Portraits of
Women

a positive life

Living with
HIV

Interviews by River Huston

Photographs by Mary Berridge

preface

In 1993, I started a job interviewing mothers with AIDS and their teen-age children for psychological research studies. The job took me all around the New York area, on subways and buses, to the most remote corners of the boroughs, and I entered the homes of countless families. I would sit with these women and barrage them with a litany of dry and invasive questions: "How many times would you say you drank alcoholic beverages in the past three months?" "Do you have enough money every day to eat three well-balanced meals?" "How many times have you had sex in the last three months?" I asked the teenagers a similar list of questions, and thus I produced the clinical data necessary for the quantitative study.

At the same time it struck me that the actual lives of these HIV-positive women were all but invisible. One could read in the paper that women, and in particular lower-income women, were the fastest growing segment of the HIV-infected community—but beyond that they were drastically underrepresented in both the mass media and the arts. And here these women were before me, struggling with their illness, working, raising children, taking care of their homes, and coping with a sense of vulnerability and uncertainty unknown to most of us.

I had recently completed a series of photographs of teen mothers, and I wasn't really sure what I wanted to photograph next. But meeting these women, seeing what their lives were like, and talking to them put an end to my confusion. At first it was difficult finding women to photograph. Why would anyone want to have her picture taken if going public would expose her to stigmatization and prejudice? I contacted support groups and social-service agencies; I placed ads in newsletters. Slowly, women began to call me back, and I hauled my camera and tripod onto the same subways and buses I had ridden for my interviewing job, only this time I was not trying to reduce their individual experiences to a set of numbers.

About a year after I began working on this project, a woman from New Hope, Pennsylvania, answered one of my ads, so I boarded a train and went out to photograph her. She immediately impressed me with her openness and ribald sense of humor. She even suggested that we do some nudes. On top of this, she patiently answered my prying and somewhat naive questions (for instance: "Do you and your boyfriend have sex?"). I had been looking for a writer to record the stories of the women I was photographing and I wanted that person to be involved in the community of HIV-positive women. Well, she was a writer and she was definitely involved. This woman was River Huston.

When I was in training for my interviewing job it was emphasized that I should be "objective" and nonjudgemental so as not to prejudice the "data." When I had to ask such questions as "Have you thought about who will take care of your children when you die?" for example, I never knew how to pose them "objectively." Even if it was designed to elicit a simple yes or no answer, the question itself bore so much emotional weight as to render such an answer almost meaningless.

My photographs are not objective. They are very much my own vision of what makes my subjects' lives compelling. At the same time, I have tried to present the women I have photographed as honestly as I could—in their own environments—so that the specificity of their lives would be both palpable and realized.

Mary Berridge

introduction

In terms of both length and number of interviews, this book is directly influenced by the perception of HIV disease in the popular imagination. Fear of losing jobs and insurance benefits, fear of losing the love of family members and friends, and especially fear of the discrimination their children would face if their stories became public kept many of the women I interviewed from allowing their words to be published in this volume. Their fear is not to be taken lightly, as any woman, man, or child living with HIV disease well knows. Between the lines, as it were, these women are nevertheless still given voice here: together they whisper that anonymity remains a necessary strategy to resist some of the nastier, more pernicious cultural sanctions and reactions associated with HIV disease. May there be another day, another book, another wholly accepting public forum in which these women can tell their stories without fear.

What's missing from this book, however, is more than compensated by what remains. The bravery, courage, and commitment of the women you will meet in these pages is both representative and exemplary. Listening, transcribing, asking questions—the whole interview process always had me on the verge of tears. Hearing these stories at once took its toll and kept me going. It meant defying doctors' orders to stay in bed; listening and writing through my own bout with pneumonia; and painstakingly transcribing interviews during long stretches on the road while someone else was thankfully doing the driving. All the while, I kept reminding myself how important these words, voices, and women were, and how what might be "bad for you" (in terms of health) in another way is good for the soul.

Even though I have become immune to the tragedy of my own story, I cannot help being affected by the sadness, power, and courage of what I have heard over the last three years while we have been working on this book. The stories these women have told me are infectious. Certain words and phrases reverberate, returning to me at the most ordinary moments. I am making breakfast or walking the dog and remember Laurie's husband, Steve, saying to someone who has asked if he isn't afraid of losing his wife: "Our forever is not like your forever."

As a woman living with HIV disease myself, I have often been the one interviewed; the one answering the questions. Like many of the women in this book I have been frequently misquoted, misunderstood, or censored beyond all recognition. Such experiences dictated the method of this book so that the voices of these women would be honored almost as if I was an oral ethnographer instead of an interviewer or editor. Quite simply, I would let them tell their stories, transcribe them, read them back, and pay the phone bills later.

I believe in the truth of these voices, and trust they have something to teach us about what it is like to be a woman living in the late-twentieth century with a disease that provokes anger, hatred, and denial, yet somehow inspires in us equal measures of compassion, faith, and humanity. This book sets out to document such extremes in the hope of moving all of us towards a response to this epidemic that we can look back on as honorable.

susan

28, HIV-positive since 1988, diagnosed in September 1994

infected through sex

I went to Boston's Children's Hospital to see if Anna's bones were in place. When they took the X-rays, they look at everything. By fluke really they saw that she had an enlarged heart. I took her to see a cardiologist. He recommended putting her in the hospital. While we were in the hospital, the doctor felt that my daughter's symptoms were very characteristic of HIV infection. He said we should get tested.

