

Shared decision-making in food allergy management

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ABSTRACT

Historically, the role of the health-care provider in medical practice has been primarily paternalistic by offering information, compassion, and decisive views with regard to medical decisions. This approach would exclude patients in the decision-making process. In a shift toward more patient-centered care, health-care providers are routinely encouraged to practice shared decision making (SDM). SDM uses evidence-based information about the options, elicitation of patient preferences, and decision support based on the patient's needs with the use of decision aids or counseling. Although there are well-known benefits of SDM, including improvements in psychological, clinical, and health-care system domains providers have found it challenging to apply SDM in everyday clinical practice. In allergy, we have a unique role in the treatment of children and adults, and SDM should be applied appropriately when engaging with these specific groups. There are many situations in which there is not a clear best option (food allergy testing, food introduction and challenges, and immunotherapy). Therefore, decision aids specific to our field, coupled with evidenced-based information that ultimately leads to a decision that reflects the patient's values will make for a vital skill in practice. In this article, we defined SDM, the benefits and barriers to SDM, unique situations in SDM, and approach to SDM in food allergy.

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WHAT IS SHARED DECISION-MAKING?

Historically, the role of the health-care provider in medical practice has been primarily paternalistic, offering information, compassion, and decisive views with regard to medical decisions. This resulted in an environment in which patients were often excluded in the decision-making process. In an effort to change this culture, the Picker Institute coined the term “patient-centered care,” which focused on shifting the focus of health care away from diseases and to the patient and family needs.¹ In 2017, the National Quality Forum defined shared decision-making (SDM) as a process of communication in which clinicians and patients work together to make optimal health-care decisions that align with what matters most to patients.² Three components to SDM are specified: (1) clear, accurate, and unbiased medical evidence about reasonable alternatives, including no intervention, and the risks and benefits of each; (2) clinician expertise in communicating

and tailoring that evidence for individual patients; and (3) patient values, goals, and informed preferences and concerns, which may include treatment burdens.²

BENEFITS AND BARRIERS OF SDM

The benefits of SDM have been observed in studies to include improvements in psychological, clinical, and health-care system domains. When a medical decision needs to be made, patients are provided evidence-based information with regard to the condition, options, benefits and risks, possible outcomes, and uncertainties.³ This is facilitated by decision aids or evidence-based tools that can help patients make decisions among the health-care options.³ A Cochrane review of 105 studies with 31,043 patients showed that, with the use of decision aids, the patients have improved knowledge, more active involvement, decreased indecision, improved satisfaction, improved patient-provider communication, and decisions consistent with patient values.⁴

There are decreased health-care costs, decreased rates of elective treatments and screenings, and decreased rates of invasive procedures.⁴ One critical strategy that has been shown to improve patient adherence is SDM.⁵ The International Patient Decision Aid Standards⁶ has established a checklist to assist users in choosing quality decision aids. This checklist uses a series of questions to engage the user to evaluate three parts: content, development process, and effectiveness.⁶ These criteria are helpful for patients making health decisions, health-care providers guiding patients in health decisions, developers, researchers or evaluators, and policy makers or payers of decision aids. With >500 patient decision aids available or being

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developed, people need to be able to know if the decision aid is reliable.⁶

Despite these known benefits, there are barriers in implementation of SDM. One of the primary barriers is the concern that SDM requires too much time. Although results of studies have shown an increase in consultation by a median of just 2.6 minutes, there is a lack of evidence on when clinicians and patients perceive that time has actually run out as well as a lack of how to better allocate time for these processes.^{4,7,8} This is particularly seen in conversations about cost. A market survey conducted by the Patient Advocate Foundation showed that, in cost of care conversations, 80% of low-income patients agreed that the out-of-pocket cost for their care is important in making treatment decisions but only 38% reported that their health-care provider explained the costs associated with their treatment options.⁹

