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Focus Groups With Deaf and Hearing Youths in Brazil: Improving a Questionnaire on Sexual Behavior and HIV/AIDS

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The authors' aim is to describe the analysis of focus group discussions with deaf and hearing adolescents. They conducted focus groups to improve a questionnaire that will be computerized to assess the knowledge about HIV/AIDS and sexual behavior and attitudes of deaf and hearing youths in the south of Brazil. They developed four groups each with three participants aged 18 to 20 years, grouped by gender and hearing status. The analysis emphasizes discourse units formed by a portion of consecutive or nonconsecutive statements by several speakers and that developed around a topic of discussion. The main aspects improved in the questionnaire, adding confidence and reliability to the research, were choice of words or expressions, contextual differences between the target population and the researchers due to age and cultural and educational backgrounds, and the appropriateness of content in questions and answers.

Keywords: *focus groups; deaf and hearing youths; sexual behavior; HIV/AIDS*

Recent studies aiming to identify sexual attitudes and behaviors of youth as well as their knowledge about sexually transmitted infections (STIs) and HIV/AIDS have increased in Brazil in the past few years. However, very little information and scarce research can be found on people with special needs (Groce, 2003; International Disability Rights Monitor [IDRM], 2004). Among some of the most marginalized in the world today, the deaf and hard of hearing and individuals with visual, mental, or physical impairments account for 14.5% of the population of Brazil (IDRM, 2004). They are more likely to live in poverty, be illiterate and unemployed, suffer sexual abuse, and be forgotten in public prevention campaigns and health care programs. Adolescence is a vulnerable period of life per se because of all the psychosocial and physical changes that occur; consequently, it is not hard to imagine that adolescents who live with a disability face some extra challenges.

It appears to be difficult for researchers to address and include this population in their research efforts. In the case of the deaf youths, this difficulty might be explained by language barriers. First, most deaf people prefer sign language as their means of communication. Sign languages are semiotic systems of gestural communication that have a morphology, lexicon, and grammar of their own as well as the communicative potential of a spoken language (Nöth, 1990). Second, the communication difficulties that hinder the ability of the deaf and hard of hearing to acquire accurate information and to access education and health care (Baker-Duncan, Dancer, Detholyn, Highly, & Gibson, 1997; Job, 2004) might also explain the barriers for standard methods of data collection among the deaf. However, according to Goldstein and Lipton (1997), researchers must address

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the difficulties of creating culturally and linguistically sensitive data collection strategies. On the cultural level, Barnett (1999) has reminded us that the deaf community shares some important characteristics with other minority groups: They tend to socialize and partner within community, they share cultural norms different from those of the majority community, and they often encounter prejudices that limit opportunities. Consequently, it is important to recognize that the language differences, health knowledge limitations, and cross-cultural research issues add to their vulnerability.

Because our objective is to collect information regarding Brazilian deaf and hearing youths' HIV/AIDS knowledge and sexual attitudes and behavior, we decided to conduct focus group discussions with both groups of youths before finalizing a questionnaire. For the development of the questionnaire we adapted questions from a study with adolescents conducted in São Paulo by Figueiredo and Peres (2002) and from the Adolescent AIDS Knowledge Scale (Zimet, 1998). The adaptations made followed the general guidelines proposed by the *Guide to Monitoring and Evaluation* (UNAIDS, 2000) and the *Epidemiological Fact Sheet: 2004 Update* (UNAIDS and World Health Organization [WHO], 2004). We added a few questions to address specific issues of the deaf population. We felt that this procedure would enable us achieve higher levels of suitability for our instrument. Ultimately the questionnaire will be adapted to a computer-based format (CASI) that allows simultaneous video translation to Brazilian Sign Language (Libras).

The study we present here describes the process of analysis of these focus group discussions conducted during 2006 in southern Brazil. Focus groups have been used in research as a technique to explore the psychosocial and cultural characteristics of a target population and (a) to improve the process of formulating questionnaires or other assessment tools, (b) to provide additional data collection strategies in qualitative studies that use observation or in-depth interviews, (c) to provide additional data collection strategies in quantitative studies like surveys, and (d) to develop interventions (Carlini-Cotrim, 1996; Kidd & Parshall, 2000; Westphal, Bógus, & Faria, 1996). The use of focus groups is valuable because they are a collective activity directed by a facilitator or moderator who keeps participants focused on a discussion that was carefully planned, such as exploring a particular set of questions (Owen, 2001). In Brazil this method has been used consistently since the 1980s.

The use of focus groups with the deaf and hard of hearing, however, is rare. Goldstein and Lipton (1997) chose this method to test a questionnaire about substance abuse that was going to be used in a video-formatted survey. The discussions we made in the focus groups with the deaf and the hearing youths offered the possibility for correcting mistakes and improving (a) the language, that is, the choice of words or expressions to better fit what is usual for youths and for deaf youths; (b) the context, that is contextual factors and differences due to age, culture, and educational background between the target population and the researchers; and (c) the content, meaning the appropriateness of content in questions and answers relating to youths' experiences and background.

Method

A convenience sample based on volunteerism and balanced by age and gender was used to form the groups. The deaf participants were contacted in the public special school for the deaf in the city of Caxias do Sul, in the south of Brazil, and the hearing participants were contacted in a public regular school in the same neighborhood. All the groups were conducted at the schools' facilities. The 6 deaf and the 6 hearing youths were aged 18 to 20. They were grouped together by gender and hearing status into four groups, each with 3 participants. The deaf participants communicate mainly in Libras. They study in the morning or evening, and some have part-time jobs. They are all delayed in terms of their grade level, considering that the average age for completing secondary school in Brazil is 14 or 15 years. Five of the hearing participants had just completed secondary education but did not continue their studies; all have full-time jobs. The deaf youths all come from hearing families, consistent with statistics that report that the majority of the deaf children (approximately 90%) have hearing parents (Barnett, 1999; Job, 2004). At home they usually use sign language with one or two members who have learned some but usually are not very fluent (in most families it tends to be the mother and a brother or sister) and a mix of other resources like lipreading or writing short messages with other members. The limitations in the communication between hearing parents and their deaf children are well documented in the literature as well as its possible effects on the development of the deaf child.

