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## Management of Adolescent-Parent Dyads' Discordance for Willingness to Participate in a Reproductive Health Clinical Trial

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### Abstract

The objective of this study is to understand the resolution of discordance between adolescent-parent dyads about participation in research. Adolescent (14–17 years) and parent dyads were recruited from NYC pediatric clinics to assess attitudes toward research participation. A subset of dyads participated in video-taped discussions about participation in a hypothetical study. Videos from dyads that held strongly discordant opinions about participation ( $n = 30$ ) were content-coded and analyzed using a thematic framework approach. Strategies used to resolve discordance included asserting authority, granting autonomy, or recognizing inaccurate assumptions using a variety of communication behaviors. Missed opportunities to enroll initially discordant dyads may be avoided by allowing time for adolescents and parents to elicit information, clarify a situation or convince the other.

### Keywords

adolescent; parent; dyads; discordance; decision making; consent; reproductive health; qualitative

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## INTRODUCTION

It is critically important to enroll adolescents in reproductive health clinical trials (Santelli et al., 2003). Many potentially risky health behaviors begin in adolescence, including sexual risk behaviors (Lara & Abdo, 2016). However, adolescents under the age of 18 years, as an age group, have often been excluded from participation in clinical trials about sexually transmitted infections (STIs) (Hoffman et al., 2016), reproductive health (Salam, Das, Lassi, & Bhutta, 2016) and other critical research efforts (Patton et al., 2016) from which this age group would benefit (Santelli et al., 2003).

When research does include adolescents, balancing respect for their emerging capacity for independent decision-making with the need for continued special protections in the context of contemplating risks and benefits (Reyna & Farley, 2006) likely requires permission by a parent or guardian in addition to the adolescent's assent (Iltis, 2013; Liu, Cox, Washburn, Croff, & Crethar, 2017). At the most basic level, parental permission recognizes the role of parents in protecting the best interests of their children, while adolescent assent recognizes the minor's right to be involved in the decision. From a more developmental perspective, assent should be an interactive process between a minor, parent, and researcher that should involve a developmentally appropriate disclosure of details about the research and solicitation of the minor's willingness to participate (Annett, 2017; Kuther & Posada, 2004). Hence, the need to obtain both permission and assent can lead to situations in which dyads may not agree about participation in a research trial (Baker, Yardley, & McCaul, 2001).

A unique aspect of reproductive health studies is that parents' accurate knowledge about the adolescents' sexual experiences may contribute to a dyad's overall level of discordance. The management of discordance between adolescents and parents during the recruitment process, specifically for reproductive health clinical trials remains misunderstood, understudied and complicated. Having a greater understanding as to how parents and adolescents discuss their discordance can help study teams ensure that both parties are supported to make a mutually agreed upon or at least acceptable decision.

The purpose of this study is to explore conversations between adolescent and parent dyads about participation in a hypothetical reproductive health clinical trial in order to understand the process and resolution of discordance. Data from this hypothesis-generating study have the potential to inform efforts to manage adolescent-parent conflict during recruitment for reproductive health clinical trials.

## METHODS

### Recruitment and Enrollment

Adolescent (aged 14 – 17 years) and parent dyads (N = 340) were recruited from the adolescent medicine clinics of two large medical centers in New York City, and through snowball sampling (where a participant was referred into the study), to participate in a study addressing attitudes about participation in research via a questionnaire. A subset of these adolescent-parent dyads (n = 186) completed a videotaped joint interview in English,

Spanish or both. The study was approved by the Institutional Review Boards of Columbia University Medical Center and Weill Cornell Medical College (approval AAAI1731), and all participants provided written informed consent/assent.

## Procedures

Adolescents and parents were initially interviewed separately in their language of choice (English or Spanish). Characteristics assessed included adolescent and parent age, ethnicity, gender of the adolescent, relationship of the parent to the adolescent (e.g., mother), and parent educational level. Adolescents' report of their sexual experience was collapsed into those who reported nothing more than kissing versus those who reported some type of sexual contact, including touching, oral, anal, or penile-vaginal sex. Parental report was divided into those who reported that their adolescent had no sexual contact beyond kissing, had sexual contact beyond kissing or the parent did not know.

