatment options. In the CDM condition, the clinician recommended the treatment in the usual manner. SDM participants exhibited significantly greater adherence to their asthma controller regimen in the first year of follow up, compared with both the usual medical care and CDM conditions. The significant advantage of the SDM approach over both usual medical care and CDM in terms of the cumulative strength of the medications dispensed also persisted through a second year of follow up. These results strongly support the hypothesis that, in adults, SDM is associated with significantly greater and longer lasting improvements in medication use.

Clinical outcomes in the first year of follow up (the only year for which they were available) were significantly better in the SDM than in the usual medical care condition – lung function, use of rescue medication, symptoms, asthma control, and asthma medical visits, and these outcomes were numerically, but not significantly, better than those of the CDM condition. For most clinical outcomes, CDM also was statistically superior to usual medical care. Additional study is needed to determine how much improvement in medication use is required to achieve a clinically meaningful improvement in clinical outcomes.

PEDIATRIC ASTHMA

Although research on SDM in adult asthma is still limited, and many questions remain unanswered, even less investigation of SDM in pediatric asthma has been reported. One large multicenter comparative effectiveness trial is underway that involves children as well as adults receiving care at 95 separate community clinical sites of a large health-care system [55]. The study aims to determine the effect of three interventions on medication adherence and asthma outcomes as compared to usual care. Interventions include adaptation of the SDM approach discussed above, an electronic medical record system that provides physician decision

support with easily generated asthma action plans and population reports, and an integrated approach to asthma care based on the chronic disease model. It will also include a comparison with a school-based asthma education program. Results should provide information on how children and parents were included in the SDM process.

A recent cohort study in 259 children ages 8–16 with asthma found an association between a provider asking for child and caregiver input into the asthma treatment plan and self-reported adherence at 1 month. This study also found that only one in three caregivers and one in 10 children who reported having an asthma medication problem asked a question during their medical visits, and many still reported these problems 1 month later [27,56²], suggesting that identifying the treatment that parents and children are most likely to implement requires directly engaging them in discussions about the treatment regimen itself.

BUILDING AN APPROACH TO PEDIATRIC SHARED DECISION-MAKING IN ASTHMA: ENGAGING PARENTS AND CHILDREN

Although the existing research on SDM in pediatric asthma is sparse, parental decision-making about their child's healthcare has been examined in a range of other conditions, including hearing loss [57–60], palliative care [61], attention deficit hyperactivity disorder [62], circumcision [63], vaccinations [64], cardiac surgery [65–67] and pediatric oncology [68–73], among others [25,74]. These studies also highlight the importance of social, environmental and personal factors in shaping how parents view medical interventions, such as vaccination [64]. Other studies [65,75–78] indicate that, like adult patients considering their own care, parents vary in the extent to which they report that they want to take an active role in treatment decision-making related to their children's care. This may be related to a lack of experience with the SDM process, and/or a misunderstanding that they are being asked to make decisions on their own, on matters about which they may feel they have little understanding.

Surveys of parents of children with asthma suggest that clinician–parent concordance of understanding of asthma treatment is low, and that even when there is concordance, parents' negative medication beliefs may go unexplored [79]. Failure to elicit information from the parent is important, as negative asthma medication beliefs are associated with poor adherence [80,81]. Development of an SDM process for pediatric asthma could help clinicians understand and address parents' medication beliefs.

SDM in pediatric asthma is potentially problematic in that, with few exceptions [82–86], studies do not take into account the perspective of the child, nor do they sufficiently consider parental decision-making as proxy decision-making, in which the direct recipient of the risks and benefits of a selected treatment plan is not the primary decision-maker. Furthermore, the few studies [85,86] that do consider the role of the child in clinical encounters do not necessarily address the provider–parent–child triad, but focus only on the parent and child. Young *et al.* [82] did examine all members of the triad. They found that when children were involved in discussions about treatment, it was almost entirely in the self-management realm of decision-making, after the treatment decision had already been made by the physician and/or the parent.

In pediatric asthma, an SDM approach that only involves the parent would be problematic. First, clinicians may miss critical information if they only gather information from the parent, particularly as the child ages [62]. Parents are not always able to accurately evaluate their child's symptoms or medication adherence [87,88]. Children take on increased responsibility for their medications over time, but adherence often decreases with age [89]. Parents may also become disengaged from oversight of medication management as a child ages [90^a]. Addressing these issues as part of a SDM process could potentially improve outcomes.

Children's rights, their ability to consent to treatment, and their involvement in healthcare decisions have received considerable attention in recent years. Involving children in their healthcare is consistent with American Academy of Pediatrics recommendations [91] and the UN Convention on the Rights of the Child [92]. Evidence suggests that when children are involved in the decision-making process, they retain a sense of control over their situation [93]. Allowing school-age children to participate in their healthcare decisions may enhance their self-confidence and improve adherence [94,95]. However, the extent of their involvement will be mediated by their developmental stage, making the child–parent–clinician triad key in decision-making [50,91,92]. There is also a need to understand the complexities of proxy decision-making.

Research on child engagement in medical decision-making is limited. It has almost exclusively been conducted in the United Kingdom and Western Europe. One study suggests that a child's understanding and ability to participate effectively in medical decision-making depends heavily on the adult's ability to communicate effectively with the child [96]. Children may also be accustomed to

playing a passive role, particularly in the context of a doctor–patient relationship [97]. Despite international recognition of the importance of consulting with and involving children in their healthcare, their views are rarely sought or acknowledged in the healthcare system and information is often withheld from them [94].

PROPOSED ROLE AND CHALLENGES OF SHARED DECISION-MAKING IN PEDIATRIC ASTHMA

Just as the decision-making relationship in pediatrics is multidimensional, the potential benefits are as well, as discussed above. Engaging children more directly in the interview process and their care may improve information collection by the clinician, leading to a more accurate assessment of control [98,99], and also may help teach children to be more engaged in their healthcare from an early age. Finally, engaging the child in the treatment discussion also may help in improving parent–child communication about the child's asthma management and asthma control.

There are some challenges in the implementation of SDM in pediatric asthma that present a limitation to SDM research protocols in this population. First, measuring parent and child involvement in the decision-making process is difficult. Existing tools (e.g. the pediatric control preference scale [76,100], the decision role scale [32]) only consider the adult's involvement and not the child's. Second, there are parent–child differences in perception of the manifestations of asthma control, as discussed above [98,99], making it difficult to assess whether symptoms are being under-reported or over-reported by one or the other. Also, healthcare providers may develop coalitions with either the parent or the child to favor one management approach versus another [101]. The nature of this coalition may be arbitrary and has the potential of giving dominance to the healthcare provider's perspective as opposed to the family unit. Guidelines are lacking on how to engage all key stakeholders appropriately in the treatment decision-making. Furthermore, there is also a need for guidelines on how to communicate with and engage children at different developmental levels, as we explore the competency of the child to make decisions as well as the competency of the adult to communicate with them [93,94,97,101].

CONCLUSION

SDM has the promise to improve satisfaction with disease management, treatment adherence and

patient-centered outcomes in pediatric asthma, as well as adult asthma, but there is a need for research studies to establish guidelines on how best to implement SDM in the clinical setting, to include all stakeholders' (clinician's, parents' and child's) perspectives in the decision process, and to determine how doing so affects both treatment adherence and clinical outcomes.

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M.H. and K.R-S. contributed equally as first authors to this manuscript.

Conflicts of interest

The authors have no potential conflicts of interest to declare.

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