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We followed the work of Goldstein and Lipton (1997) for the use of simultaneous translation to sign language, which was made by an official Libras interpreter and tape-recorded.

The groups had three members to minimize the difficulties caused by the translation process. The groups were conducted by the research investigator (moderator) and observed by a research trainee. The research investigator knew Libras, was a trained psychologist, and had developed therapeutic groups with deaf adolescents.

Before the beginning of each group, the informed consent was presented to participants and translated to sign language in the groups with the deaf. After the consent was signed and permission to tape-record was given, we started the discussions. Each participant received a copy of the questionnaire and was told that he or she did not need to answer the questions but was asked to think how appropriate the questions and answer choices were. The moderator read each question, and then the discussion took place with the translation made by the interpreter (Libras-Portuguese). We tried to keep an informal and comfortable setting and encourage diversity of opinions among group members.

The analysis of the unabridged transcriptions of the focus groups was aimed at improving the questionnaire. According to Kidd and Parshall (2000), there is controversy about whether the individual or the group is the unit of analysis in focus group interviews. They suggested that both must be considered focuses of analysis but that the unit of analysis can be the meaningful discourse units, which might well incorporate a portion of consecutive (or even nonconsecutive) statements by several speakers, representing multiple, and at times conflicting, viewpoints. We followed their group perspective, considering discourse units that developed around a topic of discussion. Samples of these discourse units are presented below and are termed interaction excerpts. Each intervention (modification in the questionnaire) made after a group session was related to a discourse unit. Some of these units can be thought of as personal narratives that emerged during more conversational moments of group interactions. In this perspective of analysis, it is the group interaction that allows perceptions, attitudes, and beliefs to emerge, and insights happen that otherwise, without the dynamic of the relations that happen in the group, would not arise (Carlini-Contrin, 1996; Nogueira-Martins & Bógus, 2004; Winslow, Honein, & Elzubeir, 2002).

We also followed the methodological approach of Vogt, King, and King (2004) regarding new or redundant items. We did not develop specific decision rules for exclusion or inclusion of information gained from focus groups. When we felt that we had new information that was unaddressed previously, we made inclusions; when we felt that questions were redundant or easily misunderstood or the content was of limited meaning, we made substitutions or eliminated items or questions.

Results

Gender Issues

Although participants were told that there was no need to disclose personal information, some comments arose spontaneously during the group interactions. Two deaf girls revealed they had already had sexual relations; one of them was dating, and the other was not. One deaf girl had a boyfriend but said that she was going to wait to have sex after marriage, mainly because her parents are very controlling about her behavior. A similar situation was seen with one of the deaf boys but was associated more with a personal choice than with fear of his parents' reactions. One deaf boy said that he had a girlfriend but did not mention whether he was having sexual relations. The third deaf boy was very clear about his sexual relations with several male partners, preferring to have sex with hearing men than with deaf men.

The hearing boys never mentioned girlfriends or sexual relationships. One of the hearing girls had married early in life. She was insecure about her marriage but said that she had married to improve her life. Another hearing girl was dating but did not comment on her sexual life. The third girl did not have a boyfriend and indicated she had never had sex. Although some of her girlfriends and acquaintances tell her that she is losing out and does not know how to live her life, she said that she is waiting for the right moment and the right person. Later in the group discussion, she explained that she is afraid of sex because her father died with AIDS.

Results show that both the deaf and hearing girls communicated more and brought out details about their personal lives spontaneously. The boys, except for one deaf boy, preferred direct answers and kept more to the objectives of the focus group. Similarly, Maynard-Tucker (2000) found that women speak more openly than men during group discussions. We think that in our case, the sensitivity of the topic of discussion (sexuality) and the fact that the moderator was a woman were the reasons for the difference. It is possible that boys

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would have expressed themselves more freely if the moderator had been a man. According to Vogt et al. (2004), participants' comfort and candidness might depend, at least in part, on the person who is asking the questions, especially when examining some sensitive topics that can be directly influenced by gender.

The comments made by the deaf boy who had sex with men caused a level of discomfort for the other deaf boys but no clear reaction of nonacceptance. This participant brought the topic of homosexuality to the group discussion as well as his preoccupation with prejudice among the deaf and his worries about the way in which children learn and are exposed to sex experiences, which was probably related to his life history. This is one rich example of how focus group discussions can enlighten researchers about new topics for further research projects.

Language, Communication, and Interaction

In all four groups, both the deaf and the hearing, there was a high level of participation and interaction. We followed Owen's (2001) perspective:

> Focus groups explicitly exploit group interaction as part of the method. This means that instead of the researcher asking each person to respond to a question, people were encouraged to talk to one another, exchange anecdotes and comment on each other's experiences and points of view. (p. 655)

In the first group (Group 1: deaf girls), the discussion was broken into two sessions of 1 hour and 30 minutes each because of the emergence of several lengthy personal narratives. The analysis of the unabridged transcription of the group discussions led to 33 interventions in the questionnaire. The second group (Group 2: deaf boys) received the improved version. Their discussion led to 28 interventions and lasted 1 hour and 30 minutes. Seven interventions were made after the third group (Group 3: hearing boys). The forth group (Group 4: hearing girls) lasted for 1 hour and led to 10 interventions. The low number of interventions from Groups 3 and 4 can be explained primarily by the system we adopted for improving the questionnaire after each group. Repeatedly revising the questionnaire using information from each focus group resulted in the creation of a new and improved version of the instrument each time a group ended. In addition, the interventions were higher in Groups 1 and 2 because the deaf participants were very attentive to making the vocabulary in both the questions and the answers clear and accessible for their peers to understand. In the appendix, we present the first and final versions of the questionnaire.

