How Stigma Kills

People don't want us to: Cut their hair, Serve them food, Babysit their children, Marry them Or be their friend. Why AIDS stigma is as deadly as the virus itself.*

December 1, 2009 By Regan Hofmann

Defined as "a mark of shame, disgrace or discredit," stigma has long plagued HIV/AIDS. It is one of the defining characteristics of the disease, differentiating it from its biologically-parallel-but-socially-altogether-different retroviral kin: hepatitis, herpes and human papillomavirus (HPV). While we can chirpily discuss vaccinating our children against HPV as we choke down our Cheerios, and we can sit comfortably in front of commercials for herpes drugs, the mere whisper of the word "AIDS" often causes all polite conversation to cease.

We're not imagining this. In 2007, amfAR, the Foundation for AIDS Research, commissioned Harris Interactive to conduct a study among the general American public seeking their attitudes about women living with HIV/AIDS. The survey showed that the majority of Americans are uncomfortable around people living with the virus. More specifically, the study revealed that 59 percent of Americans are somewhat or not at all comfortable with having an HIV-positive woman providing them with child care; 47 percent of Americans are somewhat or not at all comfortable with having an HIV-positive woman serve them food at a restaurant, and 35 percent of Americans are somewhat or not at all comfortable with having an HIV-positive woman as their hairdresser. This study, which mined attitudes about HIV-positive women, flushes out that it is indeed the virus itself that makes people squirm. In other words, people don't fear HIV because (as some suggest) they misperceive it to be a gay or a black disease; they fear HIV and the people living with it, period.

The study also revealed that the vast majority of Americans are not comfortable with the idea of having a romantic relationship with an HIV-positive partner. Eighty-seven percent of Americans are somewhat or not at all comfortable dating someone who is HIV positive, and 89 percent of Americans are somewhat or not at all comfortable marrying someone who is HIV positive. One in five Americans said they would not be comfortable with having an HIV-positive woman as a close friend. Ouch.

The results of a recent survey on poz.com about stigma showed that our readers' perceptions of the general public's attitude toward people living with HIV are spot-on. Eighty-eight percent of you said that your fear of being stigmatized has made dating/relationships more difficult (remember, 87 percent of the general public said they're uncomfortable dating you), and 91 percent of you believe AIDS stigma prevents people from getting romantically serious with/getting married to you

(89 percent of the general public agreed with you). That's very close statistical mirroring.

Given that HIV-related stigma is as bad as we perceive it to be, it's no wonder then that 65 percent of you said that HIV-related stigma has prevented you from disclosing to family members; 71 percent of you said it keeps you from telling coworkers; and 60 percent of you said you don't tell friends because of fear of being stigmatized.

One statistic we found particularly disturbing in the Harris study was that very few Americans believe that HIV-positive women should have children. In response to the question, Should a woman with any of the following conditions have children?, fifty-nine percent said women with cancer should have a child; 47 percent of people said women with depression should; 37 percent said women with multiple sclerosis should; 20 percent said women with hepatitis C should; 19 percent said women with Down syndrome should; and 17 percent said women with schizophrenia should. Yet, only 14 percent of Americans said they thought women with HIV should have a child.

This points to a root cause of AIDS stigma: lack of education. Too many people still don't have the correct facts about the disease. For example, women with HIV under proper medical care can usually have a child without passing the virus on and are likely to live long enough to parent the child. Since lack of information breeds fear and fear breeds stigma, one clear prescription for fighting stigma is renewed awareness and better education around the disease.

It would be one thing if stigma stopped with an attitude. If all it meant to be stigmatized was that some people didn't like us, it would perhaps be manageable, albeit uncomfortable. But when stigma gets in the way of our survival, that's another thing entirely. Thirty-four percent of you said that fear of stigma has prevented you from seeking care, treatment and support. And 19 percent of you said you don't disclose to health care professionals because of HIV-related stigma, a fact that certainly compromises the level of care you are receiving. Imagine how many people don't get tested for HIV because of stigma. It's estimated that one in five Americans living with the disease is unaware of his or her status. And according to the CDC, it's estimated that HIV-positive people who are unaware of their infection may account for 54 to 70 percent of all new sexually transmitted HIV infections in the United States. Seems clear to us that stigma is a barrier to individual—and public—health. Not to mention that 48 percent of you said fear of stigma has adversely affected your career. It's harder to keep a good job and afford medical insurance and prescription drugs if you're not performing at optimal levels at work.

