

A Researcher's Reactions to an Atypical Respondent¹

The writer was involved in a qualitative research project of mostly female older caregivers who were caring for persons with symptomatic HIV disease. Nineteen of the respondents were mothers and grandmothers who were taking care of close relatives. The sole male interviewee ("Billy," a 51-year-old unemployed African American man) was atypical in many respects and could not easily be included in presentations of themes and patterns which emerged from the data; he was helping out with a neighbor whom he knew only casually. Nevertheless, the researcher was impressed with this man's understanding of HIV-related stigma,² which was one of the primary foci of the study, and was impressed with his attitudes toward persons with HIV. The interviewer felt that Billy's powerful narrative illustrated well the power of the HIV experience in the inner city and was moved by this man's insight and courage. This article reports Billy's story and the author's reactions to it.

by
**Cynthia Cannon
Poindexter, Ph.D.**

Cynthia Cannon Poindexter, Ph.D., faculty member at the Boston University School of Social Work, Boston, MA.

At the time of the research project in which Billy participated, Dr. Poindexter was a doctoral student at the Jane Addams College of Social Work, University of Illinois at Chicago.

In 1996 I was a research assistant and doctoral student at the Jane Addams College of Social Work at the University of Illinois at Chicago. I was at that time involved in a qualitative research study of 20 minority HIV-affected caregivers. My dissertation data came from this project and focused primarily on the respondents' experiences with and perceptions of HIV-related stigma. Nineteen of the interviewees were mothers and/or grandmothers who had been taking care of sons, daughters, and/or grandchildren who were very ill with end-stage HIV disease. Stigma was a big theme for these women, many of whom had not told their informal support networks that they had a family member with AIDS. In addition, the majority of the interviewees were quite tearful as they talked about their strong reciprocal relationships with adult children or minor grandchildren who were seri-

ously ill or who had died from AIDS.

As I discussed in a previous *Reflections* article (Poindexter, 1998), interviewing older African-American women who had decided to provide personal care and emotional support to their loved ones with HIV was an emotional experience for me. The research was intellectually interesting to me, of course, but mostly I felt sad, angry, and incredibly honored that these strangers were freely sharing their pain and grief with me. I loved sitting down at kitchen tables with these caregivers and facilitating their moving narratives, but I often felt discouraged, depressed, and drained with the subject matter. The research triggered many of my own memories and feelings as a caregiver for a loved one who had died from HIV, and it was often quite disturbing to receive the enormous sadness of moms and grandmoms who felt

¹This article was part of a research project which was funded by the Center for Health Interventions with Minority Elderly (CHIME) at the School of Public Health at the University of Illinois at Chicago (UIC) through the National Institute on Aging (Grant #HHS-AG 12042-03).

²Herek and Glunt (1988) coined the phrase "AIDS-related stigma" to designate a level of discrimination and prejudice which is deeper than that experienced by persons with other types of illnesses or conditions; this particular type of stigma sometimes makes obtaining social support and assistance more difficult for persons with HIV and their caregivers.

isolated and alone as they watched their young folks die.

Only one of the research respondents was a man. His interview was very uplifting to me because his attitudes about HIV were progressive and accepting. "Billy" was a 51-year-old African-American man from the west side of Chicago who was unemployed at the time that he spoke with me in the summer of 1996. Billy was not similar to the other research respondents, not only because he was the only male interviewee, but because he had not been deeply connected over a long time to the HIV-positive person, "Renee," whom he was helping. Renee was his neighbor, not a relative, which was another way in which his situation was different from the others. The interview itself was unique in this sample due to the absence of strong emotion such as grief or love for the care recipient.

Billy had been living in the same apartment building with Renee and her husband for the past five years and had been only casually acquainted with them over that period of time. Because of Renee's changing appearance and frequent visits from Renee's mother, Billy had recently surmised that Renee had AIDS and offered to help out during her mother's temporary absence while she visited relatives in the Philippines. Renee accepted Billy's offer of help and acknowledged her AIDS diagnosis to him. At the time of the interview, Billy had been providing companionship and transportation to Renee for approximately a month.