Two difficulties must be considered. First, the direct translation from Libras to Portuguese and its transcription present some limitations that affect the analysis of the structure of the sentences or text construction; consequently, the direct translation is much more an interpretation than a real "translation." However, we believe that this limitation in the translation/transcription process does not prevent us from analyzing the content or the themes developed by the focus groups, nor does it influence our ability to pay attention to the suggestions made by the deaf about the phrasing in Portuguese. The second difficulty refers to the management of individuals taking turns to talk during the session. It is difficult to regulate participation during group interactions in which interaction is highly motivated. For the analysis, we chose to focus on the interactions and not the individuals, so we did not worry about identifying the participants in the interaction excerpts.

Even though the deaf participants were aware that there would be simultaneous video translation to Libras during the application of the questionnaire, they were worried about the Portuguese format. This highlights the importance of these two linguistic contexts as well as the difficulties they face dealing with them. The discussion of Question 25—Can a person get AIDS by sharing syringes or needles used by someone that has AIDS?—is transcribed below and is a good example of this issue. Note that the discussion begins with participants questioning the use of the word *share*. In this interaction excerpt from Group 1, the investigator provides an explanation, a participant tries to understand the word *share* in the context of needles and syringes, and the investigator then understands that the problem is with the whole sentence:

Investigator: Ok. [question] Twenty-five.
Interpreter: Share?
Investigator: Use the same syringe.
Interpreter: Share everything, needle and syringes.
Investigator: Is it too long?
Interpreter: Everything [is difficult], needle and syringe.
Investigator: Ah.
Interpreter: Separate what is share and what is needle and syringe./ No, you need to change the word, meaning share./For instance, share, what is share?/ Needle, what is it? Needle is fine, they [the deaf]

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Table 1
Interventions per Category and Group

Category	Group 1	Group 2	Group 3	Group 4	Total
Simplification of the question					
Withdrawing words	4	5		1	10
Substituting words	24	3	2	1	30
Improvement of the question					
Introducing words	2	2	3	2	9
Reordering terms	2	4			6
Transforming into affirmative mode		2			2
Transforming into interrogative mode		12			12
Improvement of the answer	1		2	6	9
Total	33	28	7	10	78

Note: Group 1 = deaf girls; Group 2 = deaf boys; Group 3 = hearing boys; Group 4 = hearing girls.

understand. What is syringe? It has syringe [pointing to the word]. Syringe./ She didn't know [comment of the interpreter referring to a participant].
Investigator: Here, see, needle, you know [making the sign and pointing to the word].
Interpreter: Syringe, they didn't know [final comment of the interpreter referring to the three participants].

In the final format of the questionnaire, the word *share* was changed to the expression "use the same." The word *syringe*, however, cannot be replaced or removed. Consequently, this is where we will count on the simultaneous video translation to sign language, so deaf participants can choose to watch a video to elucidate the meaning of a question that could be easily misunderstood because of language differences.

This example shows the tremendous importance of the simultaneous video translation and raises the question of the validity of the numerous studies performed with the deaf that were based exclusively on written instruments. According to Pollard (2002), developing research methods that are appropriate to the cross-cultural setting that characterizes the deaf and hard-of-hearing experience is a great ethical challenge. The results highlight the risk of bias in data gathering and evaluation methods that might arise from the different sensory and, often, sociocultural experiences of the deaf and hard of hearing in contrast to hearing people.

With the help of the deaf participants in the focus groups, we were able to reach better levels of comprehension for some questions written in Portuguese. One example was the strategy of reordering terms. Questions that determined time periods were originally formulated as follows: How many people did you have sex with in the past 12 months? The difficulty for comprehension was related not to the vocabulary but to the order of the terms in the sentence. In Libras, "past 12 months" would preferably be placed in the beginning of the sentence and not at the end. As these discussions appeared in Groups 1 and 2, we decided that reordering to "In the past 12 months how many people did you have sex with?" would not hurt the structure of written Portuguese and would make it more similar to the structure of sign language, thus facilitating comprehension.

The Categories That Guided the Analysis

In Table 1 we present the categories that were used to organize the different kinds of interventions made in the questionnaire after each focus group session. The category Simplification of the Question includes the modifications made by withdrawing or substituting words in a way that it did not affect the meaning of the question as it was originally conceived. In the category Improvement of the Question, we see semantic changes made through the strategies of introducing words, reordering terms, and transforming into affirmative mode or interrogative mode. The category Improvement of Answer groups together the modifications made in the answers, either by changing words or expressions or by creating new items for the alternatives offered.

It can be seen that Group 1 was preoccupied primarily with finding synonyms that would facilitate the comprehension by their deaf peers. Therefore, they kept suggesting substitutions for the words that they could not easily understand. The major effort in Group 2 focused on standardizing questions by transforming them into the interrogative mode. They felt

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more comfortable when questions and answers followed similar patterns. It is possible that participants in Group 2 were free to focus on other issues rather than the vocabulary because the major wording issues were fixed by Group 1. Group 3 clarified some questions by introducing words and Group 4 was concerned primarily with the answers. They showed great interest in thinking of possible alternatives that would better represent adolescents' interests and lifestyle. Focus groups are commonly used as a way to list possible alternatives for answers, but as we can see in this article, this is only one of the benefits they bring to the research process.