But while much of the impact of HIV-related stigma is quantifiable, it is, arguably, those aspects of stigma not captured by statistics that prove the most devastating. As we went to press, more than 1,000 of you told us chilling stories of how stigma negatively affects your lives—breaking down your spirit and your will to live.

Only a small group of you spoke of how you fight stigma, standing proud and strong despite society's desire to keep you down. Some of you have found the inner strength and resolve to rise up in spite of people's fear and ignorance.

As a community of people living with HIV and as a society in general, we need to do a better job fighting stigma by reopening the dialogue about this disease and dragging the unseen facts and faces into the light. Because it is much easier to fear what we don't know. (Interestingly, while 85 percent of you said that President Obama and his administration are not doing enough to combat stigma around HIV/AIDS, 78 percent of you said that the HIV/AIDS community itself is not doing enough to combat stigma.)

It's a chicken-and-egg conundrum. Stigma around AIDS will only dissipate when the world is safe enough for people with HIV to no longer fear disclosing. Individually, many of us living with HIV who have disclosed in *POZ* or in our lives have seen that people can be supportive and kind once they understand the facts around the disease. (Sixty-seven percent of you said that people treated you the same, post disclosure.) But 87 percent of you said that the current anti-discrimination laws do not sufficiently protect HIV-positive people from being stigmatized, which means that things must change before we can afford to show our faces and change the way the world sees people living with HIV—for the better.

Forty-nine percent of you said that HIV-positive people's fear of being stigmatized is worse than the actual stigma. At *POZ*, we see repeatedly that this is true. For those who feel they are ready, and can safely come forward, speaking about having HIV can do much to erode the corrosive stigma that keeps us from good health. It bashes stigma when we show the world we have nothing to hide—and are nothing to fear.

STORIES OF STIGMA

The following are excerpts from some of the responses from readers to our anonymous survey about HIV-related stigma. We encourage you to post your stigma experiences as well.

I told a friend about my status while we were drinking coffee, and when I was done with the cup, he threw it out saying, "I will never drink out of that cup again."

*

When I was first going on disability, I had a doctor who was doing the intake come in the room in full hazmat suit and mask and gloves. His nurse wouldn't even let me face her. I had to sit at the opposite end of the exam table to talk to her—and face away.

*

I told [one] employer [about my HIV status] because I was out sick for four weeks. I will never tell another employer because I work total white collar and there's no threat of blood [exposure]. I don't volunteer for CPR training or participate in blood drives at work.

*

When I told a very good friend of mine (we used to camp beside each other every weekend), he cried and said he would stand with me, support me, be there for me. I have never heard from him again, not a call, not even a note or e-mail.

*

A friend in whom I was not interested romantically blurted out in front of a group of people that he could never become romantically involved with someone like me with HIV. My response was not to worry. I wasn't interested in anyone with chronic bad breath like him, either.

*

A friend of a friend who knew I had HIV disinfected the entire house after I came to pick my friend up to go out. When I walked back in a few hours later to drop her off, I noticed the whole house smelled of cleaning products.

*

I feel the stigma is HUGE, and out of the fear that my children would face repercussions from teachers, friends [and] other parents, we have decided to not tell anyone.

*

I am a nurse by profession for 20 years. I told HR the day I found out my HIV status [and] was put on administrative leave immediately and not called back or offered another job. [I had] impeccable credentials.

*

Having hemophilia, I was hospitalized last year for problems not related to HIV. A couple of nurses' bedside manner dramatically changed after they learned of my status. One actually never returned to my room. I was not spewing body fluids, so she was in no danger. She despised me for being positive.

*

A lot less of my phone calls are answered. People [who] I thought were [my] friends are too cowardly to stare something serious and life-threatening in the face—even if that means discarding me.

*

As a husband and father, I have not disclosed my status to anyone other than my wife and of course [my] health care provider.

*

All my Catholic friends whom I've know for 20 years all turned their backs on me, started making up lies in my community [and] attacking my character. I can't show up in public any longer. No one will hire me. I can't even volunteer. It feels more like they are carrying out some type of top-down orders to stigmatize people with AIDS. Probably from the Pope.

*

As someone living with HIV, I had people who never cared about my illness and worsen[ed] it. That traumatized me and [made me feel] as if I'm nothing. The more I became educated from health workers and support groups, the more I met others who comforted, understood and supported me.

