

Troubling the Angels

WOMEN
LIVING
WITH
HIV/AIDS



**PATTI LATHER
& CHRIS SMITHIES**

Troubling the Angels



Taylor & Francis

Taylor & Francis Group

<http://taylorandfrancis.com>

Troubling the Angels



Women Living with HIV/AIDS

PATTI LATHER AND
CHRIS SMITHIES

 Routledge
Taylor & Francis Group
New York London

First published 1997 by Westview Press

Published 2018 by Routledge
711 Third Avenue, New York, NY 10017, USA
2 Park Square, Milton Park, Abingdon, Oxon OX14 4RN

Routledge is an imprint of the Taylor & Francis Group, an informa business

Copyright © 1997 Taylor & Francis

All rights reserved. No part of this book may be reprinted or reproduced or utilised in any form or by any electronic, mechanical, or other means, now known or hereafter invented, including photocopying and recording, or in any information storage or retrieval system, without permission in writing from the publishers.

Notice:

Product or corporate names may be trademarks or registered trademarks, and are used only for identification and explanation without intent to infringe.

Library of Congress Cataloging-in-Publication Data

Lather, Patti, 1948–

Troubling the angels : women living with HIV/AIDS / Patti Lather,
Chris Smithies.

p. cm.

Includes bibliographic references (p.).

ISBN 0-8133-9016-8

1. AIDS (Disease)—Sex factors. 2. Women—Diseases.

I. Smithies, Chris II. Title.

RC607.A26L377 1997

362.1'969792'0082—dc21

97-3989

CIP

Internal design and typesetting: Letra Libre

ISBN 13: 978-0-8133-9016-1 (pbk)

For Rex, PAL
For Elena, CSS

How do we get people who are afraid of us to hear this stuff?

—Linda B

I was going to die *before* I got HIV.

—Sandy

I have laughed more, cried more and eaten more than at any other time in my life.

—Chris

It's OK to be a positive woman.

—Joanna

(To Patti) You've grown so much and gotten a lot smarter than when I first met you at the AIDS retreat.

—Amber

When are you guys going to publish? Some of us are on deadline, you know.

—Linda B

Contents

<i>List of Illustrations</i>	ix
<i>Acknowledgments</i>	xi
<i>Preface I: The Book</i>	xiii
<i>Preface II: The Women and the Support Group Meetings</i>	xix

STORY SERIES ONE: LIFE AFTER DIAGNOSIS

1	“I’m Gonna Die from Stress, Not HIV”	3
2	“Living with a Time Bomb”	13
3	“Full Blown AIDS Had Come”: Lori	21
4	“I Got Another Wake-Up Call”: Linda B	25
5	“I’ve Got Some Stories That Would Curl Your Hair”	29
6	“And I Didn’t Even Pay My Income Taxes”: Amber	39
	Intertext 1—AIDS and Angels: A Cloudy Place	47

STORY SERIES TWO: RELATIONSHIPS

7	“The Phony Stuff, You Don’t Want to Go Through It Anymore”	63
8	“I’m Not Close-Mouthed at All”: A Daughter	77
9	“I Don’t Have Fifty Years to Be a Mother”: Lisa	79
10	“Love and Prayers, Mom”: Linda B	97
11	“I’m a Sexy Momma”	101
	Intertext 2—The Angel of History: AIDS as a Global Crisis	113

STORY SERIES THREE: MAKING MEANING

12	“I Don’t Know How to File It Away That This Has Happened to Us”	123
13	“I’d Probably Be Dead if It Wasn’t for HIV”	135
	Intertext 3—Angelology: A History of Truths	141

STORY SERIES FOUR: LIVING/DYING WITH AIDS

14	“We Are the Teachers”	151
15	“A Greater Risk of Hope”: CR and Linda B	161
16	“We Had a Real Nice Life”: Louisa	165
	Intertext 4—Death Makes Angels of Us All	173

STORY SERIES FIVE: SUPPORT GROUPS

17	“It’s Taken Me Years to Get Here”	179
18	“We’re Supposed to Be a Support Group”	193
19	“Seize the Day”: Lori	203
	Intertext 5—An Ache of Wings: The Social Challenge of AIDS	207

EPILOGUE

20	Troubled Reading: Our Bodies, This Book, This Fire	215
----	--	-----

RUNNING SUBTEXT

“Our Learning Hearts”: Chris and Patti

	<i>Appendix: Demographic Data</i>	239
	<i>References and AIDS Resources</i>	245
	<i>“Time to Go Home”: Holley</i>	251

Illustrations

David Adams, <i>Flying Woman: And She Still Rises</i> (1995)	xxix
Elsa Flores, <i>Angel</i> (1992)	60
Paul Klee, <i>Angelus Novus</i> (1920)	119
Will Shively, <i>AIDS Angel I</i> (1994)	147
Benjamin Jones, <i>AIDS Angel</i> (1992)	175
Paul Klee, <i>The Hero with the Wing</i> (1905)	212
Ben DeVeny, <i>Untitled</i> (1995)	237



Taylor & Francis

Taylor & Francis Group

<http://taylorandfrancis.com>

Acknowledgments

We are profoundly grateful to the women whose stories we tell here. For all the obvious and many not so obvious reasons, there would be no book without them. They gave time and insight to the lengthy interview process and privileged us with the most personal aspects of their lives. We are simply and deeply touched by their trust and hope.

