"The topic of AIDS was not only painful to me, it was keeping me from healing. This pain kept me bleeding inside."

AIDS EDUCATION
A Conversation With an African American Adolescent

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Journal for a Just and Caring Education, Vol. 3 No. 3 July, 1997  289-297
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This article looks at the lessons that a novice qualitative researcher learned from interviewing an adolescent on AIDS education. The data informs us of what can be missed when adolescents are surveyed and not talked “to.” As Toni informs us, “They should teach you this.” The article points out how reciprocity, responsibility, and teaching in research is key. Toni’s response to the quantitative instrument informs us, as researchers, how the qualitative method of interviewing better served as a vehicle for reciprocity by offering the emancipation that she needed. Roles were reversed in the midst of the project. The researcher became student and the adolescent became teacher. The article concludes with what an adolescent believes researchers “should” do and what researchers are “expected” to do when doing research “on” adolescents.

Toni is a 13-year-old from Clearwater, Pennsylvania (both her name and her location are pseudonyms). The following story is about an interview that I conducted with her to satisfy requirements in my first qualitative research course. I conducted an interview in this course on qualitative field methods to gather data that might aid in producing a grounded survey instrument that would be of use in what I thought was going to be my dissertation topic on Black adolescents and AIDS education. Hence the purpose of the interview was not so much to produce data as it was to get adolescent feedback on a quantitative survey instrument that had been used with a state training school population (Lux, 1992). I was not out to do research; I was only doing a project to get practice with a method in a way that I thought might help me with my dissertation down the road.

I WAS ONLY DOING A PROJECT

For this class project, I already had an area of interest that I was becoming very familiar with—AIDS. Upon entering the Ph.D. program in the fall of 1992, I had learned that my only child, Carl, was dying from AIDS. With my interest in AIDS and my belief that Carl might have contracted this dreadful disease in our hometown of Clearwater, I decided to experiment with interviewing. I chose to interview Toni because she was an African American adolescent female from Clearwater currently residing in Ohio.

Initially, my intention was to generate a proposal from this project and build on it for my dissertation. I chose to do qualitative research because it gives the story behind the numbers that quantitative research yields. During the course of the project, however I began to realize that the topic of AIDS was not only painful to me, it was keeping me from healing. This pain kept me bleeding inside. Consequently, I decided not to continue my research in this area. Carl had just passed in November 1992, and I had buried him the day before Thanksgiving.
Carl was a heterosexual who did not use condoms. He said "Ma, I just messed up." Carl’s death devastated and crippled me. Although Carl believes he became infected in a large metropolitan city, he could have become infected at home, in Clearwater. This raised my concern and curiosity about other young people in Clearwater who might be at risk for infection with HIV. This concern and curiosity led to my inquiry into AIDS education in Clearwater and to my interview with Toni.

So I started this project off simply wanting to accomplish the requirements for this class—choosing a method of research and carrying it out. While I was home for the 1993 New Year, I began talking to friends, parents, school officials, teachers, and young people about HIV/AIDS awareness via education and prevention. Throughout the town, I discovered that AIDS was not a much talked about topic. It was during these conversations that I also realized the extent of sexual activity among adolescents in Clearwater and the potential danger of the spread of HIV. Through engaging in sexual activity, many find the love, acceptance, and family that they are so desperately seeking. My concern for HIV/AIDS awareness in Clearwater became more pressing after learning of the sexual activity and the lack of visibility of HIV/AIDS awareness advertising, both in the media and in the sole public high school. I also wanted to investigate the rumors that there are at least 14 adolescents in Clearwater with HIV. Although rumors are not usually given much credence, in a small town like Clearwater, there is a lot of truth found in rumors. Because I was no longer intending to carry out this research, if I did no more than raise the awareness of those in Clearwater, I would accomplish there what I wanted to do.

