

“I’m Still Surviving”: Oral Histories of Women Living with HIV/AIDS in Chicago

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Abstract: This article recounts the creation of an oral and public history project, “I’m Still Surviving,” which seeks to document, write, and display a women’s history of HIV/AIDS in the United States. Using feminist oral history and decolonial methods for both the collection and interpretation of oral history narratives, the project grounds and amplifies self-determination by women living with HIV/AIDS as it decenters the notions that academic historians are the experts on the history of the epidemic. The goal of the project is to collaborate with women living with HIV/AIDS so that together we can produce a decolonized public history of women’s experiences of surviving HIV/AIDS.

Keywords: HIV/AIDS, health, participatory design, public history, women’s history

HIV/AIDS is not, and has never been, an exclusively white gay male disease. While the first reported cases in 1981 were of white homosexual men, there were likely thousands of people—men and women, queer and straight, people living in poverty and those who were comfortably middle class—who were sick but not counted among the earliest cases. Perhaps they had avoided the medical establishment, fearing it would not care for them, or perhaps their ill health was not considered unique or unusual enough to be related to the illnesses afflicting white gay men. Whatever the reason, the connection between AIDS and white male gayness in the United States has remained so strong that it was not until the mid-2000s that we began to hear public health campaigns refer to

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the "new face of AIDS." The ads featured women, often Black or Latina, who had been infected by their male partners or through intravenous (IV) drug use (although female IV drug users never really got photographed or featured in publicity materials).¹ What the "new face of AIDS" phrase belied was that women, particularly Black women, were among the first people living with and dying from HIV/AIDS. In fact, some of the earliest public health reports documented that Haitian-origin women were four of the first thirty-four cases of AIDS among Haitian immigrant communities in the United States, and that an additional three women, only one of whom was identified as Haitian, bore children with "unexplained cellular immunodeficiency."² By 1990, AIDS was the leading cause of death among African American women.³ By 2013, one in four people living with the virus were women (287,500) and 60 percent of those women living with HIV/AIDS (WLWHA) were African American (it is not clear from the data where Haitian-origin women fit in this more current statistic).⁴ Many of those women are long-term survivors, defined as people who have been living with HIV since before the existence of protease inhibitors, which can effectively treat the effects of HIV.

What would it mean to take seriously the need to document this complex racialized and gendered history of AIDS and survival through oral history? How could it be done in ways that embrace feminist and decolonial methods and practices? In this article, I argue that one way to answer these related questions is to follow the lead of WLWHA at all stages of producing a women's history of HIV/AIDS, including creating mechanisms for them to make their stories publicly available. We must center their self-determination and their status as historical actors as well as makers/interpreters of history.⁵ This means focusing on

¹ The phrase, "New Face of AIDS," has its own history, which is outside the scope of this essay. Suffice it to say that the new face is often female and black or brown. See "Science and Technology: The New Face of AIDS; Women and HIV," *The Economist* 373, no. 8403 (Nov 27, 2004): 82-83. For a sampling of public health campaigns, see "Surviving and Thriving: Digital Gallery," accessed October 1, 2017, <https://www.nlm.nih.gov/exhibition/survivingandthriving/digitalgallery/index.html>.

² See "Opportunistic Infections and Kaposi's Sarcoma among Haitians in the United States," *MMWR* 31, no. 26 (July 9, 1982): 353-4; "Unexplained Immunodeficiency and Opportunistic Infections in Infants—New York, New Jersey, California," *MMRW* 31, no. 49 (December 17, 1982): 665-667.

³ Mardge Cohen, "Natural History of HIV Infection in Women," *Obstetrics and Gynecology Clinics of North America* 24, no. 4 (December 1, 1997): 743-758

⁴ See the Centers for Disease Control website, accessed October 27, 2017, <https://www.cdc.gov/hiv/group/gender/women/index.html#refd>.

⁵ As a historian of HIV/AIDS, I saw how these women narrators articulated a sense of self-determination in relation to their care and survival, in direct contradiction to the absence of women in the larger historiography of HIV/AIDS. I have learned anew from WLWHA about the social and cultural impact of the epidemic and its history from the point of view of people who have survived. In 2009, I published *Infectious Ideas: U.S. Political Responses to the AIDS Crisis*, which argues that putting AIDS at the center of our historical accounts of the 1980s fundamentally shifts the way we narrate the political reality of the period. While I used some existing oral history collections for this book, most notably the ACT UP-NY oral history collection (<http://www.actupny.org>), I did only a handful of interviews for the project, and none covered a longer life history of the narrators or focused

their articulations of gendered and racialized historical themes that, on the surface, may seem to have little to do with HIV/AIDS, such as patterns of racial segregation they experienced, or their use of drugs like crack and the effect on their reproductive and sexual health; it means exploring connections they make between those phenomena and their experience of surviving with HIV. It also requires recognizing the critical role women of color have played in and among communities of long-term survivors.⁶

