Physicians' Perceptions of Shared Decision Making in Chronic Disease and Its Barriers and Facilitators

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This study assessed pediatric physicians' use of shared decision making (SDM) in 2 chronic conditions. Most physicians indicated that parent and adolescent trust and emotional readiness facilitated SDM, physicians' preferred approach to decision making. At the same time, they perceived few barriers, other than insurance limitations, to using SDM. *(J Pediatr 2016;171:307-9).*

Shared decision making (SDM) among physicians and families of patients with chronic conditions has been shown to decrease parents' internal conflict regarding treatment options[1] and may increase medication adherence.[2,3] However, SDM does not occur consistently in clinical encounters.[4-6]

In adult-care settings, physicians perceive contextual factors, such as inadequate information at first consult, limited appointment time,[7-9] patient preference toward paternalistic models of care,[9] and patient assertiveness[10] as hindrances to SDM. In contrast, patient trust,[7,8] the presence of an additional support person,[7] and a personal connection between the patient and physician[8] facilitate SDM. This study aimed to understand pediatric physicians' use of SDM and their perceptions of barriers and facilitators to SDM with parents and adolescents, specifically during the decision to initiate tumor necrosis factor-α inhibitor (TNFαi) treatment in pediatric patients with inflammatory bowel disease and juvenile idiopathic arthritis.

Methods

We recruited rheumatologists who are members of the Pediatric Rheumatology Collaborative Study Group, and gastroenterologists working at centers participating in the Pediatric Resource Organization for Kids with Inflammatory Intestinal Diseases Risk study. Gastroenterologists and rheumatologists who provide care for children <18 years old with inflammatory bowel disease or juvenile idiopathic arthritis and have prescribed a TNFαi in the past year were eligible to participate. Potential participants received an e-mail containing information about the survey and a link to the web survey. Physicians completing the survey on-line were offered a choice of incentives: $5 sent to them or a $5 charitable donation. Non-responders received 2 reminder e-mails and then were mailed a paper survey, which included $5 and a stamped return envelope. Consent to participate was implied by survey completion. This study was approved by the Cincinnati Children's Hospital Medical Center Institutional Review Board.

To assess use of SDM, physicians were provided with examples, based on a prior study,[11] and asked which of the 4 examples best exemplifies their approach to treatment decision making. We asked about various aspects of the decision-making process using the question stem, "How important are the following to the process of shared decision making about TNF-α inhibitors [with patients over age 11]……?" This was followed by a list of aspects of the decision-making process adapted from prior research.[12] We asked about factors that influence how TNFαi treatment decisions are made using the following question stem, "To what extent do you perceive the following as [difficulties/helpful] during the TNF-α inhibitor treatment decision-making process [with patients over age 11]……?" followed by a list of barriers/facilitators.[7,11]

Multiple comparisons were addressed by considering only P value <.01 to be significant. Nonparametric statistics were used to assess differences based upon specialty (rheumatology vs gastroenterology). Percentages were used for reporting response distributions.

Results

We had 195 respondents (response rate 66%). On average, rheumatologists were older than the gastroenterologists and had been in practice longer. There were no other significant differences in demographic characteristics (**Table I**) or responses to any other survey question between the 2

SDM	Shared decision making
TNFαi	Tumor necrosis factor-α inhibitor

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Table I. Participant characteristics

Characteristics	Rheumatologists (n = 99)	Gastroenterologists (n = 96)	*P* value
Age, mean (SD) y	51.9 (10.5)	45.9 (10.2)	<.001
Sex, n (%)			.02
Male	49 (49.5)	64 (66.7)	
Female	49 (49.5)	32 (33.3)	
Years in practice, mean (SD)	18.0 (11.3)	12.4 (10.3)	<.001
Fellowship completed			.40
Yes	91 (91.9)	94 (97.9)	
No	4 (4.2)	2 (2.1)	
Practice setting, n (%)			.06
Private practice	1 (1.0)	6 (6.3)	
Affiliated with academic center or children's hospital	93 (93.9)	88 (91.7)	
Other	2 (2.0)	0 (0)	

groups. Therefore, they were combined for the remainder of the results.