This research was funded through two Ohio State University sources, the Elizabeth Gee Fund for Research on Women, 1993, and the Coca Cola Grant for Research on Women, 1995. Fieldwork and interview transcription costs were supported by an Ohio State University Seed Grant, 1992, a College of Education Small Research Grant Award, 1993, and a particularly timely cash infusion from Jim Pearsol, former Director of the East Central AIDS Education and Training Center. We thank Jim, too, for introducing us to one another and launching our research partnership.

Nancy McDonald Kenworthy of Athena's Press and Jon Brooks of Letra Libre were angels of desktop publishing and Jill Rothenberg of Westview Press helped us learn to live with the twists and turns of the publishing world.

We are grateful to the artists who have let us use their work, the community service associations that sponsor the support groups, the group facilitators, and the many members of our families and friendship circles who have stood with us through the time of bringing this book to fruition.

On behalf of the women of this book, we are pledging one-third of the royalties of this publication, after production costs, to organizations that help women and their families live with HIV/AIDS.

*Patti Lather
Chris Smithies*

The angel handed me a book saying, "It contains everything that you could possibly wish to know." And he disappeared.

So I opened the book, which was not particularly fat.

It was written in an unknown character.

Scholars translated it, but they produced altogether different versions.

They differed even about the very senses of their own readings, agreeing upon neither the tops nor the bottoms of them, nor upon the beginnings of them nor the ends.

Toward the close of this vision it seemed to me that the book melted, until it could no longer be distinguished from this world that is about us.

(Paul Valéry, quoted in Carolyn Forché's book of poems, *The Angel of History*, 1994)



PREFACE 1

The Book



AIDS is on the rise among women in the United States, especially poor African American and Latina urban women. This book explores the cultural meanings and social ramifications of the experiences and understandings of a particular grouping of women who live with the disease. Found in support groups, they both are and are not representative of the larger population of US women infected with HIV. To listen to these women deal with the disease and their experiences of the sea changes that HIV/AIDS brings to living suggests what it means for each of us to address similar issues in meeting what we cannot know: death and the future we make present in the way we live our lives. As witnesses to the women's courage and struggle, our hope is that this book will support, inform, and trouble its various readers as well as make visible the work of living with HIV/AIDS.

By raising such emotionally charged issues as death, survival and self-determination, this book walks a fine line between making a spectacle of these women's struggles and a wanting to speak quietly, with respect for all that it means to tell the stories of people willing to put their lives on public display in the hope that it will make it better for others. Charting the journey of their struggles with the disease, from initial shock to getting on with their lives in ways that make time for what matters often results in admiration for those who are HIV+. Their vibrancy and hopeful realism are lessons in living. Their journeys from infection to symptom to sickness to wasting to death are studies in what it means to be "wise before their time."¹ Their willingness to let us into their lives as witnesses to their struggles has touched us both in ways that we will elaborate upon in what follows. But before getting into their stories and our stories of listening to and then telling their stories, we want to say a few words about this book.

The question of what this book is can be approached by talking about what it is not. This is NOT a chronicle where we as researchers record events as unobtrusively as possible. The book is laid out so that, rather

than only “giving voice” to the stories of others, this is also a book about researchers both getting out of the way and getting in the way. As filters for the stories that we heard, we have written a book that is about others who both are and are not like ourselves, as we give testimony to what are our own stories and larger than our own lives. Telling of a loss beyond naming where we try to know from the inside what is our outside, a threshold between what we know and what is beyond our knowing, this book, then, is about the limits of what can be said and known about the lives of others. Doing this work as both a service and a learning, our challenge has been to risk the necessary invasions and misuses of telling other people’s stories in order to bear witness with fierce but unsentimental conviction that such stories can transfix, overwhelm, linger, and compel in taking readers to the place where this research has brought us, a place where we can see all the “truth” that we can handle and be grateful for it.

For a disease not known to exist until the last decade, AIDS has become a major part of living at the end of the twentieth century. It is understood in our culture in many ways, from “a metaphor for mortality, for human fragility and vulnerability,” in Susan Sontag’s words,² to a plague wreaked by a vengeful God, according to “the un-Christian religious right,”³ to “the battleground of moral courage,” to quote AIDS activist, Cindy Patton.⁴ Demographically, it is a disease of homosexual men and the Third World and, increasingly, the disadvantaged, especially of poor blacks and Hispanics, and women and children. Women, for example, now account for almost 40 percent of the 22 million people with the HIV infection worldwide, and in May 1994, the federal Centers for Disease Control and Prevention announced that women infected by male sexual partners are the fastest growing population of AIDS patients in the United States. Until recently, however, women with HIV/AIDS have been largely invisible in the epidemic. This book is designed to counter that silence as it explores what can be learned from the perspectives of HIV+ women about the cultural significance of the disease, its capacity to alter how we know ourselves and what we can do in the midst of epidemic.