The “I’m Still Surviving”: A Women’s History of HIV project attempts to do this kind of decolonial feminist work by according women living with HIV/AIDS what feminist theorist Chandra Mohanty describes as “epistemic privilege” for the “most marginalized communities of women.”⁷ Certainly racialized politics with deep ties to colonial notions of power and privilege have shaped who is or is not included in stories about HIV/AIDS. In 2011, I started History Moves, a community-led curation and design process and roving display space now jointly led with graphic designer Matt Wizinsky; “I’m Still Surviving” began as a collaboration between History Moves and a group of fourteen women living with HIV/AIDS—Bobbie, Cordelia, Debra, Delores, Katherine, Mae, Marta, Mary B., Mary C., Marilyn, Racheal, Rosemary, Sherri, and Sweet Pea—who are patients in the Women’s Interagency HIV Study (WIHS, pronounced *wise*) in Chicago, the longest-running longitudinal study of women and HIV in the United States. “I’m Still Surviving” exemplifies the potential of public history to center new narratives about HIV/AIDS’s past. In the process, it answers Mohanty’s call for

on women living with HIV/AIDS. There is also a small but significant number of oral history projects devoted to the history of HIV/AIDS; see the collections of interviews of activists in the ACT UP Oral History Project based in New York City (see <http://www.actuporalhistory.org> for more information) and the AIDS Activism Oral History Project based at the University of Kentucky (see <http://passtheword.ky.gov/collection/aids-activism-oral-history-project-1> for more information); medical histories of the epidemic through the voices of doctors and care providers, most notably the Regional Oral History Office’s collection focused on medical professionals in San Francisco, “Oral Histories on the AIDS Epidemic in San Francisco,” (http://bancroft.berkeley.edu/ROHO/collections/subjectarea/sci_tech/aids.html); and Ronald Bayer and Gerald Oppenheimer, *AIDS Doctors* (Oxford, UK: Oxford University Press, 2000), both of which provide detailed narratives of how the medical response emerged and how AIDS activists forced changes in the medical and political establishments throughout almost four decades of the epidemic. See also Megan Reed, “Existing HIV/AIDS-related Oral Histories?,” accessed January 25, 2016, <https://networks.h-net.org/node/16738/discussions/93138/existing-hivaids-related-oral-histories>, and Dan Royle’s collection, the African American AIDS Activism Oral History Project, which works to center the underexplored effort of African Americans affected by and infected with HIV, accessed November 7, 2016, <https://afamaidsoralhistory.wordpress.com>.

⁶ Being in conversation with them has led me to ask how I can be of service to a group of subjects who have the history in their blood and bones. As I worked to answer that question, other entities have done the same; see “What Would an HIV Doula Do?,” accessed October 21, 2017, <http://hivdoula.tumblr.com/post/138557273724/what-would-an-hiv-doula-do>, for a participatory AIDS history project, based in New York, which creates public programs where “asking questions” is “foundational.”

⁷ Chandra Mohanty, “Transnational Feminist Crossings: On Neoliberalism and Radical Critique,” *Signs* 38, no. 4 (Summer 2013): 985. Mohanty is among the most important feminist theorists writing about the decolonial imperative for the field of gender and women’s studies. See also Mohanty, *Feminism without Borders: Decolonizing Theory, Practicing Solidarity* (Durham, NC: Duke University Press, 2003).

"cross-cultural feminist work [that is] attentive to the micropolitics of context, subjectivity, and struggle, as well as to the macropolitics of global economic and political systems and processes."⁸ It takes seriously Maori scholar Linda Tuhiwai Smith's urging to build relationships and trust that give people space to tell histories on their own terms and through their own understandings or epistemologies.⁹

In "I'm Still Surviving," women living with HIV/AIDS make and take space for themselves to tell their stories, and collectively and collaboratively interpret them through dialogue with one another. These stakeholders work together to intervene in the process of collection, curation, and interpretation of the history of HIV/AIDS. The public history component consists of three different public displays: a book featuring the oral histories and photographs from the fourteen WLWHA, a short film with photographs and audio excerpts from the oral histories, and a pop-up exhibition, *In Plain Sight*, that displayed examples of all the materials (sound, image, text) and was installed at public libraries and art centers around Chicago in 2016.¹⁰ This effectively put the project, the women living with HIV/AIDS, and the History Moves team in dialogue with residents of neighborhoods that have experienced decades of profound disinvestment as well as those that have long benefitted from gentrification. Centering these women's stories challenged the existing racialized frameworks in historic and public narratives. This collaboration between public historians and women previously identified solely as medical research subjects produced not only a public women's history of HIV/AIDS in Chicago; it became a model of decolonial feminist oral history praxis.¹¹

Much of what we know about the experiences, past and the present, of US women living with HIV comes from feminist ethnographers and feminist medical researchers. Feminist ethnographers writing in and about the US context pay careful attention to how race and class intersect with gender in the HIV/AIDS epidemic, as well as to how residing in an urban or a rural area influences women's struggles and survival strategies.¹² But given the demands of their

⁸ Chandra Mohanty, "'Under Western Eyes' Revisited: Feminist Solidarity through Anticapitalist Struggles," *Signs*, 28, no. 2 (Winter 2003): 501.