During the individual interviews, research coordinators reviewed an informed consent document with each individual about a hypothetical study examining the safety of a topical microbicide for the prevention of sexually transmitted infections and human immunodeficiency virus in adolescents. The hypothetical study's consent document described a more than minimal risk randomized controlled trial in which an experimental or control gel would be assigned to each participant. The gel was described as being safe in adult women and was now being tested in adolescent females and males. An in-depth review of the procedures, including the potential risks and benefits of participation, was reviewed. After learning about the hypothetical study, each participant was asked to rank on a 6-point Likert scale his or her *willingness to participate*. Specifically, participants were asked, "If this study were happening today, please rate your agreement with the statement: I would agree to be in the study." Or if read to a parent, "I would agree for my son/daughter to be in the study." Response options ranged from strongly disagree (1) to strongly agree (6) (Catalozzi et al., 2017; Francis et al., 2016; Rosenthal et al., 2016).

After the individual interviews were completed with each dyad member (N = 340 adolescents and N = 340 parents), the first 209 adolescent-parent dyads were asked to complete a videotaped joint interview, with 186 dyads agreeing that they had the time to complete the interview in English, Spanish or a mixture of both (Chavez et al., 2016). During the joint interviews, the dyads were asked to discuss with each other the hypothetical trial described to each of them in the initial individual interviews and how each arrived at their willingness for the adolescent to participate (or not) in the hypothetical trial. The role of the interviewer during the dyad discussion was minimal, and prompts only were utilized when the interviewer needed to clarify participant responses. The conversations were considered complete after each dyad member discussed his or her willingness to participate and declared a final decision about participation.

To explore dyads' resolution of discordance, the transcripts of dyads with strong discordant *willingness to participate* scores were analyzed. Strong discordance was defined by opposing scores, i.e., differences in scores greater than 4. For example, a score of 1 (strongly disagree) was considered discordant if the other dyad member reported 5 or 6 (moderately or strongly agree); the opposite direction (6 vs 1 or 2) was also considered discordant. Prior to the joint

interview, the adolescents and parents were unaware of the other's *willingness to participate* score. These selection criteria resulted in 30 videos averaging 30-minutes in length (range 20 – 45 min).

## Analysis

The dyadic interviews were transcribed and, if needed, translated into English. The transcripts were analyzed in *NVivo* (qualitative data analysis software; QSR International Pty Ltd. Version 11, 2016) by two independent coders. Preliminary codes were generated and independently assigned to each response. Codes were refined until the sub-codes captured the range of responses within each conversation and consensus was reached between the independent coders.

## RESULTS

### Study Sample

Demographics of the 30 dyads are presented in Table 1 reflecting a largely Hispanic sample, with the majority of adolescents reporting minimal sexual experience. The demographic characteristics of the 30 discordant dyads (i.e., age, ethnicity, language, gender, sexual experience) were not statistically different from the 156 remaining, non-discordant dyadic-videos, of which 98 of 156 (63%) of adolescents would have agreed to participate (reported mildly, moderately or strongly agree to participate) and 91 of 156 (58%) of parents also would have agreed to participate.

### Coding Scheme

Content was coded using a conventional framework analysis approach (Hsieh & Shannon, 2005) to code for specific concepts that emerged from the dyadic conversations (Bradley, Curry, & Devers, 2007). Conversations were coded for the direction of the resolution of discordance (the dyad resolved to participate, not to participate, remained in disagreement or remained unclear/undecided). For those that came to a resolution, the time to resolution was noted. Strategies to resolve discordance (asserting authority, grants autonomy, inaccurate assumptions) and communication behaviors (declarative, interrogative, counters, interrupts and repetitive) were the coding structures that emerged from the conversations.