Modifying Questions

The process of improving a question following the suggestions made during each of the four focus groups, until it emerges in the final format, can be seen in the example that follows: Note the substitutions, the introduction of words, the transformation into interrogative mode, and the improvement of answers. The translation to the English language was made in such a way as to represent the structure in Portuguese. In some circumstances, the translation to English makes it difficult to represent in detail the process that the groups developed. The initial question was "A person doesn't need to worry about HIV/AIDS if he or she has a regular partner. / ☐ yes ☐ no ☐ I don't know":

> Group 1: A person doesn't need to worry about AIDS if he or she always has the same boyfriend. / ☐ yes ☐ no ☐ don't know

> Group 2: A person doesn't need to worry about AIDS if he or she always has the same boyfriend. / ☐ yes ☐ no ☐ don't know

> Group 3: A person doesn't need to worry about AIDS if he or she always has the same boyfriend/girlfriend or partner. / ☐ yes ☐ no ☐ don't know

> Group 4: Does a person need to worry about AIDS if she/he always has the same boyfriend/girlfriend or partner? / ☐ yes, she/he does ☐ no, she/he doesn't ☐ don't know

Many of the simplifications made by withdrawing or substituting words or transforming into interrogative mode led to clearer and more direct questions or alternatives that did not change the meaning and at the same time facilitated the comprehension. For example, after the comments from Group 1 were evaluated, the item formerly presented as "You can always tell if someone has HIV/AIDS by looking at them" was altered to "You can always tell if someone has AIDS only by looking at them." After Group 2 the question was finally improved to "Can you tell if someone has AIDS only by looking at them?"

There were other suggestions involving removing words that had greater implications than facilitating comprehension. This is shown in the interaction excerpt from Group 1, a unit of analysis in which the interaction develops around the use of the term *HIV/AIDS*. The final decision was to withdraw the word HIV in most of the questions where it appeared:

> *Interpreter:* Ok. The deaf, for the deaf it is hard to understand what HIV is, what AIDS is. Some deaf people are not going to understand the meaning of it, are they? The writing HIV/AIDS. How are they going to understand? How?/ They easily think of AIDS, and not HIV./ The deaf think . . .
> *Investigator:* The deaf don't know?
> *Interpreter:* They think it is not important HIV. That's the point./Ah, they don't know what HIV is, they know there is AIDS, but they don't know what HIV is./ It is an issue of the sign.
> Investigator: AIDS.
> *Interpreter:* The point is that in sign language you don't use HIV/ HIV, for HIV there is no [sign].
> *Investigator:* The suggestion is to put only AIDS?
> *Interpreter:* The deaf will keep thinking, will have doubts about HIV, but they know what AIDS is.

Although this simplification implies a conceptual difference, we considered that it was more important to make the question as clear as possible. The doubt about the vocabulary that the deaf participants presented refers to more than a simple matter of choosing a word. The difficulty to differentiate the concepts of HIV and AIDS can be seen in the next interaction excerpt from Group 1, which refers to Question 23, "Can a person have the HIV virus without being sick from AIDS?" The two groups of deaf youths were not familiar either with the word *HIV* or with the word *virus*. Not knowing the vocabulary signifies a lack of general knowledge:

> *Interpreter:* Twenty-three. What did you understand? [A] Person has HIV, but is not worried if [he/she] will

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transmit AIDS to another person, if [he/she] has AIDS. [A] Person is not worried if he/she has AIDS, it is a little confusing, I do not . . .
Investigator: Ok, that's her opinion, hard for the deaf to understand.
Interpreter: What HIV and AIDS are. / HIV-AIDS, compare the two things.
Investigator: Ok, ok, doubt?
Interpreter: I agree with what Participant 1 said before. [The] deaf do not understand what HIV is, for example, [they] know what AIDS is. What is the difference between them? What is different? It is not clear this one.
Investigator: Ok then. Ok. And you?
Interpreter: I agree with what Participant 1 said.

Public campaigns about HIV/AIDS normally use these terms and are broadcast extensively through the media in Brazil. The fact that the deaf participants were not familiar with this vocabulary raises questions related both to the quality of school basic education and to the exclusion of these groups from the majority's language-based information that could have positive effects in terms of preventing sexually transmitted infections. This was the major difference that appeared between the deaf and the hearing groups during our focus groups. The hearing youths did not express any doubts about vocabulary or concepts.

The words that were substituted or withdrawn attest to the level of attention to details and involvement that both Groups 1 and 2 showed concerning the task of making the written questionnaire accessible to their deaf peers. The question in the first version, "A person that has unprotected sex with someone who has HIV/AIDS can get HIV/AIDS," was modified to "A person that has sex with someone who has AIDS without protecting herself with a condom can get AIDS" after Group 1. Later, it was improved again by Group 2: "Can a person that has sex with someone who has AIDS without using a condom get AIDS?"

In Table 2 we present the examples of changes in vocabulary after the focus groups with the deaf participants, following their suggestions for synonyms that would be more easily recognized by their deaf peers.

There is another group of words that was substituted that refers much more to the context and vocabulary common to adolescents rather than using an academic vocabulary. These last interventions show that the cultural contexts of the researchers and the target population tend to be different, even if the researchers are careful and have some level of immersion in the culture of the target group. Examples can be seen in Table 3.

Table 2
Examples of Changes in Vocabulary After the Groups With the Deaf Participants

Before the Focus Groups	After the Focus Groups
Unprotected sex	Sex without a condom
Sexual intimacy	Take off your clothes, touch your body without your permission, or force you to have sex
High risk of getting HIV/AIDS	Easier to get AIDS
Can lower a person's chance	There is less chance
Transmit[a]	Give to[a]
Sharing	Using the same
Treatment[a]	Pills[a]
Sex worker	Prostitute (whore)[b]
Verify/examine[a]	Check[a]
Allergy	Itching

a. Differences that can be seen only in the Portuguese version.
b. Question removed later.

Table 3
Examples of Changes in Vocabulary After the Groups With the Hearing Participants

Before the Focus Groups	After the Focus Groups
Sexual intercourse	Have sex
Check your sexual health	Check your genitals (vagina, penis)

Participants tried to improve questions by introducing words. This kind of intervention differs from the previous ones in the sense that it shows a preoccupation with the content of the information being asked. In the examples that follow, the introduced word(s) are shown in the brackets:

Group 1: [Without using condoms], can you get AIDS by having anal sex with someone who has AIDS?