Like the women we have listened to, our hope in the book is to provide support and information to women with HIV/AIDS and their friends, families and loved ones, to educate and inspire women with HIV/AIDS to advocate for themselves, one another and their communities, and to promote public awareness of women’s HIV/AIDS issues and a compassionate response for all people with HIV/AIDS. The subject of AIDS is as much about categories of inside/outside, us/them, innocence/guilt, as it is about viruses and healthcare needs. As such, it is not so much a story about “some others” as it is a story of how AIDS shapes our everyday lives, whether we be “positives” or “negatives” in terms of HIV status.

According to 1996 figures from the Centers for Disease Control and Prevention:

- It is estimated that 750,000 to a million and a half Americans are infected with HIV, approximately 1 in 250. This breaks down to 1 in every 100 men and 1 in every 600 women, but the risk is distributed unevenly across race, age and sexuality.
- More than 343,000 people have died of AIDS related complications since the disease was first reported in the US in 1981, more than have died in the Gulf, Vietnam and Korean wars combined.
- Of the 548,102 reported cases of those living with AIDS, 7,296 involve children under age 13 and 78,654 are women.
- 40,000 to 50,000 Americans are infected with HIV yearly. Half are under the age of 25. Rates are leveling for men who have sex with men and for pediatric cases, but increasing for women.
- Among persons 25 to 44 years old, AIDS is the leading cause of death for men and the third leading cause for women.
- In 1995, women accounted for 19 percent of new AIDS cases and 14 percent of the cumulative number. Three out of four of these women are women of color.
- HIV/AIDS in women increased 20-fold between 1981 and 1990. Black women are sixteen times more likely than white women to be diagnosed with AIDS.
- About 46 percent of the reported cases of women with AIDS in the US is from IV drug use. About 38 percent were infected through sexual contact with an HIV+ male. In contrast, heterosexual contact was the means of transmission for only 4 percent of reported cases of men.
- Of women who contract HIV sexually, the portion who are infected by bisexual males remains 10 to twenty percent; 80 to 90 percent are infected by intravenous drug users.

In terms of the changing demographics of the infection:

- African-Americans constitute 12 percent of the United States population, but account for over half of all US women with AIDS.
- Hispanics/Latinos constitute 9 percent of the population, but account for 20 percent of 1995 AIDS cases.
- In children reported with AIDS, 84 percent were black or Hispanic.
- More than 80 percent of all youth whose mothers have died of AIDS are offspring of African-American or Hispanic/Latina women.

This is not, perhaps, the book that any of the women would write, but it is an effort to include many voices and to offer various levels of knowing and thinking through which a reader can make their own sense. While there is some effort to look for patterns as well as differences, our primary interest is in a more interactive way of doing research than is usually the case where

researchers are presented as disembodied, “objective” knowers. We are very much in the book, but we have tried to put it together in such a way that our stories are situated among many voices where, accumulating layerings of meanings as the book proceeds, the story of these women goes far beyond the pages of this book as they change themselves, their worlds and researchers like us.

To look with restraint as we bear responsibility to the women who have told us their stories: this is our task as we accept the gift of witness proffered to us by this study. As such, this work has made a claim on us to not drown the poem of the other with the sound of our own voices, as the ones who know, the “experts” about how people make sense of their lives and what searching for meaning means. Hence the book is organized as layers of various kinds of information, shifts of register, turns of different faces toward the reader, in order to provide a glimpse of the vast and intricate network of the complexities of cultural information about AIDS in which we are all caught. While this book is not so much planned confusion as it might at first appear, it is, at some level, about what we see as a breakdown of clear interpretation and confidence of the ability/warrant to tell such stories in uncomplicated, non-messy ways. Wanting a book that puts things in motion versus captures them in some still-life, we walk a line between a victory story of triumph over adversity and a despairing story of loss and darkness. How, for example, are we to situate AIDS: as manageable? as fatal? As we trace the patterns and change of how the women make sense of HIV/AIDS, how they negotiate the balance between denial and obsession, how can we work to neither pathologize nor mythologize them? How can we not make the mistake of taking AIDS as an isolated event in someone’s life, to place it at the level of primary identity? Such questions capture our position where, while we are hesitant about adding to the avalanche of meanings caused by AIDS, our hope is to contribute to the strength needed to continue the fight.