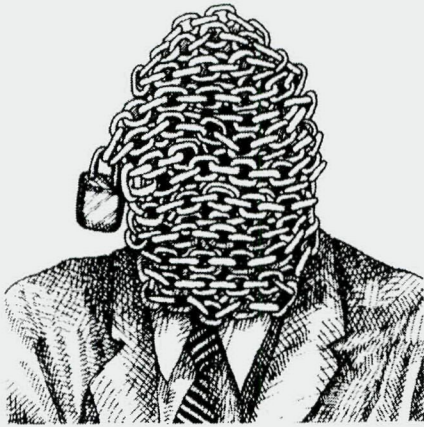
Although Billy was unlike the other 19 participants, he had the most to say about HIV-related stigma in his community. I was impressed with his awareness of the effects of HIV-related stigma, his wisdom about what perpetuated it, and his courage in facing HIV as a social problem which had relevance in his life. During the interview, I was very moved by Billy's narrative style, his sensitivity to the general climate of discrimination, and his willingness to support a casual acquaintance who was HIV-positive. I had the sense that not only was he unique in this study, he was fairly unusual in his responses to HIV.

Over a year's time, as I was analyzing the data and struggling with writing up the results, I was repeatedly frustrated at not being able to include Billy in conference presentations and articles. Each time that my dissertation chair or I wrote about or talked about the study, we realized that Billy "didn't fit" any of the patterns and we ended up leaving him out. I see his story as an important illustration of how disclosure decisions and stigma management can have an intense impact on people, and in the 18 months since I met him, I have not been able to get his comments out of my mind. I have been able to find several outlets for showcasing the powerful stories of the 19 women, such as my dissertation, several presentations and papers, and poetry (see Poindexter, 1998). I remain frustrated, however, at not being able to voice what I learned from Billy. In this article I attempt to

do so. I want people to hear his passion, his ability to "tell it like it is," and his view of urban life and of persons with HIV. I also think that African-American inner-city men are rarely heard from in our literature, especially on the subject of AIDS.

I did not interview Billy in his home, as I did most of the research participants. He wanted to meet with me in my office at the University of Illinois, which was in the building next door to the place where Renee was getting medical care. Billy was bringing Renee in for a check-up and wanted to speak with me while he was waiting for her. He called me from the Infectious Disease clinic, and I went over to get him. On the phone he told me, "I'll be the one in the Bulls cap." I said "That doesn't help; everyone nowadays wears a Bulls cap." He laughed and said that he'd wait in the hall by the elevators. He saw me approaching him and walked forward to meet me. I saw that he was a casually dressed, young looking, heavy-set dark-skinned man who was missing some teeth in the front of his mouth. We shook hands, and I walked him back to my office through a back hall so that we did not pass any of my co-workers. I set the tape recorder on my desk, sat in my desk chair, and motioned for Billy to sit in a chair in the corner near my chair. Throughout the interview he was upbeat and animated. He would periodically look around my office and interrupt his narrative to comment on posters, photographs, or personal items. He even made two

attempts to flirt with me. In the following excerpts from the interview, Billy's remarkable story emerges.



Billy's caregiving activities were both concrete and emotional; he offered instrumental support and tried to encourage Renee:

"Well, I take her....to the grocery store, and I usually take her out and about,...take her shopping and stuff....she want to go somewhere, I go with her...I usually keep her company. I try to keep her spirits up... And I try to keep her calm, you know? She just seems worried, and she misses her mother... But when she don't eat and stuff, I say, "how you gonna be if you don't eat? You know you gotta eat."

