

Real Life Clinic Visits Do Not Match the Ideals of Shared Decision Making

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Objective To use observation to understand how decisions about higher-risk treatments, such as biologics, are made in pediatric chronic conditions.

Methods Gastroenterology and rheumatology providers who prescribe biologics were recruited. Families were recruited when they had an outpatient appointment in which treatment with biologics was likely to be discussed. Consent/assent was obtained to video the visit. Audio of the visits in which a discussion of biologics took place were transcribed and analyzed. Our coding structure was based on prior research, shared decision making (SDM) concepts, and the initial recorded visits. Coded data were analyzed using content analysis and comparison with an existing model of SDM.

Results We recorded 21 visits that included discussions of biologics. In most visits, providers initiated the decision-making discussion. Detailed information was typically given about the provider's preferred option with less information about other options. There was minimal elicitation of preferences, treatment goals, or prior knowledge. Few parents or patients spontaneously stated their preferences or concerns. An implicit or explicit treatment recommendation was given in nearly all visits, although rarely requested. In approximately one-third of the visits, the treatment decision was never made explicit, yet steps were taken to implement the provider's preferred treatment.

Conclusions We observed limited use of SDM, despite previous research indicating that parents wish to collaborate in decision making. To better achieve SDM in chronic conditions, providers and families need to strive for bidirectional sharing of information and an explicit family role in decision making. (*J Pediatr* 2014;165:178-83).

Pediatric chronic conditions often result in lengthy decision-making processes that challenge parents, patients, and providers.¹⁻⁴ In adult healthcare settings, collaboration with providers has been shown to reduce patients' worry, decision regret, and decision conflict by addressing preferences and treatment goals during the decision process.⁵ Like adult patients, parents of children with chronic conditions have interest in collaborating with providers to make treatment decisions.^{1,6,7} For example, in juvenile idiopathic arthritis (JIA) and inflammatory bowel disease (IBD), parents mention interactions with healthcare providers as key aspects of decision making about higher-risk treatments, such as biologic therapies.⁸

Shared decision making (SDM) is a process whereby providers present the evidence and medical context while eliciting parents' or patients' values and preferences. They then strive to reach an agreement about the best treatment option.⁹ This approach has been encouraged by national and international organizations.¹⁰⁻¹⁴ Nevertheless, retrospective studies focused on SDM^{6,15} and observational studies focused on general clinical interactions^{4,16} show limited use of SDM in pediatrics. However, there has been little prospective, observational research focused specifically on the treatment decision-making experience, especially in pediatric chronic conditions.

Although varying in specifics, published models of SDM focus on collaborative decision making based on patient/family preferences and an understanding of the options.¹⁷ Given the known benefits of SDM,¹⁸⁻²¹ we were interested in the extent to which observed clinic visits fit an existing model, "the shared decision making model for clinical practice" (Figure; available at www.jpeds.com).²² This model was chosen because it is based on the same principles as other models but is more specific than many^{9,17} and is applicable in diverse clinical settings.

Our objective was to understand how decisions about biologics, as a model of higher-risk treatments, are made in pediatric chronic conditions by observing the extent to which they fit the chosen model.

Methods

Physicians and one nurse practitioner (collectively referred to as providers) who treat patients with either JIA or IBD were recruited from the rheumatology and gastroenterology clinics of a large academic children's hospital. All but one of the approached providers agreed to participate. Written consent was obtained from all participating providers. Eligible families were those who had a clinic

IBD	Inflammatory bowel disease
JIA	Juvenile idiopathic arthritis
SDM	Shared decision making

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appointment scheduled with a consented provider and the provider anticipated discussing biologic treatment initiation, based on preclinic planning or providers' personal knowledge of the patient. After provider approval to approach the family, consent and assent (for children age 8-17) was obtained from anyone who would be in the room during the visit. We recruited families until we reached informational saturation, the point at which 2 consecutive visits revealed no new approaches to discussing treatment decisions.²³

Families were compensated \$30 for participation. Cincinnati Children's Hospital Medical Center's Institutional Review Board approved this study.

