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High Levels of Decisional Conflict and Decision Regret when Making Decisions about Biologics

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Authors' Roles

Dr. Lipstein conceived and designed the study, acquired the data, performed the statistical analyses, drafted the manuscript and approved the final manuscript as written.

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Abstract

Objectives—To understand the association between parents' perceptions of the decision process and the decision outcomes in decisions about the use of biologics in pediatric chronic conditions.

Methods—We mailed surveys to parents of children with IBD (inflammatory bowel disease) or JIA (juvenile idiopathic arthritis) who had started treatment with biologics in the prior two years and were treated at either of 2 children's hospitals. The survey included measures of the decision process, including decision control and physician engagement, and decision outcomes, including conflict and regret. We used means and frequencies to assess the response distributions. General linear models were used to test the associations between decision process and decision outcomes.

Results—We had 201 respondents (response rate 54.9%). 47.0% reported using shared decision making. Each physician engagement behavior was experienced by the majority of parents, with the highest percentage reporting that their child's physician used language they understood and listened to them. 48.5% of parents had decisional conflict scores of 25 or greater, indicating high levels of conflict. 28.2% had no regret, 31.8% had mild regret and the remaining 40.0% had moderate to severe regret. Shared decision making was not associated with improved decisional conflict, but physician engagement behaviors were associated with both decisional conflict and regret.

Conclusions—Improving decision outcomes will require more than just focusing on who parents perceive as controlling the final decision. Developing interventions that facilitate specific physician engagement behaviors may decrease parents' distress around decision making and improve decision outcomes.

Keywords

decision making; parents; chronic conditions

Introduction

Challenging treatment decisions are not uncommon for families of children and adolescents with chronic conditions. One such decision is the initiation of treatment with biologic medications for children with inflammatory bowel disease (IBD) or juvenile idiopathic arthritis (JIA). Biologics can be highly effective treatments for both conditions leading to improved clinical outcomes and quality of life.(1–3) However, such benefits come at the risk of significant side effects. It is these trade-offs that make the decision particularly challenging for families and may lead to parents feeling regretful or conflicted about the treatment decision.(4, 5)

Our previous research has shown that the process parents use to make decisions about biologics can be lengthy, stressful and involve numerous people.(5) In interviews, parents described a significant role for themselves in the decision.(4, 5) However, observational research, using video-recorded clinical encounters, indicated that the decision-making

process is dominated by information delivery from the healthcare provider, with limited elicitation of parents' concerns, preferences, or goals.(6) However, these findings do not provide any information on how parents perceived their role in decision making or whether the healthcare provider supported their decision making in ways that mattered to parents.

In other settings, the use of shared decision making (SDM), in which parents or patients work with healthcare providers to come to a mutual decision about treatment, has been associated with improved decision outcomes, such as reduced decisional conflict.(7) Based on this association, we hypothesized that for parents of children with IBD or JIA who started treatment with biologics, perceiving that the decision was shared would be associated with less decisional conflict and less decision regret. We further hypothesized that physician behaviors associated with patient engagement in decision making, hereafter referred to as "physician engagement behaviors," would be associated with parents experiencing less conflict and regret.

Methods

Sample

We surveyed parents of children with IBD or JIA, who received treatment at either of two children's hospitals and started treatment with biologics, specifically tumor necrosis factor- α inhibitors, in the prior two years. Potential participants were identified using electronic medical records and disease registries. Parents of children who had more than one diagnosis that could be treated with biologics were excluded. Patients with different names but the same address were assumed to be siblings. In this case, the survey was addressed to the parents of the sibling who had most recently started biologics.

Survey procedures

Collaborating clinics mailed potential survey participants an introductory letter with instructions on how to opt-out of the survey. Parents who did not opt-out were mailed a survey, along with a postage-paid return envelope and a \$2 bill. A reminder postcard was sent one week later, followed by a second copy of the survey. Non-responders were then called and given the opportunity to complete the survey over the phone.(9)

Completion of the survey was considered consent to participate. This study was reviewed and approved by the Cincinnati Children's Hospital Medical Center Institutional Review Board which served as the institutional review board of record for the study.

