Original Study

Adolescents and Their Parents Differ on Descriptions of a Reproductive Health Study

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A B S T R A C T

Study Objective: To understand how adolescents and parents describe a sexually transmitted infection prevention study to a friend.
Design: Adolescents and parents participating in a study about willingness to participate in a hypothetical microbicide clinical trial were interviewed separately and asked to describe the clinical trial to a friend. Qualitative responses were written down verbatim and coded using a thematic framework analysis.
Setting: Adolescent medicine clinics in New York City.
Participants: The participants consisted of adolescents, 14-17 years old, and a parent (n = 301 dyads) who spoke English or Spanish. Most adolescents (72%) identified as Hispanic and 65% reported minimal sexual experience (ie, nothing more than kissing).
Interventions: None.
Main Outcome Measures: Qualitative responses were content coded for: (1) overall approach; (2) opinion rendered; and (3) details mentioned using thematic framework. The relationship of demographic characteristics, sexual history, and recruitment method to how adolescents and/or parents described the study was evaluated.
Results: Adolescents (n = 293) differed from parents (n = 298) in their overall approach to describing the study ($P < .01$) with more adolescents than parents providing a "purpose with detail" (54% adolescents vs 31% parents) and less providing a "commentary" description (6% adolescents vs 28% parents). Fewer adolescents (25% of n = 301) provided an opinion compared with parents (75% of n = 301; $P < .01$). A greater proportion of adolescents (70% adolescents, n = 206; vs 48% parents, n = 144) provided a detail ($P < .01$). Adolescents provided a greater number of details than parents ($P < .01$).
Conclusion: Adolescents in this sample were more focused on the details of the study. Parents were focused on their impression of the study. Adolescents and parents might need to be approached differently about reproductive health studies.
Key Words: Adolescent parent dyads, Reproductive health, Recruitment, Descriptive

Introduction

Because of the continuing public health problem of sexually transmitted infections (STIs),[1,2] the development of new biomedical options, such as microbicides are needed.[3] With adolescents as a high-risk group for STIs,[1,4] the safety, efficacy, and acceptability of microbicides will need to be evaluated in this age group.[5] Understanding how adolescents and parents view and describe reproductive health studies might foster strategies to enhance adolescent enrollment.

Particularly for phase I clinical trials (eg, microbicide safety studies), it is highly likely that parental consent and adolescent assent will be required. However, parents and adolescents might approach potential participation differently. Studies show that predictors of parental consent for their adolescent's participation in sexual health research include parents believing that their teenager is already sexually active[6] or parents perceiving a benefit for their adolescent to participate, such as the adolescent receiving sex education.[7] Others show that adolescent predictors of participation focus on the role of peers,[8–10] altruism,[11–13] privacy assurance,[14,15] and compensation or incentives.[16]

One way to understand how adolescents and parents perceive a study is by examining how they would describe it to their respective peers. Their descriptions might reflect salient aspects which, in turn, might affect study recruitment, final decision-making regarding participation, and/or retention.[17–19] Understanding the information about studies that adolescents and/or parents might share with their peers in the community might provide insight regarding the use of snowball sampling (in which an individual is referred into the study by a current study participant), respondent-driven sampling (chain referral sampling with good estimates to compensate for any nonrandom selection often used when accessing hard-to-reach populations), or community advisory boards (using representatives of the general public to advise representatives of an institution about research recruitment and/or design).[20–22]

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Thus, we analyzed adolescent and parent responses to "how they would describe a hypothetical phase I microbicide clinical trial to a friend" after being read a consent form for such a trial. We examined adolescent and parent's overall approach to describing the study, if they expressed opinions while describing the study, and finally, what details they chose to include. We evaluated whether demographics, sexual history or recruitment method influences how each group (adolescent and parent) chose to describe the study.

Materials and Methods

Recruitment and Enrollment

Participants were recruited from the adolescent medicine clinics of 2 large medical centers in New York City, and through snowball sampling (in which an individual is referred to the study by a current study participant), to participate in a longitudinal survey study on willingness to participate in a hypothetical clinical trial on the safety of a topical microbicide in adolescents. To be included in the study, the adolescent (14-17 years of age) and their parent and/or legal guardian had to agree to participate and speak either English or Spanish. The study was approved by the institutional review boards of Columbia University Medical Center and Weill Cornell Medical College, and all participants provided written informed consent and/or assent. Only baseline data were used for the present analysis.

Procedures

At baseline, adolescents and parents were interviewed separately with a research assistant who read a structured interview aloud in the participants' language of choice (English or Spanish) and participant responses were written down verbatim by the research assistant. Demographic characteristics assessed in the interview included adolescent and parent age, Hispanic ethnicity, sex of the adolescent, relationship of the parent to the adolescent (eg, mother), and parent educational level. Adolescents' report of their sexual experience was collapsed into those who reported nothing more than kissing vs those who reported some type of sexual contact—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 was not sure.

Research coordinators reviewed an informed consent document with each individual about a hypothetical study on the safety of a topical microbicide for STIs and/or human immunodeficiency virus prevention in adolescents. The hypothetical study's consent document described a randomized controlled trial in which an experimental or control gel would be randomly assigned to each participant to use once daily for a week. The gel would be applied intravaginally, or topically to the penis, and the adolescent would be asked to abstain from sexual contact during use. The study duration was approximately 1 month, which included 3 study visits, each consisting of a genital exam, blood draw, urine test, and answering a series of questions. Total compensation for participation in this hypothetical study would be $300 cash plus round-trip subway fare at each visit.

After listening to the hypothetical study's informed consent, each participant was asked, "If you were to describe the study to one of your friends (or the parent of the adolescent's friend) what would you tell them?" Responses were written down verbatim.

Analysis

All written responses were coded in NVivo (qualitative data analysis software; QSR International Pty Ltd, version 10, 2012) by 2 independent coders. The coders used a thematic framework analysis approach to code for specific themes that emerged from the responses.[23] Preliminary codes were generated and modified until the subcodes captured the range of responses within each theme and consensus was reached between the independent coders. The participant responses were coded for content using 3 major themes. First, the responses were coded into mutually exclusive themes representing the main approach used by the participant to describe the study (overall approach). Second, regardless of overall approach, we coded whether the participant rendered an opinion of the study (opinion), and third, how many and which specific details were mentioned (detail).

Within the 3 themes, codes were given numerical scores for quantitative analysis. Bivariate analysis using χ^2 tests were used to compare rates of overall approach, opinions, and details between adolescents and parents. In addition, we examined the frequency of details mentioned using the Wilcoxon rank sum test for nonparametric distributions to compare counts of details between adolescent and parent groups. For evaluation of associations between demographic characteristics, sexual history, and recruitment method, and the adolescents' or parents' overall approach to describing the study, we used bivariate analysis (χ^2 or analysis of variance) to explore possible relationships using SAS version 9.4 (SAS Institute Inc, Cary, NC).

Results

Study Sample

Three hundred forty-three families were enrolled; 1 family withdrew and was not included in any analyses. Two families enrolled twice and only their initial data were included. In an examination of the demographic characteristics of those approached through clinic or snowball sampling (in which an individual is referred to the study by a current study participant), there were no differences with regard to sex, Hispanic ethnicity, or age of the adolescents between those who participated and those who did not. Of the 340 adolescent-parent dyads, there were 31 families with 2 siblings, and 4 families with 3 siblings per family. Because these parents were asked to describe the hypothetical study twice, only the first adolescent-parent dyad was retained for analysis. Thus, our final analysis included 301 unique adolescent-parent dyads.