⁹ See Linda Tuhiwai Smith, *Decolonizing Methodologies: Research and Indigenous Peoples*, 2nd ed. (London: Zed Books, 2012).

¹⁰ See www.historymoves.org for photographs of all the final products made during this collaboration.

¹¹ With generous support from the MAC AIDS Fund, the "I'm Still Surviving" Project has since expanded to two additional sites: Brooklyn, New York, and Durham, North Carolina. We now have collaborated on almost forty interviews, and we are planning a three-part book series and a second exhibition. This essay focuses on Chicago, where we started, in November 2014.

¹² See, for example, Michele Tracy Berger, *Workable Sisterhood: The Political Journey of Stigmatized Women with HIV/AIDS* (Princeton, NJ: Princeton University Press, 2006); Sabrina Chase, *Studies in Medical Anthropology: Surviving HIV/AIDS in the Inner City; How Resourceful Latinas Beat the Odds* (Piscataway, NJ: Rutgers University Press, 2011). There are a few exceptions that center journalistic or literary analysis. See, respectively, Gena Corea, *The Invisible Epidemic: The Story of Women and AIDS* (New York: Harper Collins, 1992) and Katie Hogan, *Women Take Care: Gender, Race, and the Culture of AIDS* (Ithaca, NY: Cornell University Press, 2001). The work of

disciplines, they have focused on producing generalizable knowledge about WLWHA; we therefore know more about women as types than as individuals. Ethnographers tend to group women by such characteristics as history of drug use, level of poverty, or access to housing, so that the typology drives the analysis. While we might hear a woman's voice in a portion of the interview transcripts included in the ethnography, the creation of useful composite categories is often the goal. The effect is a well-reasoned and supported generalization about how women of color survive in a neoliberal system, as, for example, in the case in Alyson O'Daniel's work on North Carolina.¹³

A substantial body of literature on the natural history of women and HIV/AIDS complements the ethnographic and social scientific record. One of the key producers of this literature is the medical research effort run by WIHS. A national consortium of women's health researchers and practitioners working in sites across the country, from New York to Illinois, from Alabama to California, WIHS first received funding from the National Institutes of Health in 1994. For twenty-plus years, WIHS has mapped much of the scientific knowledge we have about women's experience of HIV/AIDS. It has done this through the accumulation of data from thousands of research visits by the thousands of women enrolled in the study.

Twice a year, every year, women participants (the majority of whom are HIV-positive—there is also a control group of HIV-negative women) spend half a day with WIHS staff for a "research visit," which consists of a detailed psychosocial and medical interview about their daily lives, education, income and employment, household burdens and supports, sexual practices, drug use, medications, and mental and physical health; a gynecological exam with pap smears and biopsies, if necessary; body measurements; and the collection of as many as fourteen tubes of blood to assess HIV disease progression, kidney and liver function, infections, and genetic conditions. The medical researchers (MDs, MPHs, and nurses) organize WIHS as a study that documents the comprehensive physical, mental, and social health of women with HIV. WIHS staff listen to what the women participants have to say, rather than seeing them only as patients to be studied. Over the last two decades, the women have become a vast biosocial-medical archive of the epidemic, and the national consortium of medical researchers had produced well over 600 publications as of 2015.¹⁴

In both bodies of research (the ethnographic and the medical), the women are anonymized research subjects who are remixed into new categories—the

anthropological and sociological ethnographers in other geographic regions, most notably sub-Saharan Africa, have been informative to the field but are too numerous to list here and are beyond the scope of this essay.

¹³ Alyson O'Daniel, *Holding On: African American Women Surviving HIV/AIDS* (Lincoln: University of Nebraska Press, 2016).

