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

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Abstract

This study assessed pediatric physicians' use of shared decision making (SDM) in two 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.

Keywords

chronic disease; physician decision making; biologics

Shared decision making (SDM) among physicians and families of patients with chronic conditions has been shown to decrease parents' internal conflict regarding treatment options¹ 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 care⁹ and patient assertiveness,¹⁰ as hindrances to SDM. In contrast, patient trust,^{7,8} the presence of an additional support person⁷ and a personal connection between the patient and physician⁸ 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,

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specifically during the decision to initiate tumor necrosis factor- α inhibitor (TNF α i) treatment in pediatric patients with IBD and JIA.

Methods

We recruited rheumatologists who are members of the Pediatric Rheumatology Collaborative Study Group (PRCSG) and gastroenterologists working at centers participating in the Pediatric Resource Organization for Kids with Inflammatory Intestinal Diseases (PROKIIDS) RISK study. Gastroenterologists and rheumatologists who provide care for children < 18 years old with IBD or JIA and have prescribed a TNF α i in the past year were eligible to participate. Potential participants received an email 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 two 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 four 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 TNF α i 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 <0.01 to be significant. Non-parametric statistics were used to assess differences based upon specialty (rheumatology vs gastroenterology). Percentages were used for reporting response distributions.

Results

We had 196 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 groups. Therefore, they were combined for the remainder of the results.

75% of respondents indicated that SDM was their typical approach to decisions about TNF α i. 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 the 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 bi-directional 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 to be 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 factors¹⁷ 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 assertiveness¹⁰ as detriments to the SDM process. Although these were barriers for some in our survey, insurance concerns were the barrier most often perceived as hindering SDM when making decisions about the initiating treatment with TNF α i. 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 two different subspecialties, our results may not be generalizable to other fields or treatment decisions other than TNF α inhibitors.

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 TNF α 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.

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Abbreviations

JIA	juvenile idiopathic arthritis
IBD	inflammatory bowel disease
SDM	shared decision making
TNFα	tumor necrosis factor- α inhibitors

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Table 1

Participant Characteristics

Characteristic	Rheumatologists (n=99)	Gastroenterologists (n=96)	P Value
Age, mean (SD), y	51.9 (10.5)	45.9 (10.2)	< .001
Sex, n (%)			0.02
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			0.40
Yes	91 (91.9)	94 (97.9)	
No	4 (4.2)	2 (2.1)	
Practice Setting, n (%)			0.06
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)	

Table 2

How important are the following to the process of shared decision making...

	Not Important N (%)	Somewhat Important N (%)	Important N (%)	Very Important N (%)	Extremely Important N (%)
<u>For parents?</u>					
<i>The doctor gives information (about the disease, the risks and benefits of treatment options) to the parent</i>	0 (0)	0 (0)	4 (2.1)	37 (19.0)	154 (79.0)
<i>The parents and the doctor discuss the pros and cons of the treatment options</i>	0 (0)	0 (0)	4 (2.1)	49 (25.1)	142 (72.8)
<i>The doctor shows care and understanding</i>	0 (0)	1 (0.5)	9 (4.6)	45 (23.1)	140 (71.8)
<i>The doctor and family together agree on the treatment to be given</i>	0 (0)	0 (0)	13 (6.7)	47 (24.2)	134 (69.1)
<i>The parents give information to the doctor about what is important to them</i>	0 (0)	2 (1.0)	26 (13.3)	60 (30.8)	107 (54.9)
<i>The doctor gives a treatment recommendation to the parents</i>	3 (1.5)	10 (5.1)	43 (22.1)	58 (29.7)	81 (41.5)
<i>The family alone decides on the treatment</i>	121 (63.0)	53 (27.6)	16 (8.3)	2 (1.0)	0 (0)
<i>The doctor insists that the parents accept the treatment recommendation</i>	136 (71.2)	36 (18.8)	16 (8.4)	3 (1.6)	0 (0)
<u>For patients over age 11?</u>					
<i>The patient and the doctor discuss the pros and cons of the treatment options</i>	0 (0)	2 (1.0)	24 (12.5)	41 (21.4)	125 (65.1)
<i>The doctor gives information (about the disease, the risks and benefits of treatment options) to the parent</i>	0 (0)	4 (2.1)	25 (12.8)	52 (26.7)	114 (58.5)
<i>The patient gives information to the doctor about what is important to them</i>	0 (0)	3 (1.5)	32 (16.4)	73 (37.4)	87 (44.6)
<i>The doctor gives a treatment recommendation to the patient</i>	4 (2.1)	12 (6.3)	46 (24.0)	67 (34.9)	63 (32.8)
<i>The doctor insists that the patient accept the treatment recommendation</i>	130 (67.7)	42 (21.9)	15 (7.8)	2 (1.0)	3 (1.6)

Italics indicate when > 50% of respondents fell at an extreme.

Table 3

To what extent do you perceive the following as helpful during the TNF- α inhibitor treatment decision making process...