### Direction of the Discordance

Prior to the joint interview, 18 parents did not want their adolescent to participate (reported strongly or moderately disagree) and the remaining (n = 12 parents) wanted their adolescent to participate (strongly or moderately agree). Overall, after the joint interview, of the 30 initially discordant dyads, 21 dyads (70%) came to a resolution: 16 dyads resolved NOT to participate and five resolved to participate. Of note, in each of the five dyads who resolved to participate, all of the parents were initially not interested in participation and were persuaded by their adolescent to agree for their son/daughter to participate in the study. The remaining dyads (n = 9) did not come to a resolution. Two were still in disagreement and seven were unclear or undecided (i.e., needed more time or wanted to discuss with another family member). Neither the demographics nor sexual experience (or parental perception) of the 30 dyads were related to the direction of discordance.

## Time to Resolution

The median time for a dyad to come to a resolution (in either direction) was 2.5 minutes (range 30 seconds – 18 minutes). Overall, four dyads came to a resolution in under one minute, all of which decided not to participate. One dyad finally came to a resolution after 18 minutes, and this dyad also decided not to participate. Of the five dyads that came to a resolution to participate, all conversations were under 3.5 minutes.

## Strategies to Resolve Discordance

**Asserting Authority**—Sometimes one individual in the dyad made it clear that only one person had the final say in the decision. For example, a mother asserted her authority over her 15-year-old son: *“I’ll take his input, you know, because it is his life, but if I don’t agree, I’m not going to ... let it happen ... unless he does it behind my back.”* Asserting authority could also come from the adolescent, as with the following 14-year-old daughter:

I’m just saying that you said that you would let me do it and I’m saying I don’t wanna do it. So that’s two different answers. So I have to come to a conclusion. So it should be up to me to be fine with this.

This strategy was most commonly used to convince in the direction of not participating. In one dyad, however, a 16-year-old adolescent asserted her authority by noting it was her body and her decision to participate:

*I will persuade her [mother] into doing it because it benefits me more than it would benefit her. So it’s like mostly my decision because it’s me.*

**Grants Autonomy**—Some parents changed their initial position about participation when learning of their adolescent’s desire to participate and granted their adolescent the autonomy to make the decision. At times, the adolescent might persistently state a reason for wanting to participate. Then, the parent might grant autonomy for the adolescent to decide about participation, such as the following mother who responded to her 17-year-old son:

I will say no to it but if he decides that he wants to be part of it, usually I will support him...he’ll insist and if he insists that it’s—I have no other choice.

The parent also might grant autonomy for the adolescent to decide not to participate, such as the parent who agreed with her 15-year-old daughter not to participate: *“...your decision is what counts... because it’s her body. So, she’s in charge of her body.”*

**Inaccurate Assumptions**—A few parents recognized they had inaccurate assumptions about their adolescent’s interest in participation. After realizing that their adolescent wanted to participate, a few parents changed their mind to allow for participation, such as the following mother of a 15-year-old son:

I’m just surprised. I didn’t think he would want to, because he’s kind of mushy at times... but maybe times have changed and I don’t know ... he’s saying he wants to do it, then okay.

## Communication Behaviors

Regardless of the direction of the resolution (or lack thereof), the conversations included the following types of verbal communication behaviors.

**Declarative**—statements were the most common method that dyads would use to discuss their discordance about participation. A declarative statement provides a fact or an argument and does not end with a question inflection. For example, a 15-year-old told her mother why she did not want to participate, *“I don’t want them to check down there.”*

**Interrogative**—questions were used within the dyad to elicit more information and for clarification. This did not always move a dyad to resolution, as in the following conversation in which the final decision to participate remained unclear:

**16yo son:** Would you participate in this thing?

**Mother:** What?

**16yo son:** Would you participate?

**Mother:** Yeah. And you? You wouldn’t want to?

**16yo son:** No.

**Mother:** Why?

**16yo son:** Because I don’t know the effects the gel will have ... why do you want to do it?

**Mother:** Because it’s so you’ll have more protection and you can take care of yourself ...

**16yo son:** That’s good that she says yes, but I’m still not going to participate.

**Mother:** Not yet. But when the time comes, would you do it?

**16yo son:** ... I’ll think about it.

The conversation between a dyad often began with interrogation from one dyad member seeking to uncover the other’s viewpoint about participation. The following dyad came to a resolution to not participate in the beginning of the conversation after the mother probed her daughter’s opinion:

**Mother:** You tell me? Will you sign up for it?

**16yo daughter:** I don't know.

**Mother:** You don't want to?

**16yo daughter:** ... *I would not do it because you don’t know the exact risk of using the gel ... They’re putting – making you to put gel in your thingy [vagina]. You don’t even know*

*which gel you're using. Why would you put a gel that you don't know which one it is in your vajay [vagina]? It doesn't sound safe.*

**Mother:** ... I wouldn't force her to do it, if she doesn't want to do it.

**Counters**—Another communication behavior used to discuss discordance about participation was the use of countering statements. For example, a 16-year-old son countered his mother when she described the possible risk of becoming sterile from using an experimental microbicide gel, *“But if I become sterile, it doesn't even matter yet. I'm not even sure if I want a kid.”* Of note, there was no evidence in the consent form of the hypothetical study that there would be a concern about future fertility. In this instance, the adolescent was countering the relevance of his mother's statement. This is a dyad that was not perceived to have resolved their discordance.

**Interrupts**—Another communication behavior dyads would use to discuss discordance was to interrupt one another. In the following example, the dyad did not come to a resolution by the end of their conversation:

**Mother:** To me it's more cons than ...

**17yo daughter:** Can I speak, lady? Okay, let me talk and then you answer. Just like I let you talk. Okay?

**Repetitive**—statements were another mode of communication used to convince the other member of the dyad. For example, a 16-year-old son repeated seven separate times throughout the conversation to his mother the same reason why he wanted to participate in the study, i.e., “to help other people in the future.” The final decision of whether the adolescent would participate remained unclear by the end of their conversation.

## DISCUSSION

In the context of a clinical trial in which the adolescent would participate and the parent would need to provide permission, conflicting decisions about participation among adolescents and parents are likely to resolve quickly. In fact, some dyads came to agreement in under one minute and all of the dyads that decided to participate came to this resolution in under 3.5 minutes. In this study, the process to come to a resolution was difficult and prolonged for only a few dyads. Although most dyads resolved not to participate, there were parents who were easily convinced to participate after a brief discussion with their adolescent. In some cases, this discussion resulted from parents making inaccurate assumptions about the adolescent's wishes. If both parents and adolescents are not engaged in the conversation, there could be missed opportunities to facilitate and best support adolescents' participation in research.

The goal of clinical trialists and study coordinators is to make everyone involved in the decision-making process comfortable with the final decision. This includes limiting barriers for those participants who may want to join a study while at the same time avoiding coercion into a study (Jecker, Wightman, Rosenberg, & Diekema, 2017; Walter & Davis, 2016). In

one study of adolescent and parent willingness to participate in hypothetical asthma research vignettes, 74% of dyads agreed on research participation decisions (Brody, Scherer, Annett, & Pearson-Bish, 2003). For the remaining dyads in disagreement, psychological discomfort (aversion) was a distinct and salient consideration for discordant adolescents and parents about participation (Brody et al., 2003). The strategies used to resolve discordance about participation among the dyads in this study were similar to strategies seen in other studies of adolescent-parent conflict resolution (Behrman, 2016; Semeniuk, Brown, & Riesch, 2016).

This study was specifically about a reproductive health topic, and this topic may have had more of an influence on the communication patterns of these families than the fact that the topic was also about research (McGue, Elkins, Walden, & Iacono, 2005). This would suggest that skills (verbal and non-verbal cues) to help parents and adolescents talk to each other in general might also have relevance for research participation decision-making (Lipstein et al., 2015). Thus, interventions designed to improve adolescent research participation should focus on training recruitment staff in a standardized way to smooth the process of adolescent-parent conflict (Eccleston, Fisher, Law, Bartlett, & Palermo, 2015; Van Lissa, Hawk, & Meeus, 2017). Importantly, recruiters should focus on trying not to be intimidated by conflict between dyads because the conflict may resolve relatively quickly.