Survey items

We assessed the decision-making process in several ways. The first was the Control Preferences Scale-Pediatric,(10) which is designed to assess preferences for parent-led, shared or physician-led decision making. As had been done elsewhere,(11) we modified the scale to assess how the decision occurred rather than how parents wanted it to occur, asking parents to pick which response "best describes how you made the decision to have your child start treatment with biologics." Parents were then asked how much involvement in the decision they would have preferred with response options of "a lot more involvement," "a

little more involvement,” “about the same involvement,” “a little less involvement,” or “a lot less involvement.”

We also adapted questions from an Institute of Medicine survey that assessed the link between patient engagement and satisfaction,(12) asking parents the extent to which their child’s gastroenterologist or rheumatologist used specific engagement behaviors. Prior to fielding, these questions were tested via cognitive “three-step test” interviews (26) with parents who had previously made a decision about biologics. Recruitment continued until no major changes to any part of the larger survey, of which this study was a part, were needed in three consecutive interviews. Only minimal changes were required to the survey items reported here.

The final questions were of the form “when deciding about treatment with biologics did your child’s gastroenterology/rheumatology provider...” with response options of “yes, completely,” “yes, somewhat” and “no.” Due to the expectation that most providers should engage in these behaviors, these response options were dichotomized by combining “no” and “yes, somewhat”, according to our *a priori* plan.. In our study, Cronbach’s alpha for this group of adapted questions was 0.85.

We measured two different decision outcomes: decisional conflict, which relates to feeling uncertain about the course of action taken, and decision regret, which relates to remorse after a decision. The Decisional Conflict Scale is a validated, 16-item scale with scores from 0–100. Higher scores are associated with greater decision conflict and a score greater than 25 is associated with being less likely to implement a decision.(13, 14) The Decision Regret Scale is a validated, 5-item scale with scores from 0–100.(15) A score of 0 is considered no regret, 1–24 is mild regret and greater than or equal to 25 is moderate to severe regret.(16) Each scale was adapted slightly to address this specific decision that parents made for their children. For each scale parents were instructed to consider how they felt when they first made the decision about treatment with biologics.

We assessed current parent stress using the 4-item Perceived Stress Scale.(17, 18) We inquired about both parent and patient demographic information.

Data analysis

All survey data were double-entered and discrepancies were resolved through review of the original paper survey. Questions for which a respondent gave multiple responses or their response was unclear were considered to be missing.

We used means and frequencies to assess the distribution of responses. Responses between parents of children with IBD and parents of children with JIA were compared using a series of non-parametric tests. Tests of association between decision process and decision outcomes were conducted using general linear models, as were associations between decision process and demographic characteristics. Because of concerns that current stress may alter parents’ recollection and perception of the decision process, we then adjusted these models for parental stress, as measured by the Perceived Stress Scale. Due to potential

for correlated outcomes only p-values <0.01 were considered statistically significant. SAS 9.3 (SAS Institute Inc., Cary, NC) was used for all analyses.

Results

Demographics

We had a total of 201 respondents (response rate 54.9%). On average patients were 13.7 years old and had started biologics 17.9 months prior to the survey. Although the patients with IBD and those with JIA differed in some demographic characteristics (See table 1), there were no significant difference in responses to survey measures, including decision conflict, regret and physician engagement behaviors. (See table 1.) Therefore, the two disease groups were combined for the results.

Decision Process: Parent Involvement

When asked to describe how they made the decision to have their child start treatment with biologics, 37.4% reported parent-led decision making, marking either that they made the final decision about which treatment their child would receive or they made the final selection of their child's treatment after seriously considering their doctor's opinion. Another 47.0% reported shared decision making by indicating that they and their child's doctor shared responsibility for deciding which treatment was best for their child. The remainder (15.7%) reported physician-led decision making, indicating their doctor made the final decision about which treatment would be used but seriously considered their opinion or they left the final decision to their doctor. Among all parents, 10.0 % would have preferred more involvement in the decision about biologics and 0.5% would have preferred less involvement. There was no significant association between how the decision was made and parents' preferred level of involvement ($p = 0.18$).