By moving from inside to outside, across different levels and a multiplicity and complexity of layers that unfold an event which exceeds our frames of reference, we hope to create a book that does justice to these women’s lives, a book that exceeds our own understandings, some widened space to speak beyond our means. Via a format that folds both backward and forward, the book moves toward a weaving of method, the politics of interpretation, data, analysis—all embedded in the tale. Challenging any easy reading via shifting styles, the book positions the reader as thinker, willing to trouble the easily understood and the taken-for-granted. Within such a book, reading both becomes a kind of brooding over that which is beyond the word and the rational, and gestures toward the limits as well as the possibilities of knowing.

Some liberties have been taken, particularly the blending of different support group voices into one story about various aspects of living with HIV/

AIDS. Hence quotes from interview transcripts have sometimes been taken out of sequence and combined from across varied support groups for purposes of theme development, dramatic flow and to protect confidentiality. Efforts were made to not “sanitize” each woman’s way of speaking and each thematic grouping of chapters includes some of the women’s own writing. Each story series is followed by an intertext on angels which chronicles the social and cultural issues raised by the AIDS pandemic. The angels of the intertexts are intended to serve as both bridges and breathers as they take the reader on a journey that troubles any easy sense of what AIDS means. Across the bottom of much of the book is a continuously running commentary by us, Chris and Patti, the co-researchers, regarding our experiences in telling the women’s stories that moves between autobiography and academic “Big Talk” about research methods and theoretical frameworks. Occasionally, the subtext opens out to include one of the women, as she narrates her recent changes, providing a counter-story to her earlier story at the top of the page. Finally, scattered throughout the pages are “factoid” boxes which contain information about AIDS and writings from some of the women in the form of poems, letters, speeches and e-mails.

Networking across all of these parts, the effort of the book is a work which will not be exhausted by the meaning given to it by any one person, be they readers or the authors or the women themselves. Using a kind of speaking out ahead of itself, the book addresses the beyond of what we think we believe through the multiplication of layers of meaning that trouble what we come to such a book to understand and what it means to know more than we are able to know and to write and read toward what we don’t understand. It is our hope that the combination of all of this will work in ways we cannot even anticipate.

Notes

1. Ann Richardson and Dietmar Bolle (1992). *Wise Before Their Time: People From Around the World Living with AIDS and HIV Tell Their Stories*. London: HarperCollins.
2. Susan Sontag (1990). *Illness as Metaphor and AIDS and Its Metaphors*. New York: Anchor Books.
3. Phrase from former Surgeon General Joycelyn Elders, referring to opposition to educational programs in such areas as sex and AIDS (*USA Today*, June 24, 1994).
4. Cindy Patton (1991). Visualizing Safe Sex: When Pedagogy and Pornography Collide. In Diana Fuss, ed., *Inside/Out: Lesbian Theories, Gay Theories*, 373–386. New York: Routledge.



Taylor & Francis

Taylor & Francis Group

<http://taylorandfrancis.com>



PREFACE 2

The Women and the Support Group Meetings



We begin by introducing the Ohio women whose stories are the heart of this book. Through their words, we take the reader into the experience of daily living with HIV /AIDS. The journey of each woman is uniquely her own, but marked by one common decision: to join a support group created specifically for women infected with HIV. It is through the support groups in Dayton, Columbus, Cleveland and Cincinnati that we find these women. The support group is the backbone of this project. The women are the voice, the researchers are the hands and feet. Together, we write this book.

Originally, we planned to conduct multiple individual interviews. In the autumn of 1992, we met with one of the support groups to explore what questions we should use in the interviews. The women attending this meeting were spilling over with excitement and ideas; their talk became a dialogue of issues and feelings and insights. Group process was producing a form and level of collaboration that could not be remotely duplicated in one-on-one interviews, so the decision was made to maintain the group format for most of the data collection. As feminists, we were interested in working in participatory and collaborative ways, particularly in an area where efforts toward “knowing” have often been intrusive and exploitative.

Group interviews occurred from 1992–1993. We met with groups in their usual meeting places, which ranged from a living room in a home to meeting rooms in an AIDS community center or healthcare facility. After discussion of the project and confidentiality, each woman signed a consent form. The time was generally in the early evening; the meetings were marked by laughter, tears, self-disclosures, AIDS jokes, disagreements, hugs, and breaks for pizza. In addition to formal taping sessions with each group, we spent time with various participants at holiday and birthday parties, camping trips, retreats, hospital rooms, funerals, baby showers and picnics.

In the autumn of 1994, we met with some of the women so that they could help make decisions about the actual form of the book intended to address the relative invisibility of women in AIDS discourses. In winter, 1994, several women were frank with their impatience: "Where's the book? Some of us are on deadline, you know!" We decided to desktop publish an early version, thus getting the book to the women sooner rather than yet later and beginning the process of securing a book contract. The epilogue includes the women's reactions to the desktop printed version, as well as an update on them and their support groups.

