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Enrolling adolescents in asthma research: Adolescent, parent, and physician influence in the decision-making process

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Abstract

Background—The factors influencing family decisions to participate in adolescent asthma research are not well understood. Legal and ethical imperatives require adolescent research participation to be voluntary. While parents and adolescents often agree about research decisions, disagreements may also occur with relatively frequency. Physician recommendations are also known to influence research participation decisions. Little attention has been given to how these dynamics may affect adolescents' involvement in decisions to participate in research.

Objective—To examine the influence of family and physician-investigator relationships and recommendations on adolescent asthma clinical research participation decisions.

Methods—A statewide community sample of 111 adolescents aged 11–17, with a diagnosis of asthma, and their parents participated in this study. Adolescents received a medical evaluation from an asthma specialist and then the family was offered participation in a hypothetical asthma clinical trial. By random assignment, the research study was presented by either the same or an unknown asthma specialist and half the families in each group also received affirmative recommendations from the asthma specialist to participate in the hypothetical asthma clinical trial. Parents and adolescent made initial private decisions about participating in the trial. Then, following a family discussion of the clinical trial, a final research participation decision was made.

Results—Thirty three percent of parents and adolescents initially disagreed about the research participation decision. When disagreements occurred, final decisions followed the parents' initial views except when the physician-investigator was known and a recommendation was made. Families with initial disagreement about participating were less likely to enroll when the investigator was unknown or when no recommendation was made. Adolescents who initially disagreed with parents'

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views were less likely to concur with the final research participation decision, felt less comfortable, and were less likely to feel they influenced the decision.

Conclusions—Parents' views on research decisions take precedence over adolescents' views in most circumstances. Physician-investigator relationships may reduce parental resistance to participation and enhance adolescent decision-making autonomy when research participation is desired by the adolescent.

Keywords

biomedical-research-ethics; adolescent-assent; research-participation-decision-making; patient-physician relationship

The factors influencing family decisions to participate in adolescent asthma research are not well understood. Legal and ethical imperatives require adolescent participation to be voluntary, primarily through the process of assent. However, decisions to participate in research occur in the context of family roles and physician relationships. Parents are required to provide permission for adolescent research participation under most circumstances. Physicians may have a variety of roles in research participation decisions, ranging from disinterested advisor to direct involvement in research recruitment. Little attention has been given to how these relationships may enhance or constrain adolescents' involvement in decisions to enroll in asthma clinical research. While both sets of relationships are thought to exert influence in the consent/assent process, the manner in which these complex relationships operate in asthma clinical trial participation decisions remains ambiguous.

A small body of empirical literature on the role of families in adolescent asthma research involvement has recently begun to emerge (1). This literature has examined parent-adolescent perceptions of responsibility for, and influence over, asthma research decisions for adolescents. Differences between parent and adolescent perceptions of research risks and willingness to participate in various research protocols have also been explored. Findings suggest that although parents and adolescents frequently agree on decisions to participate in asthma clinical research, a significant proportion do not agree on these decisions (2,3). In general, adolescents express greater willingness than parents to enroll in above-minimal risk asthma research (3). Both parents and their adolescents assert they have participation decision-making authority within the family, with parents indicating a willingness to be influenced by their adolescent (4). By contrast, adolescents report that they are less willing to be influenced by the opinion of their parents (2,4), a finding consistent with the developmental literature on parent-adolescent communication (3,5–8). Both parents and their adolescents each assert that they have participation decision-making authority within the family.

There are diverse views on the participation of physicians in patient research decisions. Some have cautioned that power and authority differentials between physicians and patients may pose threats to patient autonomy (9). The potential for physicians to provide helpful guidance and support for research participation decisions has also been acknowledged (10). While no data directly addresses physician influence, trust in physicians has been identified as an important factor in some research participation decisions (2,11,12), and parents in particular may be swayed by the opinion of a physician, especially when considering above-minimal risk research (4). Moreover, recent debates about the safety and ethical acceptability of placebo controlled asthma clinical trials serve to highlight the important role physicians may play in advising families about participation (13,14).