For the dyads in which the discordance was not resolved, inherently poor communication in the dyad may have been reflected with a general level of conflict. The communication behaviors used in these conversations may mirror other discordant discussions in the lives of some families, including communication behaviors of being repetitive, interrupting, or the continual acts of countering. Carefully considering the process by which families are offered the option of adolescent research participation (Brody, Annett, Scherer, Perryman, & Cofrin, 2005), and designing interventions to assist families who are experiencing strongly discordant views with certain communication behaviors may be an area ripe for further study. These future studies could improve recruitment procedures as well as help guide the best approach to manage difficult clinical conversations and medical decision-making among dyads in disagreement (Lipstein et al., 2015; Van Doorn, Branje, & Meeus, 2011).

One of the biggest ethical concerns regarding adolescent research participation is when parents give permission and may subsequently coerce a dissenting adolescent into participation (Scherer et al., 2013). In the hypothetical study presented in this study, this situation (parent approves and adolescent dissents) was seen initially in 12 dyads. After a joint discussion, each adolescent's dissent was permitted by the parent who agreed to decline permission, except for two dyads in which the final decision about participation was unclear. Presumably, it was the discussion that permitted time for the adolescent to explain his/her dissenting viewpoint. Parental approval of an adolescent's dissent was found in this study, not parental coercion or undue persuasion to participate, perhaps because this was a prevention study for healthy volunteers and not a treatment study. Certainly, an adolescent's right to dissent could present an ethical issue when the study is for treatment otherwise not available.

Given the importance of both allowing adolescents to participate through a voluntary assent, and protecting the dissent for those that do not want to participate (Brody et al., 2003), our



results suggest the need for a tiered approach to recruitment. The possibility for individual conversations with the adolescent or a joint conversation with both parents and adolescents together may support adolescent decision-making competence (Albert & Steinberg, 2011). If parents are the initial gate-keeper, then some adolescents will not be approached who could participate. In all of our interviews, the adolescent was able to express their reluctance. Research staff should be trained to solicit the adolescent's opinion, to honor the adolescent's right to dissent, and to support the adolescent's involvement in the decision-making process (Miller & Harris, 2012). If there is any question as to whether the adolescent is (or is not) fully assenting, then the adolescent can be interviewed alone to ascertain their thoughts and support their involvement in the decision (Scherer et al., 2013). In the case where the investigator anticipates that the parent might be more interested in participation than the adolescent, the investigator could approach the adolescent first.

Limitations of this study include the "artificial" setting (responses are based on a hypothetical trial and dyads are asked to discuss their decision while being videotaped). The lack of the need to make an actual decision about the clinical trial on the day of the interview may have altered the participants' responses. This study was not a "pure" adolescent-parent discussion in which the dyad discussed the trial naturalistically; this could be viewed, however, as a strength as it may partially mimic the typical setting of assent/permission during a recruitment process in which research personnel may be present. Adolescents and parents were recruited together; thus, this study potentially included dyads that may be in less conflict given the fact that both agreed to enroll into this study together. Finally, the study population was primarily of Hispanic ethnicity. Hispanics, however, are often underrepresented in clinical studies and should be understood in more depth (Murthy, Krumholz, & Gross, 2004).

### **Best Practices**

This study provides a unique glimpse into the conversations between adolescents and parents who disagree about participation in research. As might have been predicted, yet rarely considered, this study shows that dyad discordance may be resolved through brief discussion. In some dyads, the gatekeepers (parents) may think they know what their adolescent's preferences would be regarding research participation (Tait, Geisser, Ray, Hutchinson, & Voepel-Lewis, 2017), but parents might be wrong and easily convinced otherwise. Missed opportunities to enroll initially discordant dyads may be avoided by allowing time for adolescents-parents to elicit information, clarify a situation or convince a dyad member into resolution. Conversely, safeguards against parental coercion of a dissenting adolescent into participation must also be prevented to assure a truly voluntary participant. (Brody, Annett, Scherer, Turner, & Dalen, 2009)