Group 3: Can a pregnant woman with HIV give [HIV] to her unborn baby?

Group 4: Using condoms [properly], is there less chance to get AIDS?

It is important to note that improving the questions by reordering terms, as previously shown, did not happen in the hearing groups. The difference is related to the

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characteristics of the structure of sign language compared to Portuguese and other oral/written language systems. As mentioned before, one of the main concerns of Group 2 was to standardize questions, transforming the ones that were not direct questions into direct questions. They also were careful about transforming the negative form formerly adopted in some questions to a positive format. This last intervention enabled more accurate comprehension and avoided possible inconsistencies in the answers due to misinterpretation.

Improving Answers

The attention to general characteristics, to the sociocultural context, and to the possible experiences of the young people that the questionnaire aims to assess can be seen in the suggestions made to improve the answers. They were the primary focus of attention for Group 4, but some examples can also be found in the other groups. The possible answers for the question on marital status, for instance, were modified by Groups 3 and 4. This question first appears in its traditional format after the suggestion from Group 2 of introducing this question in the beginning of the questionnaire. Comments made in Group 3 revealed that the alternative "single" does not adequately express all the possible ways to establish relationships that the young people see in the world today. Following incorporation of the suggestions from Group 4, the alternatives for the answer are: (you) are not dating nor staying with anyone at the moment, date without commitment, have a boyfriend (girlfriend) or partner, or are married or live with partner. The interaction excerpt that follows shows how the process developed in Group 4:

> *Investigator:* Then read Question 4. See how you would answer, if it would be good for you.
> *Participant 1:* I am not committed to anybody.
> *Investigator:* Ok, then.
> *Participant 1:* There's no possibility for me.
> *Investigator:* Ok, then there is one alternative that is missing here. Then it is missing one alternative that would be kind of . . . "is not committed to anybody at the moment," something like that?
> *Participant 1:* Something like that. (. . .)
> *Participant 2:* All right, I think this is ok because for me is "has a boyfriend," I have a boyfriend.
> *Investigator:* Fine. For you, Participant 3, do you think there is another alternative that should be included here or everything is correct?
> *Participant 3:* I am married.
> *Investigator:* You are married. So, if I write . . .
> *Participant 1:* There's people that only "stay," "stay," "stay."
> *Investigator:* If I write, ah, the first alternative "is not committed to anyone at the moment," then it would be ok for everybody?
> *Participant 2*: Yes.
> *Participant 1:* There's people that only "stay," don't date.
> *Investigator:* "Stay" is still the best word to use, isn't it, that's it, everybody uses it, right.
> *Participant 1:* The girls say "stay," the boys, no, they say "I caught that one, I caught that other one."

Narratives

The discussions in the focus groups also led to the substitution, withdrawal, and introduction of whole questions. These major modifications made to the initial version of the questionnaire were developed based on the analysis of interactions that are detailed descriptions of events or narratives. The discussions broadened the researchers' perception about the deaf and hearing youths' life experiences.

One example is the question that was originally written to ask about prostitution. Groups 1 and 2 preferred the word *prostitute* (adding whore in parenthesis) over the term *sex worker*, which was used in the initial version. Analysis showed that this question was not very relevant in the groups with the deaf, but some narratives pointed to situations where older deaf people were paying young kids for kissing, touching, or having sex. Therefore, it was later modified to "Has someone ever given you money, drugs, or gifts in exchange for having sex with you?" and "Have you ever given someone money, drugs, or gifts in exchange for having sex with someone?" We understand that it changes the meaning of the former question because the new questions are not specific about the relation between the adolescent and sex workers. However, we also understand that the modified version allows us to investigate some risk behaviors that involve sexual exploitation among this group that can happen with both boys and girls, as it was described as happening at the school facilities. The interaction excerpts transcribed below are from Groups 1 and 2:

> Group 1: Within the deaf group, see, sometimes it happens that a smarter deaf guy will pay, for example, an older deaf [will pay] [to] a younger deaf, I give one dollar, got it? (. . .) It already happened in the school, in the restroom, sometimes they talk. Nobody sees, it is quick. Get out. There's a lot.

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> Group 1: I remember a man that asked me to have sex, he would pay 50 bucks. / Deaf or hearing? / Ah, deaf. He asked only to take advantage.
>
> Group 2: And also [the] deaf [boys] provoke go, go, go, get a stupid deaf [person], ah, all right, I go. That's it, a lot. Then you get used [to it], then you feel like it, you feel like having sex.

Participants often seized opportunities in the conversation to tell about their experiences. In these circumstances, individuals knitted together several themes into accounts that have a certain level of coherence and develop around a theme and therefore can be viewed as narratives (Riessman, 1993). These narratives are extremely valuable for helping researchers understand more deeply the target population because they show how individuals organize and attribute meaning to their experiences. One example is the narrative that emerged during the discussion about HIV/AIDS testing. One of the participants started an account explaining that she got tested for HIV/AIDS because her father died with AIDS. Her level of knowledge about HIV/AIDS, the patterns that guided her highly protective sexual behavior, and her general attitudes toward sexuality, family, and friends are strongly related to how she sees her father's illness and death. Consequently, we introduced the question "Do you know anyone who has HIV or AIDS?" with the alternatives for answer being "yes, a friend," "yes, a family member," "yes, an acquaintance," and "no."