¹⁴ See <https://statepi.jhsph.edu/wihs/wordpress/publications/>, accessed October 20, 2017.

women living with HIV in menopause, those who have suffered trauma, those who gave birth to children while living with HIV. In this process, they become representative of different collectives rather than individuals. This is, to be sure, still a feminist process, even an intersectional one that considers how structural and overlapping forms of inequality affect the women. It also potentially names their struggles to survive as meaningful and valuable. Generalizable research does not necessarily move us, however, toward a model that decenters or decolonizes knowledge production about women living with HIV/AIDS.¹⁵ I make this criticism of my fellow feminist scholars and research *not* because I think medical research and social science studying WLWHA do not value women's individual stories, but rather because I see these research processes as unable to hold individual women as whole subjects in the collective history of HIV/AIDS. Here I use the term *whole subject* in opposition to *research subject* to underscore that women's subjectivity, sense of self, and their understanding of the stories they want to share are critical to any interpretation that seeks to detail and center their histories. These women live lives that exceed, yet are often defined by, their serostatus, their experience with poverty, their status as mothers, daughters, and sisters. Their lives are both sums of these parts and more than the sums of these parts. Legal historian of slavery Annette Gordon-Reed suggests that writing about disenfranchised people "sociologically—what happened to the group as a whole" should not keep us from considering individual lives. "We learn much about the institution [here she is writing about slavery] from both perspectives," she concludes.¹⁶ The promise of historical inquiry, with its insistent refusal of the generalizable, has moved me toward a feminist oral history praxis that centers collaborative interpretation with living historical subjects and engages a decolonial framework to write a women's history of HIV.

Oral historians have long grappled with issues of how shared or sharing authority affect their work with narrators.¹⁷ Linda Shopes has explored the challenges of shared interpretive authority and the dissemination of oral history research beyond the archive. She writes, "'Sharing authority' may be a principle, but . . . it is often misconstrued and oversimplified. Working out what sharing

¹⁵ Mohanty's commentary on how Western feminists have relied too heavily on generalization is spelled out in "Under Western Eyes' Revisited," 502.

¹⁶ Annette Gordon-Reed, "Sally Hemmings, Thomas Jefferson and the Ways We Talk about Our Past," *New York Times*, August 24, 2017 (electronic version, accessed August 25, 2017).

¹⁷ There is an extensive literature on shared authority that readers of this journal will be familiar with. See, for example, Katharine T. Corbett and Howard S. Miller, "A Shared Inquiry into Shared Inquiry," *The Public Historian*, 28, no. 1 (February 2006): 15-36; Michael Frisch, "Commentary: Sharing Authority; Oral History and the Collaborative Process," *Oral History Review*, 30, no. 1 (January 2003): 111-113; Michael Frisch, "From a Shared Authority to the Digital Kitchen, and Back," in *Letting Go?: Sharing Historical Authority in a User-Generated World*, ed. Bill Adair, Benjamin Filene, and Laura Koloski (Philadelphia, PA: Pew Center for Arts and Heritage, 2011), 126-137; Linda Shopes, "Commentary: Sharing Authority," *Oral History Review*, 30, no. 1 (January 2003): 103-110.

means in practice is never easy.”¹⁸ This is a continuation of conversations feminist oral historians have had about the extent to which they can or should separate themselves from the process of knowledge production. One need only return to the anthology that serves as inspiration for this journal issue, *Women’s Words: The Feminist Practice of Oral History*, to see various approaches to feminist praxis that complicate oral historians’ work in and beyond the interview.¹⁹ Katherine Borland’s critical essay about her interpretive battle with her grandmother over the meaning of the elder’s oral narrative is a case in point. She concludes that, “by extending the conversation we initiate while collecting oral narratives to the later stages of interpretation, we might more sensitively negotiate issues of interpretive authority in our research.”²⁰

History Moves engages with questions of interpretive control by sharing authority in and beyond the interview in ways that Shopes, Borland, and others have called for. It gives narrators the space to develop, interpret, and curate history based on their own words and memories. As an ongoing project with changing themes, it uses two kinds of historical materials: narratives produced in and through oral history interviews between two historical narrators and one oral historian/technical advisor, and archival and personal photographs that narrators bring with them to the interview. Graphic and interactive designer Matt Wizinsky and I jointly supervise a team of students, and together we create platforms for the collection of historical records and the interpretation and presentation of that material culture to underserved audiences in Chicago. Our goal is to create dynamic space for community-based curation that allows narrators to add to and change displays. *History Moves* thus decenters the curator/historian in the production of public history (based in part on oral history) and contributes to decolonial historical work by focusing on stories that challenge the racialized hierarchies that have silenced or hidden them.

Equally formative to the project was my desire to intervene in how my work as an academic and public historian functioned in one of the most racially segregated cities in the United States. To this end, as an interdisciplinary team of historians and designers, we have built a practice of what I call the “mobile humanities”; in so doing, we suggest new ways to imagine an antiracist public history practice that highlights how history can speak to design. The mobile humanities move public history processes and historical displays through segregated and underserved neighborhoods. Like its antecedent, the bookmobile, *History Moves* functions as a roving educational space that tries to mobilize

¹⁸ Linda Shopes, “After the Interview Ends: Moving Oral History out of the Archives and into Publication,” *Oral History Review*, 42, no. 2 (Summer/Fall 2015): 308.