Seventy-five percent of respondents indicated that SDM was their typical approach to decisions about TNFαi. When asked the importance of specific aspects of the process of SDM, most physicians reported that a discussion of pros and of cons of the treatment options between the parents and physician, as well as care and understanding from the physician, were factors that are very or extremely important (**Table II**; available at www.jpeds.com). Additionally, 55% of physicians felt that parents giving information to a physician was extremely important, and 79% of physicians felt that information from the physician to the parent was extremely important. Aspects that were very or extremely important to the process of SDM with adolescents included giving and receiving information, providing a treatment recommendation to the patient, and a discussion between the physician and patient of the pros and cons of the treatment options.

Most respondents felt that parent trust (87%) and parent emotional readiness (70%) facilitated SDM a great deal. When making a decision with adolescents, most respondents stated that patient trust (80%), emotional readiness (63%), and the patient being prepared for the discussion (61%) can help a great deal in facilitating SDM (**Table III**; available at www.jpeds.com).

Respondents felt there were few barriers to SDM with parents or adolescents. The barrier that most respondents perceived as interfering a great deal in the SDM process was the limitations associated with a family's insurance (30%). For barriers to SDM with adolescents, 21% of respondents perceived that difficulty accepting his/her diagnosis interfered with SDM a great deal (**Table IV**; available at www.jpeds.com).

Discussion

The large percent of physicians who reported using SDM is in contrast to what has been found in our observational research that showed clinic visits focused on decision making largely involved physicians providing information and recommendations to parents with limited elicitation of their values and preferences.[6] This suggests that even though physicians are interested in engaging in SDM, they may not fully understand that SDM includes bidirectional exchange of information and collaborative decision making based on family preferences and physician expertise.[13] On the other hand, research has shown that patients may perceive there was SDM even when there was no interactive communication process between the physician and patient.[14] Therefore, it is possible that physicians similarly perceive there to be a more interactive decision process than typically occurs.

Interestingly, not many differences were found in the perceived facilitators of SDM with parents compared with adolescents. The perceived facilitators of SDM are consistent with what adolescents have reported as being important in communicating with their physicians.[15,16] However, prior research indicates that parents and adolescents may differ in how they weigh decision factors[17] and their preferences regarding SDM.[18] This suggests that different approaches may be necessary to facilitate SDM with adolescents compared with parents.

In other studies, physicians reported factors such as insufficient information, limited time,[7-9] and patient assertiveness[10] as detriments to the SDM process. Although these were barriers for some in our survey, insurance concern was the barrier most often perceived as hindering SDM when making decisions about initiating treatment with TNFαi. Even then, this barrier was reported by less than one-third of respondents. The emphasis on insurance in our study, compared with others, likely relates to healthcare system differences, as many of the adult studies were conducted in Canada and Australia. On the other hand, other barriers, such as treatment or disease misconceptions, may indicate a true difference between SDM barriers in the pediatric and adult-care settings.

Our response rate, 66%, is much higher than is typical in surveys of physician specialists.[19] However, we have no information on non-respondents. Another limitation is the risk of a social desirability bias that may have led physicians to indicate greater SDM use or acceptance.[20] Finally, although we included providers from 2 different subspecialties, our results may not be generalizable to other fields or treatment decisions other than TNFαi.

Our findings reveal that physicians are interested in sharing decisions with families and perceive only limited barriers to the SDM process. Although systems barriers such as insurance may be more difficult to overcome, other barriers may be eliminated through the use of new interventions that teach SDM skills to physicians and facilitate discussing TNFαi treatment with families. Such tools will help minimize the barriers to SDM, strengthen the facilitators of SDM, and assist physicians in engaging parents and patients in these challenging treatment decisions. ■