As demonstrated by the quotes which follow, Billy's reasons to offer help to Renee were closely connected to his awareness that persons with HIV are not treated well in his west side Chicago neighborhood, as well as his sense of fairness and his empathy for what persons with HIV might feel and need. He demonstrated an intense dislike of what he perceived to be the usual attitude toward persons

with HIV and wanted to be different from his neighbors and buddies. Billy talked in this way about the unfriendly climate of his neighborhood regarding persons with HIV:

...they whisperin' and [makes whispering sounds]....and spread rumors about what they don't know nothin' about. I tell 'um, you want to know somethin', just ask me, I'm serious, you know, but don't spread rumors. You know, that's bad. That's very bad....so they spread rumors....they just be gossipin'. Gossip, gossip, gossip, gossip, gossip. There don't be nothin' to gossip about; they don't have nothin' to say. You know what I'm sayin'?

Billy thought that people in the neighborhood bad mouthed people with HIV because of ignorance: "People are always afraid of somethin' that they don't know anything about." He said that persons with HIV are just like other people and need to know that someone cares. When I reflected, "it sounds like you don't have a problem being with people who have HIV," he responded:

No, well, you know people are people....and you just have to be educated about what's happenin'... and they need to be, they need to know somebody cares. Just like you or I. Who's to say? It's way out.

Further explaining his disagreement with the way persons with HIV are treated in his neighborhood, he spoke of his sense of

how people with HIV want to be treated and his own commitment to treat them well:

And that's not fair....because you have to put yourself in their position, you know? How would you want to be treated? And you would want to be hugged and touched, you know. It's way out. It take all types of people to make the world go round....I ain't gonna stoop that low. I mean, I'm gonna try to keep it focused. It's hard, but I keep tryin'.

Billy was aware that his attitude toward persons with HIV was unusual among the group with whom he hung out. In the following interchange, he spoke about why and how his own accepting attitude toward persons with HIV differed from most of his neighbors:

Billy: I always been different from a lot of the people in my neighborhood. [Chuckles]...I went to school with a lot of Black people, White people, Puerto Rican people,...a lot of different people,...I know people. A lot of different people....so I don't have....if I have prejudices,...I guess everybody do, to a certain degree, but that's [HIV] not one a 'um....I try to keep a open mind... You're nice to me, I'm gonna be nice to you. If you aren't nice to me, I might not be nice to you. Somethin' like that... A lot of people, they just nasty. [Chuckles]...they just nasty, period.

Cynthia: And sometimes they get nasty to people with HIV?
Billy: Yeah, real nasty.

In the next excerpt, Billy elaborates on how he is governed by his own sense of right and wrong, not by the opinions and actions of his peers:

It's hard....but a lot of people want to go with the majority. And I never liked to go with the majority, so it's kinda easy for me....I know what's right and what ain't. If it ain't right, it ain't right. [Laughs] And that's what time THAT is.

I asked Billy how he had come to be so knowledgeable about the disease. He replied that he had sought educational resources so that he could be more informed about HIV:

Just....listening and knowing.... and everywhere they had an opportunity to study or talk, I went....and listened to it and participated. You ain't gonna learn nothin' if you go through with blinders on. You know, ain't no tellin' what might happen tomorrow.

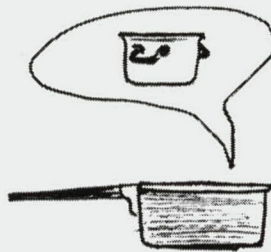
Billy had previous experience with friends and acquaintances who had HIV and this seemed to influence his thoughts about the illness:

I know some guys, I know some chicks. And I know some white ones, I know some Black ones, I know some Puerto Rican ones, some Jews... It's an equal opportunity disease. You know? And it doesn't discriminate.

Billy explained that his determination not to mistreat or ignore persons with HIV stemmed from his sense that he

was fortunate not to have been infected with HIV himself. His empathy seems to be closely linked to that awareness:

So I just got lucky. I'm serious. It could have been me. And.... how would I have felt? As far as people and friends turnin' their back on me? I wouldn't like that very much.