¹⁹ Sherna Berger Gluck and Daphne Patai, eds., *Women’s Words: The Feminist Practice of Oral History* (New York: Routledge, 1991).

²⁰ Katherine Borland, “That’s Not What I Said’: Interpretive Conflict in Oral Narrative Research,” in *Women’s Words*, 73.

cultural accommodations.²¹ Unlike its predecessor, however, History Moves, as a defining example of the mobile humanities, includes a process of lasting community engagement to make the humanities accessible and meaningful to wide audiences. We constantly resist moving *through* communities and instead seek to transform historical processes that amplify historians over historical subjects in situ. We shift the ground of who does the interpretation and in the process change the content of public history. With the potential to regularly change the topics under discussion and on display, History Moves gives communities access to various historical exhibitions *and* the ability to engage in the cocuration of them. (A women's history of HIV is the largest and most developed project we have undertaken, but we are starting to think about new subjects to explore through this process.)

History Moves starts the process of community-based history making with a refinement of the project's focus and ends with deciding what to make public and when. We do this at five distinct points in the collection and curation process, each as part of a series of workshops: first, community members decide the scope of the project or the topic of inquiry; second, they shape the questions and topics they will ask one another and engage in a group interview; third, those who have become narrators select the sections of their transcripts to be shared and jointly interpreted; fourth, we all determine and agree on a series of themes that will shape the various displays created by the graphic designers; finally we produce displays (books, exhibitions, films, audio pieces) that reflect the entire process. This requires collaboration and sharing authority at various points, allowing us to see what happens when historians step out of the way and let historical subjects determine the historical content and the method for sharing that knowledge. In effect, we build a process for concretizing Mohanty's notion of "epistemic privilege."

As is the case for most oral history projects, and certainly all those that seek to be engaged in antiracist and feminist work, History Moves's decision to begin work with the women of WIHS required us to develop an egalitarian consent process. As with any health/medical study that involves human subjects, WIHS's IRB oversees and regulates its research staff and their data collection. The IRB compels anonymity as an a priori condition for acceptable research on human subjects. Among other things, this means that women are assigned a number, and all data collected on them are coded with the number. The

²¹ The history of the bookmobile, as described by historian Derek Attig, suggests a complicated racialized history that was born of Jim Crow, when public libraries were for whites only. As the bookmobile traveled through all-black towns, it left only books and never models for integrated public spaces. In this respect, the bookmobile in its inception was more segregationist than anything else. According to Attig, it came and went, leaving African American communities unchanged and racial segregation intact. For an illustrated discussion of Attig's work see <http://ultimatehistoryproject.com/bookmobiles-racial-and-cultural-battlegrounds.html>, accessed November 1, 2017.

anonymity/confidentiality required by IRB has not kept WIHS staff from knowing and developing relationships with the women who participate. Over the course of twenty years, they have built deep and close connections across the staff-patient divide, which contribute to the care the women receive and their survival rates. WIHS's IRB process provides a critical function, making sure women's personal information is kept completely confidential and their privacy is maintained. But one of the consequences of this action is that the IRB marks all the women as patients, always in need of protection, a process that reduces them to objects rather than subjects.

Despite the importance of external oversight for medical studies on people who are often the most disenfranchised, there is a growing literature on the creeping power of the IRB to control anything it defines as research on human subjects.²² This is particularly true when the subjects of the research are considered vulnerable (queer, people of color, and/or poor women, for example), and IRBs have hampered many oral history projects originating from academic institutions.²³ "I'm Still Surviving" sought to intervene further in the restrictive IRB protection model by practicing an ongoing process of consent and empowerment of narrators. At the administrative level, we worked to convince the IRB at both my university and the WIHS that oral history is not research on human subjects. Both IRBs responded that oral history is not generalizable and therefore is not *research*. I argued, more to myself than to the IRB, that oral history is not research *on* human subjects and instead should be done *with* people who have historical *subjectivity*.²⁴

With the initial part of the consent process established, the History Moves team moved to a second stage of the project, conducting a series of workshops for the women on how and why to do oral history. We trained all fourteen participants to interview one another about their lives as people living with HIV/AIDS and as Chicagoans. This included (not surprisingly to the readers of this journal) how to actively listen and how to ask questions that would draw out narrators' experiences and memories. We worked as a group on a possible interview script. The questions they asked one another covered a wide range of topics including early family life, how they learned they were HIV-positive

²² Zachary M. Schrag, *Ethical Imperialism: Institutional Review Boards and the Social Sciences, 1965-2009* (Baltimore, MD: Johns Hopkins University Press, 2010); Laura Stark, *Behind Closed Doors: IRBs and the Making of Ethical Research* (Chicago, IL: University of Chicago Press, 2012); Robert Klitzman, *The Ethics Police? The Struggle to Make Human Research Safe* (New York: Oxford University Press, 2015); Carl E. Schneider, *The Censor's Hand: The Misregulation of Human-Subject Research* (Cambridge, MA: MIT Press, 2015).