CLEARWATER

It wasn’t always like this—the small town of Clearwater—so desolate. But Toni had never seen Clearwater any other way. So dry and ugly. So dark, dirty, and greasy. The thick layer of greasy, green, slimy mist that sprinkled from the sky came from the steel mill. Carrying with it a sense of despair, this green slime deliberately placed a blanket of hopelessness and lovelessness (nihilism) over the Black area of town. Restlessness, anger, and unemployment engulfed this Black community. You could see and feel the child neglect; you could hear the verbal abuse.

So several years ago, when Toni moved with her mother to Columbus, I was glad that she "made it out" of Clearwater. I was also happy to talk with her about the other young people in Clearwater. I wanted to get her opinion on my suspicions and about the rumors that there was little or no AIDS education in the school and that sex is so prevalent among adolescents. As I began my
discussions and sharing my concerns with Toni and by phone with friends in Clearwater, I sadly discovered how prevalent sexual activity is among young people.

THE INSTRUMENT

The instrument used for this project is a tool developed by a 1992 Ph.D. graduate, Dr. Lux, at a large Midwestern research institution. The design for her study was a concurrent relational design. The purpose is to predict relationships. In concurrent relational studies, a relationship is drawn on characteristics of the same group at the same point in time asking how well Y can be predicted from X.

I chose to use this instrument because it was developed to measure perspectives and show relationships, and this was what I intended to do in Clearwater. I also chose this instrument because I had some suspicions regarding surveys and questionnaires when used with African Americans, suspicions that I wanted to investigate. Initially, I wanted to help to educate Clearwater youth about HIV/AIDS. I wanted to explore a possible parallel between the low self-esteem, particularly feelings of hopelessness and not being loved, and sexual activities that many youth were engaging in (I was to discover) and the potential for contracting HIV. I wanted to explore adolescent perspectives on how HIV/AIDS education helps in making decisions to engage, or not engage, in sexual intercourse.

So I started out by using this instrument as a foundation for developing an instrument that would be better geared toward 13- to 16-year-old, inner-city, lower socioeconomic African Americans. In examining the instrument, my experience as an African American informed me that the language needed to be more culturally appropriate for African Americans. My suspicions also informed me that a survey would not be the best tool to use for getting the kind of information that I was seeking, which was information that would “tell a story about the lives” of the economically and socially depressed adolescents in this small rural town. I believed that an interview would better yield the kind of rich, in-depth information that I was seeking. My suspicions were confirmed following the interview with Toni.

THE INTERVIEW SESSION

Toni’s attitude was one of anger stemming from something that I would never have imagined of this 13-year-old. During the interview and while she was responding to the instrument, I could not understand why she appeared to
be so angry, so frustrated. Initially, I thought that it was just my imagination. After all, many young people today just seem to be angry at the world. However, it felt like more than just a bad attitude. This “attitude” draped the air, like a coarse blanket surrounding Toni’s youth, rubbing against her soul, agitating her existence, her space. It was as if the more she examined and reworded the instrument, the more it seemed to trigger something inside of her—to remind her of something. I had discussed this topic with her before, and she had not reacted this way; however, this was the first time that she had seen the instrument. I wondered what was causing these reactions from her. Was I getting into an area with this young girl that I was not going to be able to handle? Was she about to have some kind of flashback that needed medical attention? I didn’t know. Was she angry, frustrated, or nervous because she was discovering something very important to her? Was there something here that would have been helpful to her if she had known it earlier? Perhaps it was as simple as being Saturday morning and her wishing she was someplace else.

I believed Toni was perfect for the interview. She was eager to help with the instrument and wanted to see AIDS education in Clearwater. I also knew that she wanted to know more about AIDS. She kept saying throughout the interview, why don’t “they” teach you these things? When I asked who, she said “teachers. They’re supposed to teach you this.” The first Saturday that we met, Toni critiqued the original instrument. She was changing and adding words that she thought kids back home would better understand and respond to. Everything that said I will, for instance, “I will have sex with someone who does not use a condom,” Toni changed to say “I will not . . . .” Her argument was that “you shouldn’t teach kids that it’s OK to have sex; you let them know that it’s not OK.” She did this throughout the survey. It was because Toni was angry and expected to be “taught” rather than surveyed that I asked her if she understood that these were just questions.