Focus groups provide excellent opportunities for researchers to confront the ideas they have about certain real-life social situations. There often is a significant gap between the fast-changing world of young people and the academic world. We know, for instance, that the mean age for the first sexual relationship in Brazil is estimated to be 15.5 for men and 17.8 for women (Ministério da Saúde, 2004). However, the narratives that emerged in the focus groups inform us that one deaf girl is a virgin at the age of 18; one had her first sexual relationship when she was 10, and the other when she was 14 years old. Although estimates or averages allow us to depict a whole population in very general terms, individual stories help us understand the complexity of a group that is highly heterogeneous in its characteristics, demands, and needs. Therefore, in addition to helping researchers better understand the ways in which the people under study perceive and signify their own experiences, focus groups enable researchers to avoid the tendency to impose concepts and perceptions from their cultural beliefs and values that would lead to ethnocentric assumptions and misinterpretation of other cultures' behaviors and experiences (Vogt et al., 2004).

Discussion

Developing focus groups with deaf and hearing youths has proven to be an interesting and valid strategy for refining a questionnaire to be used with deaf adolescents. The participation of hearing youths was important because they expressed the worries and life-styles of the majority of adolescents. The participation of deaf youths provided insight into the deaf community and allowed us to face some of the linguistic difficulties that a bilingual and cross-cultural research setting enhances.

Both the deaf and the hearing participants helped us to gain insight into a topic of research that is sensitive to approach and important in terms of health and emotional development: their knowledge of HIV/AIDS and their sexual attitudes and behaviors. The process of analyzing the interactions that occurred during the four focus groups offered us the opportunity to gain knowledge about the language that members of the deaf youth community and adolescents in general use to describe their experiences, inform the phrasing of items, enhance contextual adequacy, and provide insight into cultural issues. Participants showed high levels of comfort and discussed a range of sexuality issues openly. In some groups, discussions reached a level of comfort that allowed or even encouraged them to narrate personal events of their lives, enriching the process of assessing their experiences and sociocultural contexts. This type of open dialogue can offer researchers the opportunity to gain insights as well as question their own assumptions and their preconceptions. Furthermore, an in-depth analysis of the narratives could be invaluable for elucidating how these adolescents understand themselves and create meaning to their experiences as well providing insight into their social lives and subcultures.

The linguistic difficulties that characterize a bilingual setting make the process of research more demanding and time consuming. However, in such situations the use of strategies that aim to make research instruments culturally appropriate is even more relevant. During the course of the project, several situations occurred where deaf participants appeared to be expressing erroneous information or conclusions due to

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their difficulties with the written language. These situations might result from their lack the linguistic abilities; inadequate school-based instruction; or the linguistic barriers that inhibit incidental learning. Some of the modifications suggested by the deaf were to make the vocabulary easier for their peers by finding synonyms, but some showed there were concepts that were unknown or confusing, like the understanding of what a virus or HIV are.

From the beginning of this project, we believed that our research instrument would need to have simultaneous translation to sign language; this explains our choice of a computer-based questionnaire (CASI). The focus groups with the deaf confirmed the importance of the simultaneous translation to sign language to elucidate the meaning of sentences that otherwise would be misunderstood. Several studies were developed and are described in the literature about the topic of HIV/AIDS knowledge among the deaf population with the use of written questionnaires. These studies do not report having involved the deaf community in earlier stages other than collecting the data or using simultaneous translation to sign language. The analysis we presented here provides evidence that the participation of deaf people in early stages of the research process and the attention to the language difficulties reduce bias and raise confidentiality and reliability for the results obtained later.

We realize that the focus groups could have been more enriching if the groups had been larger; however, the small number of participants in each group allowed us to have better control of the translation process. In addition, we recognize that the decision we made to use the improved version of the questionnaire at each group might have influenced our results. However, it proved to be efficient for analyzing the changes each group made as a process, which was one of our main goals. In future projects, it would be interesting to develop the protocol so that the groups work with the same version and then see what each group produces.

It is also important to consider that as groups develop, researchers would gain knowledge and feel more confident about handling the groups. For example, after our experiences concerning discussions of sexuality issues in the first focus group, we were able to anticipate that there might be an initial discomfort among group members followed by feelings of confidence and freedom to discuss these issues. However, although we learned what to expect, we believe this did not influence the way we conducted the focus groups because the pattern occurred in all of the groups. Consequently, we feel confident that the growth experienced by the researchers did not skew the results.

In conclusion, we feel that the high level of participation of the deaf youths, both boys and girls, their readiness to discuss each question in detail, and their seriousness when making suggestions that would facilitate the process of collecting data among their peers show that even with the linguistic difficulties and cultural differences, it is both important and feasible to include their participation in research processes.

Appendix
First and Final Versions of the Questionnaire

Thank you very much for participating in this project.
Remember: this questionnaire is absolutely anonymous (no names will be used), and there is no such thing as right or wrong answers. Make yourself comfortable and answer the best way you can.

First Version	Final Version
1. Your age (years): ☐ 15 ☐ 16 ☐ 17 ☐ 18 ☐ 19 ☐ 20 ☐ 21	1. Your age (years): ☐ 15 ☐ 16 ☐ 17 ☐ 18 ☐ 19 ☐ 20 ☐ 21
2. Your gender: ☐ male ☐ female	2. Your gender: ☐ male ☐ female
3. Your school grade: ☐ 6° ☐ 7° ☐ 8°—Elementary School ☐ 1° ☐ 2° ☐ 3°—High School	3. Your school grade: ☐ 6° ☐ 7° ☐ 8°—Elementary School ☐ 1° ☐ 2° ☐ 3°—High School
	4. You ☐ are not dating nor staying with anyone at the moment ☐ date without commitment ☐ have a boy friend(girlfriend) or partner ☐ are married or live with partner
4. You are ☐ deaf ☐ hearing [if hearing, skip to . . .] 5. Is your father hearing? yes ☐ no	5. You are ☐ deaf ☐ hearing [if hearing, skip to . . .] 6. Is your father hearing? ☐ yes ☐ no

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Appendix (continued)