Decision Process: Physicians' Engagement Behaviors

Table 2 shows parents' responses regarding physicians' engagement behaviors when making decisions about biologics. Each of the eight behaviors was experienced by the majority of parents. The behaviors most reported by parents were their physician completely using language parents understood and listening to parents. In contrast, only 69.2% of parents felt their child's physician completely explained the latest medical evidence and only 63.5% felt the physician completely explained the option of doing nothing.

Decision Outcomes

The mean decisional conflict score was 22.9 ± 15.1 with 48.5% of parents having scores of 25 or greater, indicating high levels of conflict. The mean decision regret score was 18.3 ± 17.7 , with 28.2% having no regret, 31.8% having mild regret and the remaining 40.0% having moderate to severe regret. There were no significant associations between decision outcomes and patient age or respondent education.

As shown in Figure 1, there was no significant association between whether the decision was physician-led, parent-led or shared and degree of decisional conflict. Parents who reported the decision was shared had a significantly lower regret score than those who reported

parent-led decision making. These associations were unchanged after adjusting for parental stress.

For each of the eight physician engagement behaviors, answering that it occurred completely was associated with lower levels of decisional conflict and decision regret. (See table 3) For example, reporting that the physician always “used language you understood” was associated with an average decrease of 12.6 points on the decisional conflict scale and 11.0 points on the decision regret scale, compared to parents reporting that the provider never or somewhat “used language you understood.” After adjusting for current perceived stress the results were slightly attenuated but all remained statistically significant.

Discussion

Nearly half of parents surveyed reported they shared the decision about starting biologics with their child’s physician, with another 37% reporting they led the decision. This perception contrasts with observational research in pediatric IBD which has shown decisions to be physician-led and to include only limited use of shared decision making techniques.(6, 19) This contrast may reflect a difference in how the decision is perceived or recalled compared to what occurred. It may also reflect that the visit is only a portion of the decision-making process.(6, 20, 21)

Our study also found high levels of decisional conflict and decision regret. Although decisional conflict is the more widely used of the two scales, according to a recent systematic review, only 10 pediatric studies have used it.(22) Our participants had a higher average score than in other studies, where they ranged from 6.25 for a decision about elective otolaryngology procedures(23) to 20.9 among parents making decisions about their child’s life-threatening illness.(24) We found only two other pediatric studies that have used the decision regret scale, both with lower levels of regret than in our study.(25, 26) It is possible that the higher levels of conflict and regret we found are due to our retrospective data collection. However, they also suggest that, as seen in prior qualitative research,(4) the decision to initiate treatment with biologics is unusually difficult for parents.

In both adult-care and pediatric settings, interventions designed to facilitate SDM have been associated with improved decision outcomes, such as reduced conflict and regret.(22, 27) However, in our study SDM was associated only with decreased regret, not conflict. Some have suggested that poor decision outcomes may be more associated with a lack of congruence between the type of decision making a person desires and what actually happened.(28) Yet, in our study nearly 90% of participants were satisfied with the extent of their involvement in the decision. Several other possibilities exist for why reporting that the decision was shared was not associated with decreased decisional conflict. First, it is possible that parents reported more shared decision making than occurred or that the adapted control preferences scale did not correctly measure the use of shared decision making. Second, it may be that SDM in the setting of decision support interventions is substantially different than what parents experienced in making decisions about biologics treatment. This idea is supported by a systematic review focused on SDM interventions in which only half of studies using patient-report of SDM had an association between SDM and improved

outcomes.(29) Finally, it may be that the trade-offs in this particular decision are especially challenging and the use of shared decision making is insufficient to address the conflict.