### **Research Agenda**

Communication strategies and behaviors should be the target of future interventions to develop mechanisms to support smooth decision-making regarding adolescent participation in clinical research, particularly in cases where a dyad's conflict is difficult to resolve. Future studies should seek to understand the impact of different communication strategies used among discordant adolescent-parent dyads and consider adolescent-parent-researcher/

physician triad dynamics to improve the assent and decision-making process about adolescent participation (Brody et al., 2009; Brody, Scherer, Annett, Turner, & Dalen, 2006; van Staa & On Your Own Feet Research, 2011). Interventions designed to improve adolescent research participation should also focus on training staff in a standardized way to smooth the process of managing adolescent-parent conflict and possibly increase autonomy-supportive communication (i.e. supportive verbal behaviors to promote motivation) without consuming excessive time or resources. Finally, studies should seek best practices to ensure that staff and parents honor the right of the adolescent to dissent.

### Educational Implications

This study suggests educational implications should focus on training investigators and research staff to manage adolescent-parent conflict during the recruitment and enrollment process. Specific strategies to facilitate adolescent autonomy while respecting parent authority should focus on methods of conflict resolution and appropriate communication behaviors to reach discordant dyads, as seen in the results of this study (i.e. the strategies of asserting authority, granting autonomy or recognizing inaccurate assumptions). Appropriate use of these strategies and safeguards to avoid parental coercion may prove to make everyone involved in the decision-making process comfortable with the final decision, to limit barriers to those participants who may want to join a study, and also to ensure voluntary adolescent participation. In this setting, training staff to manage a discordant dyad may also have downstream benefits for the research study, such as possible enhanced self-efficacy, improved adherence with research procedures, or study retention for dyads able to come to a mutual consensus (Miller, Feudtner, & Jawad, 2017).

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**Table 1**Sample Characteristics of Adolescent and Parent <sup>a</sup>

| Adolescent Characteristics   | Discordant Dyadic Videos | Remaining Dyadic Videos |
|--|--------------------------|-------------------------|
|  | n = 30 (%)               | n = 156 (%)             |
| Age, in years, <i>mean (SD)</i>  | 15.8 (1.09)              | 15.6 (1.06)             |
| Hispanic ethnicity   | 21 (70)                  | 124 (79)                |
| Spanish language (yes)   | 11 (37)                  | 79 (51)                 |
| Female   | 19 (63)                  | 98 (63)                 |
| Highest Level of Intimacy Reported by Adolescent                                       |                          |                         |
| • Nothing more than kissing  | 19 (63)                  | 98 (63)                 |
| • Touching, oral, anal, or penile-vaginal sex  | 11 (37)                  | 58 (37)                 |
| <b>Parent Characteristics</b>  | <b>n (%)</b>             | <b>n (%)</b>            |
| Age, in years, <i>mean (SD)</i>  | 46.6 (7.5)               | 44.1 (7.5)              |
| Hispanic ethnicity   | 20 (67)                  | 121 (78)                |
| Relationship to Adolescent   |                          |                         |
| • Mother   | 29 (97)                  | 140 (90)                |
| • Father   | 1 (3)                    | 9 (6)                   |
| • Other (GM, GF, aunt, uncle, stepmom, stepfather)                                     | 0                        | 7 (4)                   |
| Education Level  |                          |                         |
| • Did not finish high school   | 10 (33)                  | 49 (31)                 |
| • Graduated high school or some college  | 4 (13)                   | 35 (23)                 |
| • Graduated college or advanced degree   | 16 (54)                  | 72 (46)                 |
| Parents' Belief that Child Has Experienced Touching, Oral, Anal, or Penile-Vaginal Sex |                          |                         |
| • No   | 15 (50)                  | 64 (41)                 |
| • Yes  | 7(23)                    | 43 (28)                 |
| • Don't know   | 8 (27)                   | 49 (31)                 |

GF = grandfather, GM = grandmother, SD = stand deviation

<sup>a</sup>There was no statistically significant differences (at  $p < 0.05$ ) in participant characteristics between the discordant dyads (n = 30) and the remaining dyadic video groups (n = 156); t-test used for continuous variables (age) and chi-square test for remaining categorical variables.