First Version	Final Version
6. Is your mother hearing? ☐ yes ☐ no	7. Is your mother hearing? ☐ yes ☐ no
7. Do you have deaf brothers or sisters? ☐ yes ☐ no	8. Do you have deaf brothers or sisters? ☐ yes ☐ no
8. Most of the time, how do you communicate at home, with your family? ☐ use sign language ☐ use pen and paper ☐ speak and lipread	9. Most of the time, how do you communicate at home, with your family? ☐ use sign language ☐ use pen and paper ☐ speak and lip read ☐ use communication system developed by the family
The next questions are about knowledge related to HIV/AIDS.	
9. What do you think is the best way for a person to avoid getting HIV/AIDS? [. . . . . .]	10. What do you think is the best way for a person to avoid getting AIDS? [. . . . . .]
10. A person that has unprotected sex with someone who has HIV/AIDS, can get HIV/AIDS. ☐ no ☐ yes ☐ don't know	11. Can a person that has sex with someone who has AIDS without using a condom get AIDS? ☐ no ☐ yes ☐ don't know
11. Using a condom can lower a person's chance of getting HIV/AIDS? ☐ no ☐ yes ☐ don't know	12. Using condoms properly, is there less chance to get AIDS? ☐ no ☐ yes ☐ don't know
12. Is it wrong for a woman to ask the man to use condoms? ☐ no ☐ yes ☐ don't know	
13. There's a big risk of getting HIVAIDS by kissing someone on the mouth who has HIV/AIDS. ☐ no ☐ yes ☐ don't know	13. If you kiss on the mouth someone that has AIDS, can you get AIDS? ☐ no ☐ yes ☐ don't know
14. A person that only has oral sex doesn't need to worry about HIV/AIDS? ☐ no ☐ yes ☐ don't know	14. Can a person that only has oral sex get AIDS? ☐ no ☐ yes ☐ don't know
15. A person that only has sex with people that he or she knows very well will never get HIV/AIDS. ☐ no ☐ yes ☐ don't know	15. Can a person that only has sex with people that he/she knows very well get AIDS? ☐ no ☐ yes ☐ don't know
16. There's a high risk of getting HIV/AIDS by having unprotected anal sex with someone who has HIV/AIDS. ☐ no ☐ yes ☐ don't know	16. Without using condoms, can you get AIDS by having anal sex with someone who has AIDS? ☐ no ☐ yes ☐ don't know
17. There's a high risk of getting HIV/AIDS by having sex during menstruation with someone who has HIV/AIDS. ☐ no ☐ yes ☐ don't know	17. During menstruation, is it easier to get AIDS by having sex with someone who has AIDS? ☐ no ☐ yes ☐ don't know
18. People can get HIV/AIDS if they get a blood transfusion. ☐ no ☐ yes ☐ don't know	18. Can people get AIDS if they get a blood transfusion? ☐ no ☐ yes ☐ don't know
19. Married people can get HIV/AIDS. ☐ no ☐ yes ☐ don't know	19. Can married people get AIDS? ☐ no ☐ yes ☐ don't know
20. A person that has sex with more than one person has more risk of getting HIV/AIDS. ☐ no ☐ yes ☐ don't know	20. Is it easier to get AIDS if a person has more than one sex partner? ☐ no ☐ yes ☐ don't know
21. A person doesn't need to worry about HIV/AIDS if he or she has a regular partner. ☐ no ☐ yes ☐ don't know	21. Does a person need to worry about AIDS if she/he always has the same boyfriend/girlfriend or partner? ☐ no, she/he doesn't ☐ yes, she/he does ☐ don't know
22. You can always tell if someone has HIV/AIDS by looking at them. ☐ no ☐ yes ☐ don't know	22. Can you tell if someone has AIDS only by looking at them? ☐ no ☐ yes ☐ don't know
23. A person can have the HIV virus without being sick from AIDS. ☐ no ☐ yes ☐ don't know	23. Can a person have the HIV virus without being sick from AIDS ☐ no ☐ yes ☐ don't know
24. A pregnant woman with HIV/AIDS can give HIV/AIDS to her unborn baby. ☐ no ☐ yes ☐ don't know	24. Can a pregnant woman with HIV give HIV to her unborn baby? ☐ no ☐ yes ☐ don't know
25. A person can get HIV/AIDS by sharing needles with someone that has HIV/AIDS. ☐ no ☐ yes ☐ don't know	25. Can a person get AIDS by using the same syringe or needle used by someone that has AIDS? ☐ no ☐ yes ☐ don't know
26. People don't need to worry about AIDS because there is treatment. ☐ I agree ☐ I disagree ☐ I don't know	26. People don't need to worry about AIDS because there is treatment. ☐ I agree ☐ I disagree ☐ I don't know
	27. Do you know anyone who has HIV or AIDS? ☐ yes, a family member ☐ yes, a friend ☐ yes, an acquaintance ☐ no

(continued)

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Appendix (continued)