The purpose of the present study was to examine the impact of physician-investigator relationships and clinical research-participation recommendations on family decisions to enroll adolescents in a placebo-controlled asthma clinical trial. The extent of physician influence

when the parent and adolescent initially disagreed on the research participation decision was of particular interest. This study examined the hypothesis that families would be more influenced in decisions to enroll in the research when a relationship with the physician-investigator existed, and when a positive participation recommendation was made by the physician.

METHODS

Study Design and Sample

The study sample was drawn from a statewide recruitment of adolescents with asthma and their parents in New Mexico recruited between 2001 and 2005. Families were recruited using brochures, advertisements, mailings and referrals from a variety of sources including, schools, the general pediatrics clinic of the local university health sciences center, private practice pediatrician offices and managed care organizations. Adolescents were eligible to enroll if they had a prior diagnosis of asthma, could read in English, and were between 11–17 years of age. The Oregon Research Institute IRB, the University of New Mexico Human Research Review Committee and the Presbyterian Health Systems IRB approved the study. Informed consent/assent was obtained from parents and adolescents prior to initiating study procedures.

Procedures

Adolescents, in the company of their parents, received a 90-minute clinical examination by a physician specializing in pediatric asthma., The evaluation included spirometry and allergy skin testing. This examination was employed to confirm the diagnosis of asthma and to establish clinical relationships among the adolescent, parent and asthma specialist that served as an experimental manipulation for this study. None of the participants had prior clinical experience with the study specialist. At this visit, parents and adolescents together completed the **Asthma History Questionnaire**.

At the completion of the clinical examination, adolescents and their parents came to the research laboratory (separate from the medical clinic) and independently completed the **Physician Satisfaction Questionnaire**. They then were shown a videotaped vignette of an asthma clinical trial. Families knew in advance that the clinical trial vignette was hypothetical. The hypothetical asthma clinical trial was evaluated under one of four randomized conditions: (a) a description of the trial and a recommendation to participate was made by the asthma specialist who conducted the clinical assessment, (b) a description of the trial without a participation recommendation was made by the asthma specialist who conducted the evaluation, (c) a description of the trial and a recommendation to participate was made by an unknown asthma specialist, (d) a description of the trial without a participation recommendation was made by an unknown asthma specialist. The videotape explained all elements of the trial associated with a fully informed consent, and lasted approximately 10 minutes. Family members were instructed to attend to the video and not discuss their reactions.

Family members first provided private evaluations and decisions concerning willingness to participate in the clinical trial by completing the **Vignette Evaluation Questionnaire**. Adolescents were asked about their willingness to participate in the clinical trial and parents were asked if they would volunteer their child for the clinical research. Both family members were asked to indicate the factors most responsible for their participation decisions. Once private views had been obtained, the family was prompted to discuss the research protocol during a 10-minute videotaped interaction and then make a final decision about whether they would participate in the hypothetical clinical trial. Family members independently completed a **Family Discussion Questionnaire**, which assessed their views of the family discussion. Participants were each compensated $25.00 per person for their time and inconvenience. In

addition, families traveling from rural areas of the state to participate received overnight accommodations and mileage reimbursement.

Clinical Trial Vignette Development

The video vignette described a previously conducted, IRB approved, above minimal risk asthma clinical trial. This clinical trial was selected from among nine studies previously evaluated by a sample of adolescents with asthma and their parents (3). The clinical trial chosen for use in the current study was selected for its high potential for disagreement between parents and adolescents. Previous findings suggested that parents and adolescents might disagree about participating as much as 45% of the time (3). The focus of the current study was to examine influences on decision-making when parents and adolescents disagree on research participation decisions.

The vignette was adapted directly from the original asthma clinical trial and research protocol obtained from the investigators. It explained that the purpose of the trial was "to see whether it is safe and effective for adolescents with asthma to take asthma medicine only when they are having symptoms, or whether it is better for them to take medicine all of the time." Participants were told the trial would last 26 weeks and procedures would include: randomization to treatment (Albuterol or placebo), rescue medication, twelve physical exams, spirometry at each clinic visit, seven methacholine challenge tests, an allergy skin test, EKG, daily diary cards (including peak flow monitoring), and completion of a quality of life questionnaire. Risks associated with the clinical trial were described and participants were informed that they could be temporarily taken off the research protocol if their symptoms worsened or required additional treatment. Compensation was described as $1,000 for completion of the trial, which was the actual amount offered in the original research.