Billy also believed that his perceived good luck (which had enabled him to not die and not be in jail) was connected to God's having a purpose for him which he had not yet discovered:

Billy: I just came to the conclusion, I say, Man, listen. All these people I know, they dead or in the penitentiary.... and I've been lucky so far, so man, He must have put me here for somethin' other than what I'm doing. I have to find out what the Hell it is.

Cynthia: God has some purpose for you?

Billy: Yeah, you know. People ask me, I say I feel like I'm gonna be a preacher or somethin' [laughs]. And they laugh, you know. But the Man got somethin' for me to do! This ain't it! So, I say, let me check it out. So...I'm tryin' to get ready for to check it out, see what's happenin'... I need to do

somethin' other than what I'm doin'. I ain't doin' nothin'.

When he was telling me his ideas about why people hide the fact that they have HIV disease, Billy related (with a mixture of bewilderment, sadness, and amusement) the story of a friend who was very ill from AIDS, but who had been one of those who had speculated aloud about Renee's HIV status:

Billy: And then I got another friend a mine, talkin' about he got cirrhosis of the liver, he drink every day. He used to get high, and then he quit gettin' high, and now he drinkin' every day, but he done had two or three ladies that have the HIV virus, and he don't wanna admit that he got it. And I think he gonna drink himself to death to keep people from knowing that he got the virus. That's dumb. I mean,...That's what he thinks. Cynthia: Did he tell you that he had AIDS?

Billy: No, he didn't have to tell me. I know the background. Ain't no way he can not have it.

Cynthia: People are real secretive sometimes. They don't want to say they have AIDS.

Billy: Yeah, but it's the same guy that's spreading rumors about Renee! Yeah, he's one of them, he's one of them. The pot talkin' about the kettle... And he started that last year. And, you know, I don't understand. I quit tryin' to figure that out. It's the same guy that was talkin' about her, and now people talkin' about him, and

he can't stand it. And when she [Renee] found out he was in the hospital, I told her, and she went to see him, and he almost jumped out the window [laughs heartily]... He wasn't expectin' to see her.

Billy described Renee's concern with hiding her HIV diagnosis and said that he had encouraged her not to bother with what others thought:

It's way out. I say [to Renee] 'don't let that worry you, man.' That's so...all the folks outside, she be worried about some would treat her like that. I wouldn't even let that worry me, but she does.

Given Billy's advice to Renee not to let the opinion of others worry her, I was curious about how that had played out in his life. Ironically, Billy had not told anyone that he was involved with anyone with HIV. Referring to his decision not to disclose the fact that he had a relationship with an HIV-positive neighbor, he described his secrecy as a sense of privacy:



Cynthia: Is there anybody in your life who knows that you are friends with Renee and that she has AIDS?

Billy: No... I don't think it's anybody's business, myself. But if, you know, if somebody was to ask me....and I thought it was important, I wouldn't deny it, [but] I wouldn't talk either. But it all depends. I don't really think it's anybody's business... I treat it like that.

Billy had not disclosed the situation with Renee to the family members whom he described as the most significant to him, because he anticipated that they would judge him harshly for providing care to someone with AIDS:

Cynthia: Do your mom and grandmom know that you have friends with AIDS, and you're taking care of Renee?

Billy: I think they do. I'm quite sure they do.

Cynthia: But you haven't said it out loud?

Billy: Uh-huh [no]. But I know that, they nosey, nosey, nosey... Nosey. Yeah, man, they run around [makes whispering sounds]. My grandmother, she sets out front of my house and [speaks as his grandmother] 'what are

you goin' up there for?'... They all in my business.... I know them. They

done figured it out [about helping someone with AIDS].

Cynthia: What do you think they would think about you having friends with AIDS?

Billy: Uh, I don't know. They probably wouldn't care for that.

Cynthia: They wouldn't like it?