In contrast to SDM, the physician engagement behaviors we assessed were associated with both less decisional regret and less decision conflict. This may indicate that it is the process of decision making and the specific behaviors within that process that are the key to decision outcomes, rather than who makes the final decision or the parent's global perception of the decision process. Additionally, some deficits may reflect providers' decision to limit information in order to not overwhelm parents(30) or to guide families towards the decision they feel is best,(19) both of which are counter to most definitions of SDM.

Our results suggest that improving the high-levels of regret and conflict may require tools that provide opportunities for on-going engagement in decision making. We imagine that the most effective tools would have both clinic-based and home-based components, so that the decision process continues even when providers and parents are not in each other's physical presence. The development of tools designed to be used at multiple clinic visits, not just visits focused on making a "final" decision, could provide repeated opportunities for engagement and help physicians and other healthcare providers guide families through the decision-making process. This, in turn, may ameliorate the regret we found associated with parent-led decision making, while improving physician's engagement behaviors. Decision interventions designed for longitudinal use could also improve communication (7, 31, 32) and foster engagement by providing a framework to help physicians engage families, particularly through explanation of the latest medical evidence and the risks associated with the treatment options.

We believe this study is the largest to date to evaluate parents' decision process and outcomes related to a specific decision. Nevertheless, the study does have limitations, including our response rate of 54.9%, despite having used multiple evidence-based methods to improve our response rate.(9) The generalizability of this study may be limited by the sample's demographics and our inability to identify and survey parents who decided against having their child initiate biologics. The time lag between when parents made the decision and when they completed the survey may have introduced recall and response bias due to interim disease activity and treatment decisions. Although, a recent study showed that, in the case of breast cancer decisions, decisional conflict is stable over time,(34) we know of no such evidence existing in pediatrics or for our other measures. Our decision outcome measures were developed for patients reporting on their own decision making and have not been used widely in the pediatric literature. Similarly, the measure we used to assess physician engagement behaviors (12) has not, to our knowledge, previously been used to assess the decision-making process.

In this study we found that although shared decision making is not consistently associated with improved decision outcomes, specific physician engagement behaviors appear to be. For some challenging decisions it may be appropriate for families to feel conflicted,(35) but the on-going emotional concerns parents expressed here and in prior studies(4, 5) suggest that there is room for improvement. Improving decision outcomes will require more than just focusing on who parents perceive as controlling the final decision, given that SDM was

not associated with improved decision conflict in our study. Increased awareness of the longitudinal process by which families make decisions in IBD and JIA,(5) rather than focusing on the clinic visit, may help. Additionally, developing interventions that facilitate specific physician engagement behaviors, such as discussing risks and helping families make decisions by better understanding their goals and concerns, may improve decision outcomes.

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What is known

- Challenging treatment decisions, such as that to start biologics, are not uncommon in inflammatory bowel disease and juvenile idiopathic arthritis.
- In other settings, using shared decision making can improve the decision outcomes associated with challenging decisions.

What is new

- Specific physician engagement behaviors are associated with improved decision outcomes, although shared decision making is not.
- Decreasing parents' distress around decision making will require more than just focusing on who parents perceive as controlling the final decision.

Figure 1.
Association between Parent Perception of Decision Control and the Decision Outcomes of Conflict and Regret