Many of the women wrote their own introduction; when this was not possible, we wrote it. Each woman also chose either to use a pseudonym or to keep her own name, if she is "out" as an HIV positive woman. After the introductions, we take the reader to a support group meeting that we pulled together across the various times and places where the women talked about why they wanted to help in the making of this book.

Persons and Places

SUPPORT GROUP 1: Chris began her HIV/AIDS work here in 1988 when she started this group with the support of the local AIDS treatment facility. It was working with these particular women that inspired Chris to expand her AIDS work, to envision a book, and eventually to find Patti as a co-author. Chris moved in 1991 and commuted to group meetings until 1993, when she finally left the group in the hands of the current facilitator. This group meets at the local AIDS community center twice a month. We taped this group in August and October of 1992. Additionally, Chris taped with this group in July 1993 and February 1994.

CR: I am a 49 year-old African-American woman, mother of four daughters and seven grandchildren. There has always been a struggle in my life: incest, being poor and a single parent. When AIDS came into my life I had to accept it as another obstacle in my life, something I've been dealing with for years. I love myself more now but hate the disease and what it does to our bodies. As of this date, February 1995, I've been HIV positive for nine years, with an AIDS diagnosis for three years. I've met many loving people and lost them to this devastating disease. I know what's to come and, in the words of my favorite author, Maya Angelou, "And Still She Rises."

Lori: I am a 37 year old native Cincinnatian. I was diagnosed HIV+ in 1989, along with my husband who died one year later. My health held out until 1994 when my first AIDS infection hit, and I have been battling several illnesses since then. As I am no longer able to work, I have been involved in many AIDS organizations and enjoy speaking to public groups to share my experiences. [Lori died on August 8, 1996.]

Linda B: I am a 47 year old mother of two grown daughters and the grandmother of three (one girl, two boys). I was born and raised in a small north-west Ohio town. A high school graduate, I've had and still have a career in civil service—19 years. I now live in southwestern Ohio. I've been infected since my 39th birthday (8 years). I'm still asymptomatic. I'm very active in AIDS education. My mother, brothers and sisters know I'm infected. My Dad, who abused me as a child and teen, has not been told. My family is *very* supportive. Humor sustains me! I remain widowed—husband infected me.

Rosemary: Rosemary was 48 in 1992, when she attended support group meetings quite regularly, often accompanied by her young grandchild who lived with her. She described herself as “Afro-American, four kids, seven grandchildren, high school education, diagnosed in 1992, infected in 1987.”

Carol X: I am a 29 year old African American female challenged with “HIV,” healthy and protecting my health status. I am winning and will continue to win. I have obtained a lot in my few years of life, although there is so much more out there for me, and I will be around for the cure. Someone told me that I could do “ANYTHING THAT I SET MY MIND ON.” Why did they tell me that? I am going for it. I have obtained a BS and MS in mechanical engineering, and hope to start medical school to become a physician by the year 2000. Life with the “virus” is “no different.” I can say that the knowledge of living with the virus is a blessing in that there are so many people walking around without any knowledge and carrying the disease. I am blessed to have the knowledge and know that I have to take the best care of myself, to protect my health. I am LIVING.

Rita: Rita was 38 when we talked with her group. She described herself as “Caucasian with a sixteen year old child, unemployed with two years of vocational education, diagnosed in 1989, possibly infected in 1984.” Rita abused heroin and other drugs, and used sex to support her habit. Since her diagnosis with HIV, she has struggled to remain drug free.

Robyn: Robyn was 26 when we talked with her group. At that time, she described herself as “a Caucasian redhead, employed with a high school degree, diagnosed in August of 1991, not sure of infection date.”

Barb: I am 28 years old and have been a widow since October 8, 1993. Although Bill is no longer a physical part of my life, his memory, strength and courage will forever survive within me. I go on and live each day with the knowledge and certainty that we will be together again one day. But—until then—there are things I still need to do here. My life continues for reasons that aren't always clear to me.

SUPPORT GROUP 2: This group began in the fall of 1991. Begun by Hispanic community activists, this group met during the afternoon so that its members would not be away from husbands and children in the evenings. This group met at a community center, for about two years, and then disbanded. We met with this group in December of 1992.

Geneva: Geneva was unemployed with 14 years of education. She stated that she was “diagnosed June 21, 1991; I don’t know when I was infected. I am 23 years old.” Her daughter was 4 years old at the time of the interview.

Sandy: I am 29 years old and Hispanic. I welcome the idea of living with AIDS. It has taught me to love myself and to live every day to the fullest. My health is pretty good.

Maria: Maria described herself as “Hispanic, 39, no children, employed full time with some college education, diagnosed in 1987, infected in 1985. My health is fine, but emotionally it’s killing me, especially dealing with the public and their crude jokes.” She was a “drop-in” to the support group who agreed to be a part of the taped interview.

Ana: Ana was 40 and “out” as an HIV+ activist when we talked with her group. She described herself as “white, three children, unemployed, high school education. I was diagnosed June 14, 1989. My health is fine.”