Four video vignettes corresponding to the four experimental conditions described above were created. Each vignette contained the same description of the trial. The asthma specialist who provided the clinical examination was the "known asthma specialist." The "unknown asthma specialist" was an actor matched in age, gender and ethnicity to the actual asthma specialist.

Measures

Measures used in our analyses included adolescent and parent responses to several questionnaires. Two questionnaires focused on the adolescent's asthma and the visit with the asthma specialist. A 32-item **Asthma History Questionnaire** examined diagnosis, symptom history and treatment. The questions were developed from the NHLBI expert panel guidelines (15). A 17-item **Physician Satisfaction Questionnaire** was adapted from a measure to assess parent and adolescent perception of the physician conducting a medical visit (16). Item content assesses several domains, including communication, rapport, and perceived knowledge of the physician. The adaptation consisted of developing parallel forms that could be independently completed by parents and adolescents.

Two of the questionnaires, developed specifically for this study, assessed parent and adolescent views of the research vignette and family decision-making process. The 60-item **Vignette Evaluation Questionnaire** asked participants to indicate their willingness to participate in the research ("How likely would you be to enroll in this study?"), using a 7-point Likert scale from "not at all" to "definitely yes". Participants were also asked to make a participation decision, using a "yes or no" format. ("If you had to say for sure, what would your answer be?"). The questionnaire also assessed the extent to which each aspect of the protocol influenced the participation decision (e.g. "How important is the number of study visits to your participation decision?"). Participants also indicated their perceptions of overall risk and benefit they perceived in the hypothetical trial, and their views of the physician who described the trial.

The 21-item **Family Discussion Questionnaire**, completed following the family interaction/discussion, independently evaluated parent and adolescent perceptions of the families' final research participation decision. This included questions on how much each family member agreed with the final decision, the level of their own participation, and comfort with the decision (e.g. "How much do you personally agree with the decision?"; "how influential do you feel you were in making the decision?"; "I was able to express my opinions during the discussion".)

This paper compares the initial individual views of parent and adolescent willingness to participate in the research with the families' final participation decisions in order to determine the extent to which having a prior clinical relationship with a physician-investigator may influence research participation decisions in families.

Statistical Analyses

Chi-square and binary logistical regression analyses were used to evaluate associations between major independent variables (i.e., prior physician-investigator relationship, participation recommendation made by the physician, and initial concordance or discordance between parents and adolescents on their willingness to participate) and the families' final participation decision regarding the asthma clinical trial (dependent variable). Analysis of variance was used to examine adolescents' views on the final decision in relation to whether they initially agreed or disagreed with their parents' participation decision. A *t* test was used to compare parent and adolescent satisfaction with the asthma specialist.

RESULTS

One hundred fifty six families responded to recruitment efforts by scheduling research appointments. Of those, 45 families cancelled or no-showed and either declined or could not be reached to reschedule their initial appointment. None of these 45 families were consented into the study. Of the remaining 111 families, all but 2 completed the protocol, yielding a final sample of 109 families. Participants were all able to read English and thus able to read the study consent form and complete questionnaires. They were primarily mother-adolescent dyads, although 32 of the families included both parents. In three of the two parent families, the 2nd parent was a guardian. See Table 1 for additional demographic information. All adolescents had a prior diagnosis of asthma. Using the National Heart, Lung, and Blood Institute's guidelines that were available at the time the data was collected, a physician classified the adolescent's asthma severity by a physician while on current therapy or treatment as 73% mild-intermittent, 19% mild-persistent, and 8% moderate- persistent (15).

Asthma Evaluation

Overall satisfaction with the asthma specialist evaluation was quite high for both parents and adolescents, although parents' ratings were significantly higher than adolescents' ratings. The mean score on the Physician Satisfaction Questionnaire for parents was 79.7 (*sd* = 5.9) (range 60 to 85; maximum score 85) and for adolescents was 73.7 (*sd* = 9.9) (range 33 to 85; maximum score 85) suggesting that positive relationships with the families were established through the asthma specialist evaluation.