	Not At All N (%)	A Little Bit N (%)	Somewhat N (%)	A Great Deal N (%)
<u>For parents?</u>				
<i>The parents trust me</i>	0 (0)	1 (0.5)	23 (12.0)	167 (87.4)
<i>The parents are emotionally ready for decision making</i>	0 (0)	5 (2.6)	52 (27.1)	135 (70.3)
<i>The parents are prepared (knowledgeable about their child's disease and treatment options) for the discussion</i>	0 (0)	7 (3.6)	59 (30.7)	126 (65.6)
<i>The parents want to participate in making the treatment decision</i>	0 (0)	11 (5.7)	64 (33.3)	117 (60.9)
I have provided written information to the parents	5 (2.6)	47 (24.7)	84 (44.2)	54 (28.4)
The parents have spoken to other parents whose child has the same diagnosis	5 (2.6)	50 (26.2)	86 (45.0)	50 (26.2)
<u>For patients over age 11?</u>				
<i>The patient trusts me</i>	0 (0)	1 (0.5)	36 (18.8)	155 (79.5)
<i>The patient is emotionally ready for decision making</i>	0 (0)	13 (6.7)	59 (30.4)	122 (62.9)
<i>The patient is prepared (knowledgeable about their disease and treatment options) for the discussion</i>	1 (0.5)	12 (6.3)	62 (32.3)	117 (60.9)
The patient wants to participate in making the treatment decision	1 (0.5)	14 (7.3)	91 (47.6)	85 (44.5)
The patient has spoken to another child with the same diagnosis	11 (5.7)	49 (25.3)	80 (41.2)	54 (27.8)
I have provided written information to the patient	15 (7.8)	65 (33.7)	76 (39.4)	37 (19.2)

Italics indicate when > 50% of respondents fell at an extreme.

Table 4

To what extent do you perceive the following as difficulties during the TNF- α inhibitor treatment decision making process...

	Not At All N (%)	A Little Bit N (%)	Somewhat N (%)	A Great Deal N (%)
<u>For parents?</u>				
The family's insurance limits the available treatment options	12 (6.3)	57 (29.7)	66 (34.4)	57 (29.7)
The parents have misconceptions about the disease or treatment	9 (4.7)	60 (31.3)	71 (37.0)	52 (27.1)
The parents refuse a treatment that may benefit the patient	8 (4.1)	69 (35.8)	65 (33.7)	51 (26.4)
The parents have difficulty accepting the patient's diagnosis	17 (8.8)	76 (39.4)	52 (26.9)	48 (24.9)
The parents request a treatment not known to be beneficial	12 (6.2)	72 (36.9)	65 (33.3)	46 (23.6)
Insufficient time to spend with family	30 (15.4)	36 (18.5)	90 (46.2)	39 (20.0)
The parents do not understand the information I have given	6 (3.1)	56 (29.2)	94 (49.0)	36 (18.8)
The parents are too anxious to listen to what I have to say	24 (12.4)	82 (42.3)	64 (33.0)	24 (12.4)
The family has received conflicting recommendations from various specialists	34 (17.5)	88 (45.4)	51 (26.3)	21 (10.8)
The parents want to make a decision before receiving information from me	87 (45.8)	51 (26.8)	32 (16.8)	20 (10.5)
The parents are indecisive	23 (11.8)	80 (41.0)	75 (38.5)	17 (8.7)
The parents bring information I feel is incorrect	26 (13.6)	97 (50.8)	53 (27.7)	15 (7.9)
The parents do not want to participate in treatment decision making as much as I would like them to	35 (17.9)	82 (42.1)	66 (33.8)	12 (6.2)
The parents want to participate more in deciding on the patient's treatment than I would like them to	59 (30.0)	72 (37.1)	56 (28.9)	7 (3.6)
There are cultural differences between the family and me	58 (29.7)	95 (48.7)	35 (17.9)	7 (3.6)
The patient has other health problems	51 (26.3)	106 (54.6)	30 (15.5)	7 (3.6)
The parents come expecting a certain treatment	61 (31.8)	86 (44.8)	40 (20.8)	5 (2.6)
The family brings too much information to discuss	53 (27.5)	105 (54.1)	33 (17.0)	3 (1.5)
<i>I experience difficulty knowing how to frame the treatment options for the parents</i>	<i>122 (63.2)</i>	<i>53 (27.5)</i>	<i>16 (8.3)</i>	<i>2 (1.0)</i>
<u>For patients over age 11?</u>				
The patient has difficulty accepting his/her diagnosis	16 (8.2)	65 (33.5)	72 (37.1)	41 (21.1)
The patient refuses a treatment that may be beneficial	20 (10.4)	70 (36.3)	69 (35.8)	34 (17.6)
The patient has misconceptions about the disease or treatment	11 (5.7)	72 (37.5)	77 (40.1)	32 (16.7)
The patient does not understand the information I have given	7 (3.6)	57 (29.4)	98 (50.5)	32 (16.5)
The parents and patients have conflicting treatment preferences	11 (5.8)	82 (42.9)	67 (35.1)	31 (16.2)
The patient requests a treatment not known to be beneficial	53 (27.3)	77 (39.7)	38 (19.6)	26 (13.4)
The patient does not want to participate in treatment decision making as much as I would like them to	19 (9.8)	52 (26.8)	102 (52.6)	21 (10.8)
The patient is too anxious to listen to what I have to say	16 (8.3)	86 (44.6)	71 (36.8)	20 (10.4)
The patient wants to make a decision before receiving the information from me	73 (37.6)	69 (35.6)	32 (16.5)	20 (10.3)
The patient brings information that I feel is incorrect	59 (30.7)	73 (38.0)	42 (21.9)	18 (9.4)
The patient is indecisive	23 (11.9)	97 (50.0)	65 (33.5)	9 (4.6)
The patient wants to participate more in deciding on the treatment than I would like them to	81 (41.8)	70 (36.1)	35 (18.0)	8 (4.1)

	Not At All N (%)	A Little Bit N (%)	Somewhat N (%)	A Great Deal N (%)
<i>I experience difficulty knowing how to frame the treatment options for the patient</i>	104 (53.6)	60 (30.9)	23 (11.9)	7 (3.6)
The patient comes expecting a certain treatment	68 (35.1)	83 (42.8)	38 (19.6)	5 (2.6)

Italics indicate when > 50% of respondents fell at an extreme.