Louisa: Louisa’s daughter was conceived and infected *in utero* in 1987. Louisa, a 24 year old Hispanic, received her HIV diagnosis in 1988. The child died from AIDS complications at the age of 4, in 1991. [Louisa died in June 1993 after many months of illness.]

SUPPORT GROUP 3: This group began in 1990 and continues to meet monthly. Chris has been a co-facilitator since fall of 1991. The group has always been sponsored by the local AIDS Task Force and meets at Chris’ office. We interviewed with this group in April 1993.

Diane: I’m 39 and I know I have grown so much in the past three and a half years since being diagnosed HIV. I have found an inner strength that I didn’t know I had. I’m a better friend than I ever thought I could be. I’ve taken responsibility for my own actions instead of blaming everyone else. I like myself. I like what I am; I like what I have to offer to people. Before HIV, I never thought I did. My friend, Holley, says I’ve been through a metamorphosis, changing before her eyes. For myself, now that I like who I am: if other people don’t, they can go to hell.

Joanna: I’m a 43 year old Gramma (three daughters and one granddaughter) with two years of college. My husband (my daughters’ step-father) and I were diagnosed positive in 1989 when he was hospitalized with PCP. He passed away February 1990; I have remained asymptomatic. Yes, there is love after HIV+. The spring of 1995, my beau and I were married.

Alisha: I am 38 years old. I graduated from Gallaudet University, Washington, DC, with a BS degree in Business Administration/Accounting. I have worked as an accounting technician for the federal government for ten years. I am divorced. I was diagnosed HIV+ in November 1991. My health is stable with medication, AZT. Support group is really wonderful although it is a very difficult time to get through. My great emphasis is that you are NOT alone!

Tracy: My name is Tracy. I am a 30 year old African-American graduate student. I never thought I would ever be caught up in one of the worst trag-

edies of the 90's. Unfortunately I was. I was diagnosed with AIDS in the summer of 1991. The negative aspects of my situation are that I feel that I've lost my chances of living a "normal" healthy life and becoming a mother. The positive side is that I have learned to value several aspects of my life that I used to take for granted. I only wish that it hadn't taken this experience with AIDS to make me appreciate life more.

Danielle: At the interview, Danielle, 25, described herself as "white, no kids, employed with a BS degree. I was diagnosed in April of 1990, infected in 1984." In 1994 and 1995, Danielle had many health problems and a major hospitalization. She was unable to write her introduction due to poor concentration and confusion, symptoms of an AIDS-related form of dementia that are not unusual in the late stages of AIDS. [Danielle died on July 23, 1995.]

Holley: At the time of the group interview, Holley had not yet moved to this larger city, primarily to find a support group specifically for women with HIV/AIDS. Holley was settled in a new apartment, working full-time, and just married when she was diagnosed with various cancers that rapidly overtook her body. She has joined this book through her poetry. Holley's ability to discuss her impending death and say "good-byes" at a support group meeting was the first time Chris witnessed such in-the-moment courage and openness when a support group faced the loss of a member. Holley died on February 12, 1996.

SUPPORT GROUP 4: This group was an outgrowth of a retreat held for women with HIV/AIDS in May 1992. The group was facilitated by an HIV+ woman until declining health led her to turn it over to a family service counselor. It continues to meet in the local HIV/AIDS community center on a weekly basis. We taped with this group in October of 1992 when it had seven members. It now has twenty-four members.

Amber: At the interview, Amber described herself as "32, white, unemployed due to the economy, one year short of a BA, no children, married and divorced twice, diagnosed in 1991, infected perhaps in 1985."

On March 20, 1995, Amber learned that she was NOT HIV+, in spite of three tests on one sample of blood in 1991. This unusual circumstance might be due to another immuno-suppressant condition, perhaps a rheumatoid disorder. It is also possible that Amber's blood sample was mixed up with someone else's. She continues to attend group as it has become her central support network. Believing she was HIV+ for four years, she struggles to shift her identity yet again, this time to an HIV- person who should feel no "survivor guilt" when so many of her friends are sick and dying from AIDS. She has plans to write a book about this experience and has expressed hope that "Dr. Patti" might help her do so. Amber was married in 1995.

Melody: Melody was the "founding mother" of this support group. She described herself as "39, white, one child, employed 'in life' with 14 years of

Amber's unusual situation began with the usual sequence of HIV antibody tests. In 1991, she had a standard Elisa test which has the highest percentage of false positives. A second positive Elisa test was followed one week later by a confirmatory Western Blot test, all on the same blood sample, all administered through a public testing site. In March of 1995, she traveled to another town for medical care and was re-tested with the Elisa in order to gain free healthcare. When she learned of the negative results, her new hometown physician administered a second Elisa, which came back negative, and then, a week later, a PCR (Polymerase Chain Reaction) which, while expensive and not routinely offered at public testing sites, is a DNA test that is the most accurate in terms of both sensitivity and specificity to the HIV virus. The PCR also came back negative. What all of this means in terms of both any kind of certainty in testing and Amber's reaction to what happened to her is dealt with further in Story Series I: "And I Didn't Even Pay My Income Taxes."

education. I was diagnosed in 1989, infected in 1984 or '85." She was formerly a substance abuser with substantial sobriety by the time of the interview. Since then, Melody has had a grandchild. Her health is sometimes good, sometimes not so good.