Without the use of SDM, patients are not adequately able to express their concerns and values. Other principles that discouraged providers from conducting SDM included concern for involvement of specific patients with limited education or health literacy.^{10,11} However, these factors are not suggestive of a willingness to participate in SDM, which signifies that SDM should still be implemented in these patient populations.^{11,12} However, it is important to recognize that low health literacy has been associated with poor outcomes, particularly in asthma, and may also be the case in food allergy.¹² Despite the benefits of SDM, health-care providers have frequently found it challenging to apply these principles in everyday clinical practice.¹³

UNIQUE SITUATIONS IN SDM

Allergy care uniquely spans pediatric and adult medicine. Effective SDM requires a different approach, depending on the developmental stage of the patient. In children and adolescents, there is often ambiguity on when or how to involve these patients in the decision-making process. Some patients (younger, cognitive difficulties, or sedated patients) are not involved in the decision-making process, whereas some patients (adolescents and those with chronic illnesses) may be more involved. With a spectrum of possibilities, at minimum, the consideration of pediatric involvement in SDM should be considered.¹⁴ To assist health-care providers in SDM in pediatrics, a stepwise approach has been suggested. The first decision to be made is whether there is more than one medically reasonable option. If yes, then SDM should be used by discussing the options and if one has a more favorable medical benefit-burden ratio. This allows patients with the assistance of the physician to make decisions. If there are multiple, equally favorable options, then this allows physicians to elicit patient preferences in major

decisions. It also allows physicians to engage specific pediatric populations (patients with chronic illnesses, adolescents, and young adults) in some of the minor decisions that may not compromise outcomes.¹⁵

Ultimately, a fine balance between parents and children and adolescents is needed to counteract some of these factors that can negatively influence children and adolescent behaviors while still allowing them to be a part of the medical decision-making process. In adults, the process of SDM is similar: communication, elicitation of patient preferences, and a mutual agreement on the best course of action to meet the patient's personal goals. In certain populations, there may be challenges and considerations with regard to SDM. For example, among older patients, undiagnosed cognitive impairment and significant hearing loss are emerging problems.¹⁶ In addition, the support and involvement of multiple family members can be helpful but, simultaneously, may not always align with the patient's personal goals.

It is imperative to recognize the potential barrier, whether it be cognition, visual, hearing, cultural, or language barriers, or financial burdens, and to use decision aids with additional measures tailored toward the patient when possible. These factors are important because they can enhance the patient experience and overcome communication barriers.¹¹ In pregnancy and early infancy, health-care providers should elicit expecting and recent mothers on their understanding and concerns with regard to food allergy. By using the "Guidelines for the Diagnosis and Management of Food Allergy in the United States,"¹⁷ health-care providers can inform patients to not restrict their diets as a strategy for preventing the development or course of food allergy, and early introduction of peanut may prevent a peanut allergy.

SDM APPROACH IN FOOD ALLERGY

Although there are relatively few studies specific to SDM in food allergy, these principles have been widely used in patients with chronic diseases. Recently, there has been a shift in both the diagnostic and treatment options in food allergy to include more-specific testing and newer treatment options other than food avoidance, and, as a result, SDM is emerging as an increasingly vital concept in this field. As mentioned previously, decision aids have been shown to improve the overall process of health-care decisions.

A recently published study¹⁸ focused on developing a decision aid for commercial peanut allergy therapies. The decision aid aimed to explain therapies, the key risks and benefits, the importance of key attributes of the therapies, and a self-check assessment with regard to information adequacy. This was assessed by 24 subjects who stated that the decision aid had good

acceptability, high decisional self-efficacy, and low decisional conflict.¹⁸ One area of SDM that can be particularly challenging is risk communication. However, risk communication can effectively be addressed with decision aids, visual aids, numeric likelihoods of risks and benefits, and discussion of values to improve decisional self-efficacy.¹⁹ In addition to decision aids, a brief provider-delivered SDM protocol to guide health care providers may streamline SDM and be easier to implement.²⁰

The American College of Critical Care Medicine and American Thoracic Society recommend active input from health-care providers and patients and/or surrogates at three key stages: information exchange, deliberation, and make a treatment decision.²¹ In the following clinical scenario, we will use this approach. A 10-month-old infant with moderate-to-severe eczema presents to the allergy clinic after developing urticaria immediately after consuming egg for the first time. The family states that his eczema seems to worsen after he eats wheat. The family has stopped introducing any new foods and is requesting that he be tested to all the top allergenic foods.