First Version	Final Version
27. The next questions are meant to understand how people feel and think about their sexuality. We will be asking about your ideas and your behaviors.	28. The next questions are about people's opinions, attitudes, and behaviors.
28. Do your friends make fun of people who never date? ☐ yes ☐ no	
29. Do your friends criticize people who have had several boyfriends or girlfriends? ☐ yes ☐ no	
30. Do you think that most of your friends have already have sex? ☐ yes ☐ no	29. Most of your friends have already had sex? ☐ yes ☐ no
31. If you want to talk about sex, pregnancy, or sexual diseases, who do you prefer to talk to? ☐ mother ☐ father ☐ a friend ☐ a doctor	30. When you have any doubt about sex, you prefer ☐ to talk with someone (Who? _____) ☐ read a book about it ☐ search the Internet
	31. Does your mother talk with you about sex, condoms, pregnancy? ☐ frequently☐ sometimes ☐ never
	32. Does your father talk with you about sex, condoms, pregnancy? ☐ frequently☐ sometimes ☐ never
32. Did anyone ever explain to you **how** to use a condom properly? ☐ yes ☐ no	33. Did anyone ever explain to you **how** to use a condom properly? ☐ yes ☐ no
33. Do you drink alcohol when you go out with friends? ☐ always ☐ sometimes ☐ never	34. Do you drink alcohol when you go to parties? ☐ always ☐ sometimes ☐ never
	35. Do you smoke? ☐ always ☐ sometimes ☐ never
34. When you go out with friends, do you use drugs (pot, cocaine, crack, or any other)? ☐ always ☐ sometimes ☐ never	36. Do you use drugs (pot, cocaine, crack, or any other)? ☐ always ☐ sometimes ☐ never
35. Sometimes, it may happen that a child is forced to have some sort of sexual intimacy with an adult or older friend. Did that ever happen to you? ☐ yes ☐ no	37. Has someone ever forced you to take off your clothes, touched your body without your permission, or forced you to have sex? ☐ yes ☐ no
36. Have you ever had sex (oral, vaginal, anal)? ☐ yes ☐ no	38. Have you ever had sex (oral, vaginal, anal)? ☐ yes ☐ no
[For sexually active]	
37. How old were you when you had your first sexual intercourse (had sex)? [. . . . . .]	39. How old were you when you first had sex? [. . . . . .]
38. Did you have sex in the last year? ☐ yes ☐ no	
39. How many people did you have sex with in the last 12 months? ☐ nobody ☐ 1 ☐ 2-5 ☐ 6 or more	40. In the last 12 months, how many people did you have sex with? ☐ nobody ☐ 1 ☐ 2-5 ☐ 6 or more
40. Do you have a regular partner now? ☐ yes ☐ no	
41. When you have sex, do you use condoms? ☐ always ☐ sometimes ☐ never	41. When you have sex, do you use condoms? ☐ always ☐ sometimes ☐ never
42. When you use condoms, what kind do you use?	
43. The last time you had sex, did you use condoms? ☐ yes ☐ no	42. The last time you had sex, did you use condoms? ☐ yes ☐ no
44. Does your partner take drugs? ☐ yes ☐ no ☐ I don't have a partner	43. Does your boyfriend/girlfriend or partner take drugs? ☐ yes ☐ no ☐ I don't have a boyfriend/girlfriend or partner
45. In your life, you have had sex with ☐ women ☐ men ☐ both	44. You have had sex with ☐ women ☐ men ☐ with men and with women
46. The people you had sex with are ☐ hearing people ☐ deaf people ☐ hearing and deaf people	45. The people you had sex with are ☐ hearing people ☐ hearing and deaf people ☐ deaf people
47. Have you ever had sex with a commercial sex worker? ☐ yes ☐ no	46. Has someone ever given you money, drugs, or gifts in exchange for having sex with you? ☐ yes ☐ no
	47. Have you ever given someone money, drugs, or gifts in exchange for having sex with someone? ☐ yes ☐ no

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Appendix (continued)

First Version	Final Version
48. Have you ever had sex with people that are much older than you? ☐ yes ☐ no	48. Have you already talked about condom use with your boyfriend/girlfriend or partner? ☐ yes ☐ no ☐ I don't have a boyfriend/girlfriend or partner
49. Have you ever been pregnant or made a girl pregnant? ☐ yes ☐ no	49. Have you ever made a girl pregnant or have you ever been pregnant? ☐ yes ☐ no
YOUR STORY	
Write a story as if you were writing your diary. It is a secret, you can tell anything you want. Talk about the first time you fell in love or how you started dating, or kissed, or about the first time you had sex. Remember, this research is absolutely confidential.	
[For not sexually active]	
50. Do you have a boyfriend or a girlfriend?	
51. When you think about sex, do you worry about pregnancy? ☐ yes ☐ no	50. You haven't had sex because [. . . . . .]
52. When you think about sex, do you worry about HIV AIDS? ☐ yes ☐ no	
53. When you think about sex, do you worry about what other people will think about you? ☐ yes ☐ no	
54. When you go out with friends, do your parents or the people you live with worry about you? ☐ yes ☐ no	51. Do you go out or date more than one person at the same time? ☐ yes ☐ no
	52. When you go out with friends, you prefer ☐ parties, ☐ shows or nightclubs ☐ practice sports ☐ go to a shopping center ☐ go to a LAN house[a] ☐ go to a park ☐ other
YOUR STORY	
Write a story as if you were writing your diary. It is a secret, you can tell anything you want. Talk about the first time you fell in love or how you started dating or going out with someone, and the important things that happened. Remember, this research is absolutely confidential.	
55. Have you ever been to a medical doctor to check your sexual health (gynecologist, urologist, or any other physician)? ☐ yes ☐ no [if "yes"] Who went with you? ☐ a family member ☐ a friend ☐ a teacher/interpreter ☐ I went by myself	53. Have you ever been to a medical doctor to check your genitals (vagina, penis)? ☐ yes ☐ no [if "yes"] Who went with you? ☐ a friend ☐ a family member ☐ a teacher/interpreter ☐ I went by myself
56. Have you ever felt that you had some kind of allergy, pain, rash, or bad smell in your genital? ☐ yes ☐ no	54. Have you ever felt that you had some kind of itching, pain, rash, or greenish or bad-smelling discharge from your penis or vagina? ☐ yes ☐ no
57. Have you ever tested for HIV/AIDS? ☐ yes [You are ☐ HIV positive ☐ HIV negative] ☐ no [Would you like to be tested for HIV/AIDS? ☐ yes ☐ no]	55. Have you ever tested to know if you have HIV/AIDS? ☐ yes [You are ☐ HIV positive ☐ HIV negative] ☐ no [Would you like to be tested for HIV/AIDS? ☐ yes ☐ no]

a. A LAN House is a cyber café.

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