Tommie: I am a 32 year old white female who, when diagnosed in 1991, was very angry and resentful. Over the last four years, I have been able to accept and learn to be grateful for my diagnosis because I now have a new wonderful husband and I found out what unconditional love really is. I have also learned that God will help in strange ways. My health is wonderful.

Tina: I'm a 29 year old African-American woman. I'm learning to deal with being HIV+, after being diagnosed May 16, 1992. I go to support group and Healing Weekends. I'm not married and I have no children. Friends, relatives and co-workers help support me. Being a positive woman is part of my life.

Iris: Iris was 32 when we interviewed her group in 1992. She described herself as "white, two children, not employed, 10 years of education. I was diagnosed in 1990." In November 1993, Iris went through alcohol and drug treatment and has remained sober.

Iris asked to be re-interviewed in June 1995 because, "I'm not the person now that I was when you interviewed me for the book. Everything has changed so much. My recovery support group is what matters now; I don't want to continue dwelling on the HIV issue. Everyday a person changes, and I'll have changed again in another year. God willing and with the help of my recovery group, I'll keep getting better, but I really like myself better now than I ever have. My girls are my focus. Now that I'm sober, it's so wonderful that it's hard to explain. We have hopes and dreams together and plan for the future.

Little things like having a good dinner together mean so much. We want to go to the Grand Canyon and the mountains. When the day comes that I pass away, the girls can take my ashes back to where we were so we can be together even in death.”

Nancy: Nancy was diagnosed with HIV on July 5, 1991. She worked in the medical profession, and was deeply closeted about her HIV status at work. She had an adult son. She died in 1993, alone, except for her support group.

Sarah: I am a 42 year old assistant professor at a community college. I love to travel and be outdoors, camping, hiking, and relaxing in nature. I believe in using herbs, yoga and meditation for emotional and physical well-being and healing. I appreciate the loving support of my partner, family, and support group members. Where am I now? My current struggle is to cut way back on drinking alcohol and eating food compulsively. I believe stopping drinking is something that will bring direct benefits in slowing down the spread of HIV in my body, but it's also the toughest challenge I've ever faced. For me, alcohol has always been connected to socializing and good times with friends, and it's difficult to break the drinking habit and have fun without it. I'm gaining more excess weight (I'm already overweight) as I cut back on drinking; I seem to be exchanging an alcohol dependence for a food addiction. And as I gain weight, my self esteem drops and my sexuality declines. Also, my partner, who is HIV-challenged too, has begun to discover some health problems, and I worry about the impact of HIV on his life and our lives together. We've been blessed with a very special love and life together that supports me in my day-to-day living. I don't want to see him suffer; I don't want to lose our lives together; and experiencing his decline in health foreshadows my own yet to come. The HIV certainly heightens the preciousness of our time together in a very bittersweet way.

Co-Researchers

Patti: This project has come along at a time when I was asking myself hard questions about how social research could be of use to communities outside the academy. Responding to the same sorts of demographic questions that Chris and I asked of the women we interviewed, I am 48 years old, white, no children, with a Ph.D. in education and women's studies, and not yet, to my knowledge, HIV positive. Long interested in research *with* people, instead of the more typical research *on* people, what I have learned from being invited into this project has already greatly influenced my teaching and writing on issues of qualitative research in education and feminist research methodologies at Ohio State University.

Chris: I am 45 years old, I have a Ph.D. in counseling, and work as a feminist psychologist in private practice in Columbus. Since 1988, I have organized

support groups, workshops, and weekend retreats especially for women living with HIV/AIDS. I never ever thought that I would co-author a book. But then, who could foresee the AIDS pandemic? Frequently, I witness how “the VIRUS,” as it is called by the initiated, is a catalyst for finding what is really important in life. I guess this must rub off, because I credit my HIV+ friends and clients for inspiring me to become a mother to my daughter, Elena.

**“Statistics Are Human Beings
with the Tears Wiped Off” (Linda B)**

Twenty-five women with HIV/AIDS, ages 23–49, have participated in this project. Four are Hispanic, five are African-American, and sixteen are white. Thirteen are mothers and six are grandmothers. At the time of the support group interviews, in 1992, seventeen held jobs across varying professional and service sectors and eight were not employed. Twenty-three women have completed high school, and sixteen have some post secondary education. One is pursuing doctoral study, and another is preparing to take the MCAT examination for entry into medical school.