INTERVIEW

I chose to interview Toni because (a) I was testing the survey instrument, (b) I wanted to test it on someone who was familiar with the setting where I wanted to carry out my research, and (c) I wanted to see the difference in the language used for Lux’s (1992) instrument and that used by an African American adolescent. I knew that Toni could help with this. I had planned on doing fieldwork research in Clearwater, so I was really interested in how Toni felt about the language. I was also learning about interviewing and felt comfortable learning with Toni. She was someone that I knew. I wanted to learn how it felt to interview an adolescent, particularly someone whom I felt had some information that I wanted. I knew what questions to ask, or so I
thought. Toni, being from Clearwater, could give me information from her perspective on what was going on in Clearwater regarding HIV/AIDS education and sexual activity. Again, I was not out to do research, but to do what I could to make a difference in the lives of people whom I know and love. I expected that the interview would be reciprocal. I never expected or imagined that it would be emancipating. The thing that frightens me is that I was only doing a project. I had no idea that Toni would give me the information that she did.

The interview process began with Toni examining the survey instrument and forming the questions from the instrument in the way that she and her friends (she thought) would understand. The interviews were for 2 hours each on two consecutive Saturdays; however, we talked afterward for most of the day on both occasions. I am friends with Toni and her Mom, so I spent most of the day at Toni’s house just talking with her and her mom about what I wanted to do in Clearwater. How could I and others help the young people to move toward self-determination regarding drugs and sex? Toni had the same concern, and it was through these talks that I learned of her story.

TONI’S RESPONSE

Toni’s response to the instrument startled me. She was angry, almost explosive. Her anger was directed at the words she was reading. She said, “why don’t they teach you this?”—meaning the information in the instrument that she had just learned about. She reacted as if knowing this would have somehow given her and her friends a choice about their lives. But I did not know this during the interview. Toni wanted to correct the instrument (portions of interview included) the whole time she was filling it out. Why was she so angry? Why did it seem like she was on the brink of tears? I asked her if she understood the questions and what was expected of her. Although I had explained that these were only questions given to people to get their opinions on certain topics, I asked Toni again if she understood this, and she said yes. I reminded her that she was only supposed to change the words of Lux’s (1992) instrument to wording that she thought young people in Clearwater would understand better. When I asked Toni if she was OK, she said yes. I did not ask anything else. I let her complete her rewording and examination before I began the interview. Here is a portion of the instrument that was used, along with Toni’s responses:

Instrument: I am able to ask my partner how many people they have had sex with before.
Toni: It may be hard to ask your partner who they had sex with ’cause they may hit you.
Instrument: I am able to ask my partner(s) if they have ever used IV drugs (popping or shooting).
Toni: I am not able to ask my partner that 'cause I would be scared.
Instrument: I am not too young to have sexual intercourse.
Toni: I am too young to have sexual intercourse.
Instrument: I am too young to get AIDS.
Toni: I am not too young to get AIDS.

TONI'S LIFE

Toni is the oldest of two girls; the baby girl is 1 year old. Her mother has been on public assistance all of her 40 years. For most of her 13 years, Toni has known public assistance, a mother shooting heroin, and a life involving drugs and violence. While living in Clearwater, she was not encouraged to attend school and had always more or less been on her own. In school, she was labeled slow by some teachers. Her Mom confirms this, acknowledging that Toni is slow in some areas, such as math, because Toni was not raised with the kind of encouragement that she needed. “I was on drugs, always out trying to get a fix, and now my daughter has to pay for this,” her mother said. Toni is now getting stronger in math, and her Mom, who is no longer on drugs, is working with Toni more in helping with her school work.

WHAT I LEARNED ABOUT TONI FOLLOWING THE INTERVIEW

It was outside the formal interviews where Toni began to share more of her story with me. She talked of how she just hated everything and everybody. She shared how it was for her growing up in Clearwater and now here in Ohio. Toni told me about two of her girlfriends. She said these girls are not the only ones that got pregnant, but these are her close friends. One friend, 15, has two babies, ages 2 and 3, and is pregnant with a third. Each baby has a different father. The other friend, 16, has already had three abortions, and each baby was by a different boy. As an African American mother, in particular, knowing the oppressed state and condition of Clearwater, my heart aches and I am sad remembering her story.