Table 1

Demographics

Characteristic	Total (n=201)	Inflammatory Bowel Disease (n=115)	Juvenile Idiopathic Arthritis (n=86)	P Value*
Patient age, mean (SD), y	13.7 (4.0)	15.4 (3.1)	12.0 (4.9)	<0.001
Months since starting treatment, mean (SD)	17.9 (7.8)	15.5 (7.4)	20.3 (8.1)	<0.001
Patient sex, n (%)				0.003
Male	94 (47.0)	64 (56.1)	30 (34.9)	
Female	106 (53.0)	50 (43.9)	56 (65.1)	
Patient race, n (%)				0.32
White	175 (88.0)	98 (86.0)	77 (90.6)	
Black/ African American	12 (6.0)	7 (6.1)	5 (5.9)	
Other	12 (6.0)	9 (7.8)	3 (3.5)	
Patient ethnicity, n (%)				0.25
Hispanic	8 (4.0)	3 (2.6)	5 (5.8)	
Non-Hispanic	193 (96.0)	112 (97.4)	81 (94.2)	
Respondent relationship to patient				0.37
Mother	176 (88.0)	98 (85.2)	78 (91.8)	
Father	21 (10.5)	15 (13.0)	6 (7.1)	
Legal Guardian	3 (1.5)	2 (1.7)	1 (1.2)	
Respondent education, n (%)				0.06
Less than a college degree	67 (34.7)	31 (29.1)	35 (42.3)	
College degree	72 (37.3)	47 (42.7)	25 (30.1)	
Post-graduate degree	51 (26.4)	30 (27.3)	21 (25.3)	
Other	3 (1.6)	1 (0.9)	2 (2.4)	

* p-value comparing characteristics between inflammatory bowel disease and juvenile idiopathic arthritis

Table 2

Parent Perceptions of Physicians' Engagement Behaviors

When deciding about treatment with biologics did your child's gastroenterology/rheumatology provider....?	"No" n (%)	"Yes, somewhat" n (%)	"Yes, completely" n (%)
Use language that you understood	1 (0.5)	18 (9.0)	182 (90.5)
Listen to you	2 (1.0)	27 (13.4)	172 (85.6)
Explain the benefits of your options	3 (1.5)	32 (15.9)	166 (82.6)
Take the time to understand your goals and concerns	5 (2.5)	31 (15.4)	165 (82.1)
Help you make a decision after considering all the options	10 (5.0)	49 (24.3)	142 (70.7)
Explain the risks of your options	7 (3.5)	53 (26.5)	140 (70.0)
Explain the latest medical evidence	8 (4.0)	54 (26.8)	139 (69.2)
Explain the option of doing nothing	36 (18.0)	37 (18.5)	127 (63.5)

Table 3

Association between Each Physician Behavior and Decision Outcome

Physician Behavior	Decision Conflict		Decision Regret	
	β (95% CI)	β adjusted for parental stress (95% CI)	β (95% CI)	β adjusted for parental stress (95% CI)
Use language that you understood	-12.6 (-19.6, -5.6)	-11.3 (-18.2, -4.5)	-11.0 (-19.3, -2.7)	-9.3 (-17.5, -1.2)
Listen to you	-9.0 (-15.0, -3.1)	-8.8 (-14.6, -3.0)	-15.4 (-22.2, -8.6)	-14.9 (-21.5, -8.3)
Explain the benefits of your options	-15.6 (-20.7, -10.5)	-14.2 (-19.3, -9.1)	-13.2 (-23.2, -10.9)	-15.2 (-21.3, -9.1)
Take the time to understand your goals and concerns	-13.6 (-18.7, -8.4)	-12.6 (-17.7, -7.5)	-16.6 (-22.7, -10.5)	-15.5 (-21.4, -9.5)
Help you make a decision after considering all the options	-11.1 (-15.5, -6.7)	-10.5 (-14.9, -6.2)	-14.7 (-19.9, -9.6)	-13.8 (-18.9, -8.8)
Explain the risks of your options	-13.2 (-17.5, -8.9)	-12.2 (-16.5, -8.0)	-12.5 (-17.6, -7.3)	-11.07 (-16.3, -5.9)
Explain the latest medical evidence	-11.3 (-15.6, -6.9)	-10.2 (-14.5, -5.9)	-11.1 (-16.3, -5.8)	-9.8 (-15.1, -4.6)
Explain the option of doing nothing	-7.8 (-12.1, -3.5)	-7.2 (-11.4, -3.1)	-9.1 (-14.1, -3.9)	-8.4 (-13.3, -3.4)

Note: β coefficient represents the average difference in score between those responding "yes, completely" and those responding "yes, somewhat", or "not at all"