The first step would be information exchange, with the goal of the family sharing information about their values, goals, and preferences while the clinician shares information about the options and risks and benefits. In this case, the family expresses that they are fearful to introduce any new foods without testing due to the concern that he will react. The next step should include an explanation of the benefits and pitfalls of food allergy testing, including how a positive test often does not correlate with a clinical allergy and can lead to avoidance of foods that the patient may tolerate or cause harm by preventing tolerance development. We should discuss the settings in which testing might be helpful and in which settings it may be less useful, in this case, only peanut testing would be indicated. We could use a decision aid, such as one derived from the results of the Learning Early About Peanut Allergy study²² to illustrate the risks, benefits, and associated costs of introduction and avoidance, and the national allergy organizations specific educational aids available online.¹⁸

The second step would be deliberation, with the goal of all participants sharing opinions, asking questions, clarifying misconceptions, and, if appropriate, why one option may be preferable. We would acknowledge the family's worry with regard to introducing new foods given the reaction history. To help improve their understanding, we could use a decision aid to illustrate the differences in the mechanism of eczema and food allergy, specifically, the difference in pathophysiology and treatment in these conditions. We would explain how eczema triggers do not correlate to the food allergy testing. We would then proceed with our

recommendation of testing to egg and peanut only, with home introduction of other foods. To ensure their comfort, we could also offer a supervised food challenge in the clinic to some of the other foods. The final step would be making a treatment decision with the goal of a plan with which all the participants are comfortable. A possible plan would be testing to peanut and egg, a supervised food challenge to wheat, with scheduled follow-up.

In the future, if his peanut testing results remain positive, then we would discuss the options available, including continuing avoidance, using peanut oral immunotherapy (OIT), or waiting to see if another treatment (e.g., epicutaneous immunotherapy) may become available, or participating in a clinical trial (see sections 16 & 17 of this issue). For OIT, we outlined the known and perceived risks and benefits (including the increased frequency of allergic reactions) and burdens of the treatment (including frequency of visits, the potential costs) and that the duration would be indefinite. If possible, we would want to engage the patient in his understanding of OIT and food allergy as well as if the patient and his family would be a good fit for this treatment. Additional evidence-based decision-making aids related to OIT, which are beginning to emerge, may be useful in this discussion.

CONCLUSION

SDM is an important part of patient care, particularly when there may be indecision when many diagnostic and therapeutic options are available. We should recognize our unique role in treating children and adults in which the SDM should include all appropriate parties. With allergy, there are many situations in which there is not a clear best option (food allergy testing, food introduction and challenges, and immunotherapy). Therefore, an approach that is patient centered and evidence based, with the ultimate decision reflective of the patient's values will make SDM a critical skill for allergy practice. This is especially true given emerging diagnostic and therapeutic options in food allergy.

CLINICAL PEARLS

- Three main principles of SDM: use of evidence-based information about the options, elicitation of patient preferences, and decision support based on the patient's needs with the use of decision aids or counseling.
- The benefits of SDM include psychological, clinical, health-care system benefits, patient adherence, satisfaction, trust, and decreased liability. The barriers of

SDM that have been described are time, literacy, and implementation.

- Different populations, infant, child, adolescent, adult, all require a modified approach in SDM.
- With emerging diagnostic and therapeutic options, an ideal approach is patient centered and evidence based, with the ultimate decision reflective of and guided by the patient's values. Resource for SDM.²³

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