In previous studies using audio recording,⁸ we had difficulty distinguishing voices and determining when people entered and exited the room. Therefore, this study's primary mode of data collection was video recording. A video camera was set-up in the examination room and positioned to avoid viewing the examination table. A back-up audio recording was also made and used for 1 visit where video recording failed.

Recording continued until, at a minimum, the provider left the room with no plan to return. Parents and providers were informed they could turn off the camera at any time, although none did. Demographic information was collected after the visit.

Data Coding and Analyses

Each recording was reviewed to see if it included a discussion of treatment with biologics. The audio of any video in which the family discussed biologics with a provider was transcribed. Each transcript was compared with the video, corrected as needed, and nonverbal interactions and contextual details (eg, child left room) were added.

Our codebook was based on review of the first 2 visits in each clinic, our prior work in the area,^{8,24,25} and information exchange and decision-making concepts informed by Roter²⁶ and Elwyn.²⁷ After watching each video in its entirety, visits were coded from the transcripts with coders referring back to the videos as necessary. Initially, 2 researchers independently coded all video transcripts, adding codes as needed and resolving differences through discussion. Once they had only minor discrepancies in their coding patterns (after 7 transcripts), coding was completed by 1 person and reviewed by the second to look for missing codes. To facilitate content analysis,²⁸ coded data were then organized according to the 3 key provider-patient interaction steps of our chosen model (choice talk, option talk, and decision talk) and compared with the ideals set forth for each step.²² NVivo 8 (QSR International, Victoria, Australia) was used to assist with data coding and organization.

Results

We recorded 21 visits that included discussion of treatment with biologics. The demographics of these 21 families and their providers are shown in **Table I**. Four visits (2 in each clinic) included 2 providers (fellow and attending physician). Mothers were present in all visits.

Fathers were present in 2 gastroenterology and 6 rheumatology visits.

Our results primarily focus on the interaction between parents and providers because, with few exceptions, the child and adolescent patients had little role in the decision. In fact, 2 families intentionally excluded the patient from discussion by not bringing him to the appointment or by having him leave the room during the treatment discussion. Most patients sat quietly during the visit except to answer social questions or questions about their symptoms. However, there were a few instances where, at the end of the decision-making process, we observed the parent or provider turning to the patient and asking a version of "are you okay with this?" In all observed instances, patients quickly agreed to the plan.

In 3 visits with adolescents, the patient actively participated in treatment discussions; one through a preclinic "homework" assignment to read about biologics and the others through in clinic discussion. In these situations, the adolescents asked questions about treatment logistics and expressed concerns about infusions and injections but did not otherwise express treatment goals or preferences. In only 1 case was the patient's preference referenced when making the final decision.

The remaining results are structured according to the 3 key steps of the SDM model for clinical practice: choice talk, option talk, and decision talk.²² Quotations related to each step are in **Tables II-IV**, as are notations for aspects of the model we never observed. Of note, the treatment decision-making portion of observed visits did not differ noticeably between those who made a treatment decision and those decided on further testing prior to finalizing their treatment decision, nor by whether or not a father was in attendance.

Choice Talk

"Choice talk" is characterized by introducing the idea of treatment choice. Before listing specific options, providers

Table I. Participants

Characteristics	Gastroenterology	Rheumatology
Provider (n)	4	6
Years in subspecialty		
Median (range)	9.5 (3-19)	16.2 (1-33)
Sex (n)		
Male	3	3
Female	1	3
Provider type (n)		
Physician	4	5
Nurse practitioner	0	1
Patient (n)	12	9
Median age in years (range)	11.5 (7-16)	9 (2-18)
Decision made (n)		
Start biologic therapy	6	5
Start other treatment	3	0
No change in treatment	0	3
Testing	3	0
Defer decision	0	1
Maternal education (n)		
<College degree	2	5
4-y college degree	6	1
>College degree	4	3

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