²³ Michael David Franklin, "Friendship, Institutions, Oral History," in *Bodies of Evidence: The Practice of Queer Oral History*, ed. Nan Alamilla Boyd and Horacio Roque Ramirez (New York: Oxford University Press, 2012), 149-166.

²⁴ For the best primer on oral history and the IRB see Linda Shopes, "Oral History, Human Subjects, and Institutional Review Boards," accessed November 1, 2017, <http://www.oralhistory.org/about/do-oral-history/oral-history-and-irb-review/>.

(sometimes multiple times), how they managed to keep their children, what their experiences with the criminal-legal and prison systems were like, and the ways they used exchange sex (also called *sex work*) to survive and sustain themselves. It also involved questions about how their families came to live in Chicago and the Midwest as well as how the look and feel of their neighborhoods changed over the course of their lifetimes, and how lines of racial demarcation separating whites from blacks (and to some extent Latinos) moved south and west along Chicago's street grid.

We paired the women so that they could interview one another. One of the History Moves team members attended each interview session, serving as technical assistant and second interviewer. Each interview unfolded differently. When women had known each other for decades, they were able to dig deeper into shared memories; when they met through the project, the interviews served as a place to build connections with other women living with HIV.

The narrator-collaborators held little back in their interviews. They disclosed their HIV status to people who were not health care providers; they talked about the changing racial and economic contour of their neighborhoods and the impact on health care they received. Two selections from the transcripts, each chosen by the original narrator and affirmed by the other narrators—in a collaborative process described in detail below—illustrate this dynamic. The first is from Debra, a black lesbian politicized by her experience in the criminal-legal system and willing to speak truth to power from the start of the project; the other is from Bobbie, a white heterosexual woman not engaged with a larger community who had never told anyone other than her health care providers that she was HIV-positive.

I did my volunteer work, I did the MATEC [Midwest AIDS Training and Education Center] training you know. Because nobody wanted to be with the AIDS patients in Cook County Hospital. So, what'd they do? They trained the AIDS patients to go sit with the AIDS patients. Because we knew that there's nothing, we knew we needed comfort, so we took these classes and we went and comforted our people. I never forget, I walked up one day and there was this guy, he just had the sheet wrapped around him and he was just rocking. He was like—I've been here for five days, nobody's talked to me, they barely want to touch me. I'm like—we can talk, I'm here, I ain't going nowhere. And for me, that was my epiphany. To see him just wrapped up, just waiting to die. Because the nurses only came when they had to. So, from that point on I started running my mouth and talking.²⁵

²⁵ Debra, interviewed by Marilyn, Chicago, IL, January 23, 2015; unless otherwise noted, all audio interview recordings and transcripts are in the author's possession.

* * *

Still to today, my son went to his death and didn't know that I'm HIV-positive. My other two children don't know that I'm HIV-positive; my mother doesn't know, no one knows. My brothers don't know. And I lost two brothers from HIV. And I got one sitting right now in UIC that got sores all over him and everything else. He's getting ready probably to pass . . . soon. But he doesn't know I have HIV.²⁶

Debra and Bobbie each experienced a form of freedom in disclosure, the former in the late 1980s when she took control of her care and the imperative to care for others, the latter in the last year as she experienced a sense of relief in being able to talk about her serostatus with other HIV-positive and negative people outside her family. Each passage complicates the phrase most associated with the history of AIDS activism, "Silence = Death." Debra was compelled to speak when she witnessed the specter of death, while Bobbie was silent. These two examples resonated with the other women narrators, several of whom marked these as critical for inclusion in the public expressions of the project. How various experiences had silenced WLWHA, as well as how some had used silence, especially about their serostatus, as a practice of self-determination, came to be a running theme for the project. In each other's stories about decisions to tell some family members or friends and not others, they saw possibilities for their own future disclosures to people around them. More often than not, women who had spoken up about having HIV found support from the people they told, including one heterosexual Latina, Marta, whose children threw her a surprise sixty-fourth birthday party at the In Plain Sight exhibition when it was on display near her home. On the fly, because it was truly a surprise, Marta proudly used the exhibition to disclose her serostatus to extended family members she had not told in the thirty-plus years she had been living with HIV.