My first reaction was anger at him for suggesting this. He asked me, 'You don't have HIV do you?' That made me even more angry. If I had that kind of information I would mention it. All the interns were asking if I had ever slept with anyone who had AIDS. I wanted to grab my daughter and run out of there.

I was very worried about my daughter. We both took the test to rule out HIV. We were supposed to get the blood tests back in two days. We didn't hear from them for a month.

In the meantime my husband went to a place that gave you your results in one hour. His test came back negative, and that kind of gave me hope that the doctors were wrong. When we didn't hear right back from the first doctor, I decided to take my daughter to an infectious disease specialist. Initially, he gave us optimism. When he looked at my daughter's records, he said, 'It could be HIV but it could be other things also.' He gave us another HIV test. He told us we would have our answer in two days. I had said to him, 'Look, I'm not suicidal. You can give me the results over the phone.' I called two days later, and he said he didn't have the results just yet. He asked if I could come into his office the next day. Right then I kind of knew that the tests had come back positive.

We went to his office the next day. When he told us, I really had no emotions. The doctor said, addressing my

husband, 'I have good news for you.' But we already knew his test was negative. Turning to me, he said, 'I don't have such good news for you. The test came out positive for both you and your daughter.' When he started with the good news–bad news stuff I really thought maybe it wasn't HIV. I was holding my husband's hand. His voice started to tremble badly. The color drained from his face.

That was about a year and a half ago. When I first found out, I was very emotional. I dropped out of school. I acted like a machine. I did what I had to do for my daughter, Anna. Once that was settled, I took care of myself.

My daughter is a lot healthier than she was. She doesn't get as many ear infections, and she has gained weight. The thrush comes back once in a while. She doesn't know what she has. She has another health problem that they didn't diagnose until after the HIV. She has cerebral palsy. At first they just thought that she didn't want to let go of my hand. But then it became apparent that she had real trouble walking.

Anna is outgoing and friendly. She is the most intuitive child. I know a lot of children are sensitive, but I really think that she has this sixth sense when it comes to other people's feelings. She knows exactly how you're feeling. If she senses that something is wrong, she will come over and pat you on the back and give you a hug.

She has had so many tests done to her that she knows something is wrong. She has had a spinal tap, an MRI, and a catheter up her urethra so many times. With her cerebral palsy, she goes to school for therapy. They don't know how HIV affects her cerebral palsy, really. She has a mild case.

When I see how she struggles to walk it reminds me she has AIDS. It screams out at me, "AIDS!" It doesn't say, "cerebral palsy," it says, "AIDS." Sometimes, a lot of times, I feel really angry and cheated; mostly just cheated.

I always thought I should have been tested before. I dated a man once who, in retrospect, acted very strange. He wasn't working when I met him even though he had his own company. I always thought that was odd. One time I got hepatitis—he called me in the hospital and he told me he loved me. This was really inappropriate for our relationship. Earlier in the relationship, he would always say, 'Don't I look good?' like he needed reassurance. He definitely knew he had HIV when we were together. He even mentioned it once. He said it was God's way of punishing people for being too promiscuous. This was 1988. Another time, he said, 'Oh, I have AIDS.' Then he said he was just kidding. I said, 'I don't kid about things like that.' When I tried to get in touch with him about a year and a half later, his telephone was disconnected. I'm assuming he is dead.

I'm angry at him. I would like to find out why he did what he did. He was definitely sleeping around a lot. He had one steady girlfriend and tons of other girls that he was seeing. I would like to get in touch with his girlfriend. I was dating him thinking he was breaking up with this woman. I know she didn't know anything. She used to come in through the pharmacy where I worked to pick up her birth-control pills. Obviously they weren't using condoms, either.

I have 150 T-cells. I used to be afraid of dying. Now it feels surreal, like this is really not a problem for me. Besides taking all the pills, I feel like I don't really have anything wrong with me. I'm okay. I'm really healthy, though things happen to me. I get yeast infections all the time and fungus on my toenails. I get really tired.

My husband, Roy, is very supportive. We have been married for four years. He has never said to me anything like he can't take this anymore. But I know this is difficult for him. It really hurts him to not see his daughter walk. It's the 'not knowing if we will be around' that scares him the most.

We still have sex. In the beginning we had a problem with it. Really, I had a problem with it. If my gums were bleeding, we couldn't kiss. And I would always be getting yeast infections because I was so sensitive. I would think of all the consequences and that would turn me off, it still does. Roy would claim he wasn't afraid of getting infected. He pushed for us to have sex. I would go for months not wanting to do it. I know that it was very frustrating for him. Now we have protected sex, but it limits us. I fantasize about having unprotected sex.

It was really difficult telling my mother. My mom was really depressed for a long time. I finally had to say, 'Mom you have to deal with this. You have to get it together.' I have a brother and we're really close. He doesn't talk about it. My family can't deal with it. They are ashamed.

Roy's family is much more open. They tell everyone they know. They send information, offer support. They are really great about it. They are not ashamed about it. My husband's uncle died of AIDS, so they are familiar with HIV.

When I'm really down, I feel like, 'Oh my God, Anna isn't going to have a long life. Neither one of us is going to have a long life.' Then I see my doctor, and I think that everything is going to be all right—no problem. With all these new drugs there's a lot of hope. It might seem hard, but in the long run it will be okay.

It's almost like AIDS gives me some kind of freedom. Like it can't get any worse, so go for it. I have nothing to lose. Risks are not so risky, especially emotional risks. Before HIV, I wasn't very assertive. I say what I feel now. AIDS has definitely made me a lot stronger.