Initial Family Participation Decisions

When making initial participation decisions concerning the asthma clinical trial, adolescents and their parents independently came to the same decision 67% of the time, while 33% of the parent - adolescent dyads disagreed on the initial decision. Table 2 characterizes the nature of agreement and disagreement among study participants. In all but five of the two-parent families with a discordant adolescent-parent dyad both parents shared the same view. The number of parents present for the study was not a significant variable in any of the analyses.

Final Family Participation Decisions

Overall, parents and adolescents who initially held concordant views on the participation decision, were significantly more likely to agree to enroll in the hypothetical trial, while the decisions of families with initially discordant views were significantly more likely to follow the parents' opinions in making the final decision, p =.000, (Table 3).

Impact of Physician-Investigator Relationships

The unexpectedly large number of parents and adolescents who expressed initial concordance on their willingness to enroll in the hypothetical asthma clinical trial reduced our statistical power to evaluate the independent influence of physician recommendations and prior therapeutic relationships on research participation decision-making in families. Instead, we created and compared 2 conditions: The first condition was comprised of participants who received a recommendation to participate in the trial from a known investigator. This represented the maximum level of potential physician influence. The second condition was comprised of all the lesser potential influence conditions, where either the investigator was completely unknown or where no participation recommendation was made. This comparison allowed us to use logistic regression in order to determine whether decisions in a situation where a physician-investigator would potentially have the strongest influence on research participation would be significantly different from situations with less potential influence. The number, percentage and odds of families agreeing to enroll within each of these two conditions are shown in Table 4. Results demonstrate that: (a) When parents and adolescents held initially discordant views on the decision, the odds of participating were significantly higher in the maximum influence condition (OR, 10.9; CI, 1.8–64.1); (b) In the lesser influence condition, the odds of families participating in the research were significantly higher when parent and adolescent initially agreed on the decision (OR, 27.1; CI (7.7–96.1); and (c) The interaction analysis demonstrated that families who held initially discordant views in the lesser influence condition, were significantly less likely to agree to enroll in the research than were initially discordant families in the maximum influence condition (B = −2.61, Wald = 4.2, p = .039). The associations remained significant after adjusting for the physicians' assessments of asthma severity, and the families' perception of the adolescents' asthma symptoms.

Adolescent Perceptions of the Final Participation Decision

Adolescents' opinions about the final family research participation decision differed based on whether or not they had initially agreed with their parents' views (Table 5). Adolescents who initially disagreed with their parents' views on the decision were less likely to agree with the final decision than were adolescents who held views that were initially concordant with their parents' opinions (p = .001). They were also less likely to feel comfortable with the final decision (p = .003) or to feel they influenced the decision-making (p = .02). No significant differences were found in adolescents' views on their ability to express opinions during the family discussions.

DISCUSSION

This study examined asthma clinical research decision-making for adolescents. The families' relationships with the physician-investigators were systematically varied, including whether or not a research participation recommendation was provided. We then evaluated the impact of the physician-investigator relationships with the families, on the families' final decisions to participate in a hypothetical asthma clinical trial. The findings were evaluated in the context of the parents' and adolescents' initial private views regarding participation. Our findings reveal several critical points.

Overall, in almost 2/3 of the families, parents and adolescents independently agreed to enroll in the hypothetical asthma clinical trial. When parents and adolescents held initially discordant views on the research participation decision, we observed that parental opinions generally took precedence over adolescents' views on the final family decision. Moreover, adolescents who initially disagreed with their parent's decision reported significantly less comfort and agreement with the final family decision, although the magnitude of the difference was moderate. This finding suggests that parents were not fully persuading their adolescents to think differently about asthma research participation during the family discussion. Rather, the parents' views may simply supersede those of the adolescent. Adolescents denied an opportunity to participate may be disappointed, although declining to participate in research does not generally raise autonomy-based ethical concerns. However those enrolled in the study despite a preference to decline, may be participating less voluntarily, potentially compromising ethical imperatives and perhaps adherence with trial procedures. A future analysis of the communication patterns between parent and adolescent during these dialogues will help clarify the nature of these discussions and aid a full interpretation of this finding

The current findings also suggest that physician-investigator relationships and recommendations may play an enhanced role in family research participation decisions under specific circumstances. In particular, we found that physician-investigators are most likely to impact asthma research participation decisions when parents and adolescents initially disagree on the participation decision. Overall, families with initial discordance on the decision were significantly more likely to enroll in the study when the family had a prior relationship with the physician-investigator who recommended participation in the research. Otherwise, these families were more likely to decline enrollment.