Billy: No, I don't think so. They kinda stuck in the 50's. Narrow minded. They really narrow minded. They don't have nothin' good to say about nothin'... I don't want, I don't even like to talk to them about certain things. I know what

the answer gonna be before I even....before I say it... I know how they are. I just can't, I have to realize and understand that nothin's gonna change....they got their opinion and I got mine. It's a question of what matters, theirs or mine. And I think mine does. So, I don't even worry about it. I don't even discuss it... I used to value they opinions, but it really doesn't matter. Whatever what was going to happen was going to happen. So I changed. And I quit worrying about it.

When I asked what people like him might need in order to make it easier to take care of someone with HIV, Billy stated that HIV caregivers should not focus on the judgments of others:

Cynthia: What are you thinking that people need when they take care of people with HIV?

Billy: Well, they need to try and stay focused and they need to not look to what other people say so much. And to try to use their own judgment and don't depend on what other people say so much....if you know it ain't right, it ain't right. Don't be so judgmental and don't let your mind be so easily swayed. That's what I think... 'Cause if I know in my heart that it's right, ain't nothin' you can do to make it not be right... If I know that it's supposed to be up here [points to his head] then I know it's supposed to be in here [points to his heart].

Researcher Reactions

I think that Billy's experiences and observations about HIV-related stigma can help us understand AIDS-related discrimination and attitudes in urban areas where the residents are predominantly members of minority groups. The first lesson that Billy's narrative taught me is that HIV-related stigma is salient and powerful in his world. His recounting of the hiding of the HIV diagnosis by Renee and by the man in the hospital illustrates the continued fear which some persons with AIDS have concerning disclosure of the diagnosis. In addition, Billy's description of his relatives' negative views, should they learn of his having friends with AIDS, and his sense of the prejudice in his neighborhood against persons with HIV seem to point to the existence of HIV-related stigma, both experienced and anticipated.

Another thing that Billy highlighted for me is the need for continued public education about HIV. Billy said that people in his neighborhood were still ignorant about HIV and needed to be educated. Billy sought information about HIV himself because he wanted to know what was up and was

able, in that way, to respond to an HIV-positive neighbor who needed support.

I also think that Billy's eloquence concerning striving for congruence between his head and heart is an example of the integrity that he demonstrated regarding doing the right thing for persons with HIV who need understanding, compassion, and/or assistance. He told me that many of his neighbors suspect that Renee has AIDS, but they choose only to gossip. Billy guessed that she has AIDS and decided to offer his help. I find that remarkable. He is certainly not the only person who has come forward to assist fellow human beings who have HIV; this pandemic has obviously had countless heroes and heroines who have provided care despite feeling isolated and stigmatized. However, I think that his reaction as a neighbor and casual acquaintance is rather rare, and his empathic insights and altruistic motivations should be noted and appreciated. He seemed to have an attitude of "there but for the grace of God go I," which inspired him to treat others as he would want to be treated.

I disagree with Billy on one point, however. Billy said that he thought that HIV-af-

ected caregivers should not mind so much what others say about persons with AIDS and their caregivers. While that may indeed be good advice, it does not go very far toward ameliorating the problem of HIV-related discrimination and stigma. It seems to me that societal attitudes must move more toward compassion and helpful action if persons with HIV and their caregivers are going to feel safe in disclosing the presence of HIV and asking for help. Then perhaps it will be more likely that neighbors will care for neighbors. □

REFERENCES

- Herek, G. M. & Glunt, E. K. (1988). An epidemic of stigma: Public reactions to AIDS. *American Psychologist*, 43(11), 886-91.
- Poindexter, C. (1997). *Stigma and support as experienced by HIV-affected older minority caregivers*. (Dissertation).
- Poindexter, C. (1998). Poetry as data analysis: Listening to the narratives of older minority HIV-affected caregivers. *Reflections: Narratives of Professional Helping*, 4(3).

Copyright of Reflections: Narratives of Professional Helping is the property of Cleveland State University and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.