*

I am basically unable to enter into any sort of romantic relationship. [I experience] quite a bit of social isolation—and it's just so tiresome.

*

First, I'm black; and second, I'm gay. The worst stigma comes from my own community. Black people sometimes make me feel dirty. I just don't understand, [since] this is killing our people. I could say more, but I'm getting very upset just saying what I have said already.

*

As a sexually active gay man in New York City, [I know] there's still a lot of stigma against positive men. It's tiring and depressing and makes me less willing to disclose my status. [I] even lie about it sometimes.

*

HIV stigma has ruined my life, my career, my family, my finances, my self-respect and my credit.

*

Formerly close friends suddenly lose touch; people don't want to know you. I usually say, "It's them, not me," but it's me who has to deal with it.

*

Doctors won't accept me as a patient if I tell them up front that I'm HIV positive. Sometimes if I do get in with new doctors and they realize I'm HIV positive, they get mean or mad at me. People have made me

wipe down everything I've used or touched with bleach. Living in a very rural redneck area of Florida, I take extra precautions to hide my status. Having gone to the local hospital ER [or to laboratories] for tests, I've had nurses drag other nurses or techs in to show me off like a sideshow at a circus. I see so much stigma here from the medical community it's appalling. Dental care is nonexistent for anyone HIV positive in my county due to stigma.

*

I must either turn a blind eye or tune people out, because I can honestly say in the 20-plus years of being positive, I have never had a bad experience. And I am very open about my status. I have received kindness and support. And I have been able to educate others as a straight, white female (after they get over the shock first—folks don't think people like "me" get HIV/AIDS).

*

For me it just feels like a very heavy weight I carry all the time. The variety of stigmas still attached to HIV makes the necessity to keep it hidden a burden that's carried every day. Sometimes it gets very heavy. Rather than jeopardize [your] career, family, friendships and security, you keep it secret. That's hard to do when you've lived an honest and truthful life.

*

I think some of the root cause of HIV stigma is criminalization of HIV transmission. We need more public awareness that HIV-positive people have sex too. I am an openly positive individual, and it saddens me that people living with HIV are so in the closet about it.

*

I had a job working for a well-known law firm in Chicago. When I disclosed my HIV status and my mental illness, they fired me. They said people would be scared to work with me. They said if I sued they would make my life miserable.

*

I got fired from my job as an administrative assistant at my church by my pastor. I lost my best friend of 20 years. I no longer trust anybody. I am in therapy. I cannot date. I sit in my house every day unless I have to go somewhere. My life is HELL.

*

I had a cousin tell everyone I went to high school with that I was positive. I did not go to my reunion.

*

Anonymous phone calls were made to my job [by clients], stating that they were no longer coming to the hair salon.

*

I worked in because I had AIDS. I continually struggle in the dating arena [because of] too much rejection. I know that I cannot get involved with a man with any sort of social status due to my HIV; they do not want to be associated with HIV.

*

Most, if not all, of my negative experiences have been with, by or in the presence of medical or dental personnel. After the disclosure, everything changes. They look at me like I'm from outer space, and the quality of their care reflects it!

*

I found out when I was five months pregnant. I went through a custody battle, and [my child's] father tried to use my [HIV] status against me, but the judge would not allow it.

*

I dated a man once, several years ago. I kissed him. The next day I decided to share my HIV-positive status with him. He freaked out and said, "They should mark people like you, so the rest of us can tell."

*

I think one of the main problems I've had with stigma comes from myself, being a heterosexual HIV-

positive man. It’s hard for me to disclose my status for fear that I will be labeled gay. There still remains so much ignorance toward HIV.

*

I had to sue a former employer for discrimination because of stigma and fear of public disclosure of my positive status.

*

I was removed from direct patient care and placed behind a desk with a “made up” job to keep me busy and away from what I loved doing.

*

I have been asked not to share my water bottle with my 3-year-old nephew.

*

I have been fortunate in the last 10 years to have not received a negative response from anyone I had to disclose to. However, I am extremely selective about whom I share this info with.

*

I think I must be an unusual case, the exception to the rule, but in 15 years of living with HIV, I can think of only one time when I was “rejected” by a potential date because I revealed my status; otherwise, I have never experienced an obvious negative reaction to my disclosing.

*

I’ve been blessed in that I have not experienced any stigma. However, it might be that I was stigmatized and didn’t know it.

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