As with above minimal-risk research generally, the initial disagreements in this study were most often due to the adolescent's willingness to participate in the study and the parent's preference to decline. One interpretation is that physician influence may reduce parental resistance, and thereby enhance adolescent autonomy in making research participation decisions. This view is consistent with the ethical principle of respect for persons, and with calls for greater adolescent autonomy in research decision-making.

An alternative interpretation is that physician influence in these situations may limit parental perception of their ability to withhold permission, and thus protect their children from perceived research risk. Concerns have been expressed that relationships with physician-investigators may pose challenges to patient autonomy, and to the extent that physician influence overrides parental views, the influence may be inappropriate (9). However, reducing involvement from a trusted physician may also frustrate families. Parents and adolescents have acknowledged the desire for physician input, especially for decision concerning above minimal risk asthma research studies (4). Without adequate guidance, families who might otherwise agree to participate in clinical research may decline for lack of assistance in evaluating the risks and benefits of a study from a trusted professional, potentially reducing adolescent enrollment in asthma clinical trials.

Further research is needed to understand parental reactions to physician influence before more definitive recommendations or specific guidance can be proffered about how to discuss adolescent research participation decisions with families, and ethically provide a recommendation. However, the current findings suggest physicians may want to determine whether or not parents and adolescents initially agree on the research-participation decision before offering their own advice. In cases where adolescents and parents disagree about research participation, physicians may choose to be cautious in the degree of influence they exert. They may also want to clarify the importance of the adolescent's voluntary assent and the parent's permission as one facet of the discussion. Taken together, the findings from this

study provide several new insights about participation decisions in asthma research. First, parents are clearly the primary decision-makers concerning adolescent research participation, and adolescents who disagree with their parents' opinions are generally less satisfied with the final decision following a family discussion. The current findings and prior research have demonstrated that parents are more conservative about agreeing to research participation than adolescents (3). However, parents can be influenced in their own decision-making. In particular, parents who initially declined participation (when the adolescent desired to enroll) were significantly more likely to change their mind following discussion with their adolescent when a known physician-investigator had made a recommendation to participate. It's important to note this finding was obtained in the context of single, but lengthy and extensive, physician contact where participant satisfaction with the clinical exam was uniformly high. With a chronic disease such as asthma, it might be expected that families recruited for actual asthma trials would have a more longstanding relationship with a physician. Thus, the significant findings obtained for this study suggest that the effect of a real world physician-investigator relationship and research participation recommendation might actually be more pronounced.

A number of efforts were made to enhance the veracity and potency of this study. These procedures included recruiting adolescents with asthma and their parents to evaluate an actual asthma clinical trial, and providing an extensive assessment by an asthma specialist, incorporating spirometry and allergy skin testing to help create a real life doctor-patient relationship prior to evaluating the trial. However, it is important to note there are several ways this study differs from a traditional research consent process. We used a hypothetical research vignette and participants knew they were making a hypothetical decision. The vignette was presented via videotape to standardize presentation of the information. These procedures allowed us to isolate and independently examine the key questions of interest for the study. It is unknown whether informed consent/assent decisions for an actual clinical trial would differ. Moreover, it is possible that variables such as gender, ethnicity, SES, parent education level and adolescent illness severity might affect the level of influence that parents, adolescents, physician-investigators would have in research participation decisions. While the present study was not powered to analyze these variables, future research should consider these effects.