The women involved in the WIHS are used to being studied but are not often in the position of determining how the study is organized. So when one of the most vocal women, Cordelia, said she had been in WIHS for twenty years and working on the History Moves project was the first time she decided *how and what* to tell the researchers, it highlighted the power of sharing authority in oral history that medical research cannot accommodate. Cordelia, like Debra and Bobbie, wanted to write her own history, one where her life experience was defined as much by the changing nature of the block she grew up on—one that experienced the fundamental disinvestment from the Southside of Chicago in the 1970 and 1980s—as it was by HIV. As a result, her oral history contains rich details about her family's moves from a public housing project to the "nice area" of Englewood. Cordelia went on to describe how Englewood was hit hard by

²⁶ Bobbie, interviewed by Sherri, Chicago, IL, January 16, 2015.

deindustrialization and the extension and hardening of racial segregation, making it "nothing like it used to be." For Cordelia, structural inequality meant the loss of community-based care among her neighbors. This was the context and history Cordelia sought to put front and center.²⁷

We had the interviews professionally transcribed and returned printed versions to the women, not just with the intention that they would edit the transcripts, but also with the idea that they would begin to analyze them. Seeing their experiences on paper gave interpretive power to women who were not writers and who had not previously thought of themselves as narrators of written stories. The spoken words became text, while still retaining their unique voice. This is where the process began explicitly to shift from oral history to public history display. The collaborators selected portions of the text to share with one another. As the narrators found selections of the interview that they wanted to share, we created excel sheets that held all the selections (in subsequent workshops with women, I devised a system to have narrators mark up their transcripts with one of three notations: "must share, can't share, up to History Moves"). These functioned as living archives for the project, as each woman reviewed the excel sheets and made her notations. This was a practical way to support their own self-determination as collective interpreters. While the book contained every excerpt each woman wanted to include, we used the spreadsheet to help us narrow the selections for the film and exhibition to those that got the most annotations and highlights.

The History Moves team consistently made the case that narrators were in control of their own narratives, even as they also took part in shaping the narratives of other WIHS women. Because each interview involved at least two women from WIHS as well as me or one of my graduate student assistants, women heard from one another in ways that defy the privacy imperative of the WIHS research study, where patients are never joined by other patients in the exam room. At the start of each workshop and interview session, the people at the table discussed the need to affirm a consensual process of historical storytelling. This meant that narrators could decide, without explanation, that they did not want to answer a question. It also meant that upon review of the transcript, each could decide that what she said about a particular topic or person was not to be shared beyond the interview room. We all agreed to these conditions multiple times and, in the process, resisted structures that silenced some stories and perpetuated others.

The oral histories were not the only mechanism we used to center WLWHA's self-determination. In a series of seven monthly workshops, all twenty of us (the History Moves team and the fourteen women from WIHS) sat around a table at the WIHS office in the Illinois Medical District. We worked together to

²⁷ Cordelia, interviewed by Mae, Chicago, IL, February 6, 2015.

illustrate selected excerpts from the interview transcripts with photographs from the women's personal collections as well as ones we located in area archives. We developed ideas for ways to bring urban context to the forefront—we located images of the neighborhoods women talked about, for example, or churches and schools they attended. They used the photos to prompt memories and thereby create rich life histories of themselves as Chicagoans. We all—historians, designers, and women narrators—sorted the selected texts and images into four thematic areas: early life, crisis, diagnosis, and still surviving. The work around the table was a bit frenetic, but it produced a kind of connective tissue between and among the women that centered them as the historians of their own lives. We not only created a multimedia historical archive; through our growing relationships, we produced knowledge and understanding—a model of decolonial feminist history praxis.

In the next stage of “I’m Still Surviving,” Matt Wizinsky, lead graphic designer, worked directly with the women from the WIHS. While he had co-led the workshops where we named our thematic groupings and provisionally curated the collection of text and images, his graphic design work went into high gear as we began to imagine and create mechanisms to make “I’m Still Surviving” public. Wizinsky’s interest in typography and book-making became a way to make the stories legible to an audience beyond our group. The decision to produce a book and a traveling exhibition gave Wizinsky the opportunity to use the oral history excerpts in three distinct ways—as narrative history, as audio, and finally as typographical image.

In presenting the oral history excerpts typographically or as images, Wizinsky created a graphic language for the project as a whole. He replaced the women’s names with symbols (for example, &, @, and \$) when their excerpts were included in the body of the book or exhibition. This allowed the women to remain anonymous until the end of the book or exhibition, where each woman’s collection of quotes and photographs was displayed together. Wizinsky used bright orange and black to highlight different sections of the women’s narratives. The bright orange was the color of the cards that many of those in the project had carried in their wallets for over two decades as the only way to access care at Cook County Hospital, the only public hospital in Chicago. “Always carry this card with you,” the cards read, and so they did. (When I asked at our first meeting if they had any documents or objects that defined their histories, more than half of them pulled out the tattered orange cards.) This color, then, came to define the project and served as a touchstone for all the participants. Wizinsky contrasted the orange with black to emphasize certain parts of the text and to redact others. This insured the privacy of information our narrator-collaborators shared with us on medical forms and protected the identities of their children, whose names were often penned at the bottom of family photos.