Dates of HIV+ diagnosis range from 1987–1992. By September 1996, over half of the women are living with an AIDS diagnosis and four are dead. Demographic charts are included in the Appendix, including a summary table that allows the reader to track individual women across their comments in the book.

Why are these women willing to open up their lives to strangers? No other disease is associated with so many stigmas. To identify as HIV+ is to invite the most personal of questions, spoken and unspoken. It also risks loss of relationships with family and friends, sexual intimacy, jobs and, with that, insurance and financial security, housing, identity and self-esteem. Illness and mortality may assume center stage in one’s life. Denial makes sense in such a scenario, but it often results in a high price being paid in terms of attending to healthcare needs and changing risk-related behaviors. The fol-

According to current diagnostic criteria, adopted in 1993, the line between HIV+ and AIDS is determined by a T cell count of less than 200 or the onset of two or more of the numerous opportunistic infections that characterize AIDS, e.g., thrush, kaposi sarcoma (rare in women), herpes simplex with an ulcer that lasts more than a month, diarrhea that lasts more than a month, PML (affects nervous system), lymphoma, and, specific to women, vaginal candidiasis that is recurring and resistant to treatment and/or invasive cervical cancer. The criteria themselves have shifted over the fifteen plus years of the pandemic, representing the changing nature of knowledge about AIDS.

lowing presents some of what these women intend by their participation in this project. It is assembled across various support groups at various times and places.

“It’s OK to Be a Positive Woman”

Chris: Winding down our interview, is there any feedback on what this evening has been like?

Melody: It was like after the retreat weekend. Tonight I feel is one of the times I can say I feel lucky that I am HIV+. I feel blessed with something special, that I can be bonded with so many special women. I feel special to be involved, with the women and the love.

Linda B: How else do we get the people who are afraid of us to hear this stuff?

Lori: I’m really excited about you guys writing this book and I want you to get it published right away. That’s just where I’m at right now. I want to do something. I think we’ve all had this feeling, why did this happen to me? And I keep thinking that there’s something there, there’s some message, there’s something that I need to be doing. Maybe it’s connected with going public, and that’s a struggle I’m going through and then this book is coming up at the same time. And maybe this is the sign that I’ve been waiting for, that things are going to change, we have to make them change, and I think the book is really good. Going through the interviews and hearing everyone’s story, a lot of this stuff, we don’t talk about in group, we don’t talk about like how do you really feel about that stuff. I think it’s good that these interviews let us do that.

CR: I’m glad about our meetings and the book because if the interviewers would have been doctors, especially men, I would have felt exploited. But I know there are women just like us all over, and hopefully other women and some doctors will read this.

Rita: I go to the library a lot. There is not one book about women. The closest it comes is a woman writing about her husband with AIDS. Everything I’ve found out about me and what I can expect comes from the women in this group.

Sandy: The one thing I wanted to stress whether in the book or not, is how important it is for them to give more to research on women, to help women get tested earlier, to find out earlier.

Chris: Any other comments on the process, how it’s felt being here and doing this?

Diane: I think it’s good to have a forum, to be able to talk about it. And to know that what we’re talking about is really going to go out and maybe make a difference somehow.

Patti: Why did you participate?

Danielle: Well, I think, if at all possible, I would like to reach certain people like government people and say “help us.” And to reach other women or other people who are infected and say “don’t give up.”

Alisha: Also, try to reach out to the few deaf women who are HIV+. I don’t think that they have really stepped out and I would like to reach them. Maybe deaf people are very afraid of it, and they are hiding from it. The deaf community is very, very small. And they wouldn’t want to step out because everybody would know. It is like one big family. And I want to encourage deaf women to do that and for them to know that there is nothing wrong with it. It is OK to take those steps. I want to help them, but who they are exactly, I don’t know. I feel like at this point that I am the only one in the world who is deaf and has HIV although I know that I am not. I want to encourage them to come out so that we can help each other.

Joanna: I want this book to get in the right hands so that people will do something about it, take some kind of action, get more people involved, to open the door for other people, let them know that it is OK to say that I am HIV+. It’s OK to be a positive woman.

On July 1, 1994, Being Alive in Los Angeles became the first HIV/AIDS organization to comply with the Americans with Disabilities Act of 1990 by opening its programs to the deaf community. Services include an ongoing deaf support group, a phone line for deaf callers, sign language interpreters at all social and program events and the formation of a Deaf/HIV Issues Advisory Board. *Being Alive*, 3626 Sunset Blvd., LA CA 90026. *Listen to the Hands of Our People* is a documentary film about seven deaf people living with AIDS, directed by Ann Marie “Jade” Bryan, 1990.

Positive Attitude: Keep in Mind the Following Things

1. New treatments are becoming more rapidly available.
2. Support networks are available at no or little cost.
3. Quality of life can be maintained and enhanced.
4. Developing and maintaining a positive attitude can have a strong beneficial impact on your health.
5. Remember that most people who test positive remain symptom-free and healthy for many years (*The Positive Woman* newsletter, see Resources).