Conclusions

This research has demonstrated important ways in which family and physician relationships may influence informed consent/assent decisions for adolescent participation in asthma clinical research. Overall, research recruitment in the context of an asthma exam may enhance the willingness of participants to enroll in above minimal risk asthma research, regardless of prior relationships and recommendations from the physician. However, when parents and adolescents initially disagree about a research participation decision, the parents' views will generally predominate, and the parent is most likely to refuse participation in the research. Yet, recommendations from a known asthma physician-investigator may reduce parental resistance to research participation and support adolescents' views on the decision. Clarifying the nature of these relational dynamics will aid the development of informed consent procedures that enhance the ethical participation of adolescents in asthma research

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Table 1

Demographic Characteristics of Participants.

	n	%
Adolescent age, y		
Mean (*sd*)	13.6 (1.7)	
Range	10–17	
Adolescent gender		
Male	64	58
Female	47	42
Adolescent ethnicity		
Non-Hispanic, White	52	47
Hispanic	38	34
African American	8	7
Asian	1	1
American Indian	4	4
Pacific Islander	1	1
Other	7	6
Parent age, y		
Mean (*sd*)	41.9 (6.8)	
Range	29–59	
Guardian age, y		
Mean (*sd*)	45.6(14.1)	
Range	24–59	
Highest parental educational level		
Some School	8	5
High School Diploma	49	34
Associates/Vocational		
Degree	35	24
Bachelors Degree	21	15
Post-graduate degree	27	20
Missing	3	2
Yearly household income		
< $20,000	23	21
$20,001–$40,000	33	29
$40,001–$60,000	18	16
> $60,001	36	32
Missing	1	2

Table 2

Initial parent and adolescent independent participation decisions (number/percent).

	Adolescent = no	Adolescent = yes
Parent = no	4/3.7%	26/23.9%
Parent = yes	10/9.2%	69/63.3%

Table 3

Final family participation decisions (number/percent) based on initial parent/adolescent concordance or discordance.

Individual Parent/Adolescent Decisions (Initial)	Final Participation Decision = Yes *	Odds Ratio (95% Confidence Interval)
Concordance between parent and adolescent n = 73	66/73 (90%)	Reference
Discordance (n = 26) parent = no adolescent = yes	9/26 (34%)	0.06 (0.02 – 0.17)
Discordance (n = 10) parent = yes adolescent = no	6/10 (60%)	0.16 (0.04 – 0.70)

* Chi Square = 31.1; $p = .000$

Table 4

Impact of physician-investigator relationships: Initial parent/adolescent decisions and investigator/recommendation condition effect upon final participation decision.

Initial Decision to Participate (Concordance/Discordance)	**Maximum Influence**	**Minimal Influence**	**Odds Ratio (95% Confidence Interval)**
	Final Decision = Yes	**Final Decision = Yes**	**Maximum Influence**
Parent/adolescent Concordance *n* = 73	16/18 (89%)	50/55 (91%)	0.80 (0.1 – 4.5)
Parent/adolescent Discordance *n* = 36	08/10 (80%)	07/26 (27%)	10.9* (1.8 – 64.1)
Odds ratio (95% confidence interval) when initial parent/adolescent concordance	2.0 (0.2 – 16.9)	27.1** (7.7 – 96.1)	

* $p = .02$

** $p = .000$

Table 5

Adolescent perceptions of final participation decision based on initial concordance or discordance with parent.

	Mean (range)* ***p*-value****
How much do you personally agree with the final decision?	
Initial concordance with parent	6.2 (5.9 – 6.6)
Initial discordance with parent	5.2 (4.7 – 5.8)
	$p = .001$
How comfortable are you with the decision that your family made?	
Initial concordance with parent	6.2 (5.8 – 6.6)
Initial discordance with parent	5.0 (4.4 – 5.6)
	$p = .003$
How influential do you feel you were in making the decision?	
Initial concordance with parent	5.8 (5.4 – 6.1)
Initial discordance with parent	4.9 (4.3 – 5.5)
	$p = .022$
I was able to express opinions during the discussion.	
Initial concordance with parent	6.4 (6.1 – 6.6)
Initial discordance with parent	6.2 (5.8 – 6.6)
	$p = .623$

* Likert Scale: 1 = Not at All, 7 = A Lot

** Students *t*-test