We intended the visual language, when coupled with the substance of the women's histories, to encourage visitors/readers to focus on the larger history of HIV/AIDS and not solely on particular individuals' stories. In the case of Debra's quotes in the book (figure 1), the symbol and black highlighting focus the reader's attention on Debra's actions and voice, her sense of connection to other people with HIV/AIDS, rather than on her name or other identifying information.

In the exhibition, we put Bobbie's quote on a kiosk that served as the entry point to the entire gallery (figure 2). Here, the orange and black color scheme connected Bobbie's quote and story to the rest of the exhibition, even though the subject of the quote was about her decision not to otherwise disclose her HIV status in any context.

Public display in three-dimensional form of Bobbie's words about intentional silence made her story even more powerful. The extent to which people living with HIV/AIDS seek to maintain anonymity about their status is often in direct reaction to fears of discrimination and accusations of blame—by the government, healthcare systems, employers, coworkers, friends, and even family members. Strictly limiting whom you tell and whom you do not becomes a form of self-determination, as does publicly naming yourself as HIV-positive.

As a work of oral and public history (and, indeed, of public memory), "I'm Still Surviving" asked what it would take to transform women from subjects of study into historians of their own subjectivity. The name of the project came from one of the narrator-collaborators and speaks to the possibility of what indigenous scholar Linda Tuhiwai Smith calls "celebrating survival."²⁸ It also draws connections with earlier published projects driven by people living with HIV/AIDS, namely the 1987 edited collection, *Surviving and Thriving with AIDS*.²⁹ Our collaboration resists static notions of empiricist oral history research, where the researcher maps answers to her hypothesis using the evidence from her subjects.³⁰ Instead, we worked from a dynamic model that sustained an extended, ongoing process of consent; the narrator-collaborators determined what they wanted to share with one another and what parts of that collaboration they wanted to make public to audiences beyond the WIHS. Here again Tuhiwai Smith's *Decolonizing Methodologies* is instructive: "Consent indicates trust and the assumption is that the trust will not only be reciprocated but constantly negotiated—a dynamic relationship rather than a static decision."³¹ Collaboration can be a mechanism for decentering and decolonizing feminist oral history when the trained (oral) historian interprets through dialogue with and between narrators and challenges the gendered and racialized politics of knowledge production.

²⁸ Smith, *Decolonizing Methodologies*, 146.

²⁹ Michael Callen and Richard Dworkin, eds., *Surviving and Thriving with AIDS* (New York: People with AIDS Coalition, 1987), accessed February 1, 2016, <https://catalog.hathitrust.org/Record/010378276>.

³⁰ See Smith, *Decolonizing Methodologies*, 127.

³¹ Smith, *Decolonizing Methodologies*, 137.

☞ I did my volunteer work, I did the MATEC [MIDWEST AIDS TRAINING + EDUCATION CENTER] training you know. Because nobody wanted to be with the AIDS patients in Cook County Hospital. So what'd they do? They trained the AIDS patients to go sit with the AIDS patients. Because we knew that there's nothing, we knew we needed comfort,

so we took these classes
and we went and comforted
our people.

☞ I never forget, I walked up one day and there was this guy, he just had the sheet wrapped around him and he was just rocking. He was like—I've been here for five days, nobody's talked to me, they barely want to touch me. I'm like—

we can talk, I'm here,
I ain't going nowhere.

And for me, that was my epiphany. To see him just wrapped up, just waiting to die. Because the nurses only came when they had to.

So from that point on I
started running
my mouth and talking.

Fig. 1. Page spread from the book, *"I'm Still Surviving": An Oral History of the Women's Interagency HIV Study in Chicago, 2016.*



Fig. 2. Section of kiosk, part of the In Plain Sight exhibition at Pop-Up Just Art Gallery, Chicago, IL, April 2016. To see the use of color in the gallery display, view the photo in the online or PDF version of this article at doi:10.1093/ohr/ohy003. (Photograph by Roberta Dupuis-Delvin; used with permission.)

The imperative to collect an audio and material archive of women living with HIV/AIDS is more pressing than ever; treatment and prevention of HIV/AIDS may finally be in sight. We need to think anew about the role of consent, anonymity, and HIV/AIDS research, and for this we need historical examples of people who have both refused disclosure and embraced it—people who have fought for their own survival and the survival of other people living with HIV/AIDS. Collaborative oral history making offers one way to provide opportunities for decolonizing feminist praxis as it complicates who can best be defined as the interpreters and makers of a women's history of HIV/AIDS.

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