Toni’s father is also a drug user. When Toni was 11 years old, one of her father’s drug pushers got her drunk and raped her. Consequently, she got vaginal warts. The warts are painful, and each doctor that her Mom has taken her to, in Clearwater and in Ohio, has reported that because of the kind of warts they are, there is nothing they can do to remove them. She will have to live with them. Toni is 13 years old.
ANALYSIS

What was interesting to me is that Toni did not like the instrument and appeared to find it offensive at most points. She said that the instrument was telling you that "it's OK to have sex" and that "if you're young, you can't catch AIDS." I also discovered that viewing the world through a 13-year-old female's eyes was not what I expected it to be, even with someone whom I thought I knew. I was reminded of the biblical reference that "a child shall lead the way." It does make sense that if you want to know something about someone, you should ask them.

Throughout the interview with Toni, she was teaching me. She made me really take a look at how researchers and adults think that they are doing the right thing but are often missing the most important part of the story. Toni was consistent and persistent in making a distinction between saying that it is OK to have sex and saying that it is not OK. She says that grownups "should not say that it is OK to have sex because kids listen to grownups." Toni turned an interview into a teaching tool. She taught as she understood. She also made it clear that she "expected" teachers, or older people, to teach children. This was their job. Piece by piece, she deconstructed a methodological tool that a researcher had developed with a theoretical framework to assess "others." This 13-year-old female from the inner-city projects, who had been labeled slow by some teachers, was saying, "No, this will not work here."

Given this, I am concerned for what many of the young people in inner-city schools and neighborhoods like Clearwater have to face in the years ahead. Toni is frighteningly more representative of her hometown than I would like to believe or admit.

Finally, my suspicions about the lack of, or limit to, AIDS education was confirmed after speaking with officials and teachers at Clearwater High. Although the state mandates that AIDS information be provided in all public schools (K-12), according to teachers, the extent of AIDS education is to have two speakers come in during the health class (10th grade) 3 days out of a year. In addition, there is a peer group that meets after school for anyone who wants to participate. The meetings are confidential and students do not have to share what goes on with their parents.

RECOMMENDATIONS

I learned several things from this 13-year-old from Clearwater. First, I learned how the informal activity after interviewing has importance. It is here that the evidence of reciprocity and rapport begin to present itself. Second, I learned that social science instruments, although useful, socialize young
people in ways we may not be aware of. Finally, I learned that we, as researchers have ethical responsibilities to "tell it like they see it" in ways that go beyond the capacities of structured survey tools, which can provide useful information as well as suppress valuable knowledge about adolescents. Young people need to be listened to, not just surveyed. In her youth, Toni informs us—as researchers, administrators, educators, and teachers—that young people rely on and look to grownups to "do the right thing."

I recommend that researchers keep in mind that when doing research "on" young people, they are doing more than research—they are teaching, giving young people instruction. Toni viewed the instrument as a teaching tool. I asked Toni if she understood that this was only a set of questions and she said yes. Yet she expected this set of questions to "do the right thing" by teaching her right from wrong. Although she was angry, the light in her eye brought a pain to my heart as I saw how she "ate" the knowledge that she was receiving. The over 100 questions that composed the survey seemed a likely burden to me, and I thought she would get tired of helping me. But her response to my concerns was, "No, it isn't long at all; it's teaching me stuff I haven't heard before," even though Toni insisted that adolescents do not need to know that it is OK to have sex and that adolescents need to know that they are not too young to contract AIDS.

CONCLUSION

I recently received a thank you note from Toni, who is now 15, saying that "I would not have made it to the ninth grade if it was not for your help." She says that I helped her to look inside of herself and become more focused in her studies at school. Such a gesture from this adolescent informs me that as adults and researchers, we are "supposed" to and are "expected" to teach as we go. We are much more than researchers, even if we think we are not doing a project. This was the lesson Toni taught me.

REFERENCE