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EDICIONES COMPLUTENSE

Ellen Spiro's Early Documentary Films: Challenging Normative Cultural Productions of HIV/AIDS through *DiAna's Hair Ego* (1989) and *Invisible Women* (1991)

Paula Talero Álvarez[1]

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Abstract. Many cultural and scientific discourses about the HIV/AIDS epidemic in the late 1980s further marginalized those who were infected with the virus, especially vulnerable populations such as women of color and drug users. Ellen Spiro's early documentaries, directed as part of her work for the activist organization ACT-UP, maintain a strong opposition to these normative conceptions of HIV/AIDS at the time. This article analyzes two of her documentary films: *DiAna's Hair Ego: AIDS Info Up Front* (1989), and *Invisible Women* (1991, co-produced with Marina Alvarez). In both films Spiro empowers vulnerable populations and makes their stories visible, highlighting the protagonists' efforts to offer and find resources and to denounce both the inability of the governments and institutions to address the problems of women with AIDS and the lack of information about HIV/AIDS in communities of color.

Keywords: Ellen Spiro; Documentary Film; HIV/ AIDS; ACT-UP; Activist Art, Film Production

[es] Los primeros documentales de Ellen Spiro: Un desafío a las producciones culturales normativas referentes al VIH/SIDA a través de *DiAna's Hair Ego* (1989) e *Invisible Women* (1991)

Resumen. Numerosos discursos culturales y científicos sobre la epidemia del VIH/SIDA a finales de los años ochenta marginalizaron aún más a aquellos infectados con el virus, especialmente a grupos vulnerables como mujeres de color y consumidores de drogas. Los primeros documentales de Ellen Spiro, dirigidos durante su etapa en la organización activista ACT-UP, mantienen una posición diametralmente opuesta a las concepciones normativas de la epidemia que existían en aquel momento. Este artículo analiza dos de sus películas documentales: *DiAna's Hair Ego: AIDS Info Up Front* (1989), e *Invisible Women* (1991, co-producido con Marina Álvarez). En ambos documentales Spiro empodera a grupos vulnerables y hace visibles sus historias, destacando los esfuerzos de sus protagonistas para ofrecer y encontrar recursos, y para denunciar tanto la inhabilidad de gobiernos e instituciones para tratar los problemas de mujeres con VIH/SIDA como la falta de información sobre la epidemia en comunidades de color.

Palabras clave: Ellen Spiro; Cine Documental; VIH/SIDA; ACT-UP; Arte Activista; Producción Cinematográfica

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[1] Investigadora independiente (España)
E-mail: ptalero@gmail.com

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1. Introduction

American documentarian Ellen Spiro (New Brunswick, New Jersey, 1968) is acclaimed for her innovative and provocative social issue documentaries. This piece reviews her first works as a filmmaker, *DiAna's Hair Ego: AIDS Info Up Front* (1989), and *Invisible Women* (1991, co-produced with Marina Alvarez). Spiro produced these films as part of her work in AIDS activist organization ACT-UP (AIDS Coalition to Unleash Power), formed in New York at the end of the eighties. In her documentaries on women with AIDS, she highlights the need for safe sex awareness, primarily working with the small consumer format of video Hi-8 (Montgomery, 1995).

This article contributes to the discussion in feminist audiovisual products and especially in feminist non-fiction work, which has gained importance within film theory and analysis during the last few years. It discusses the role of feminist documentary to challenge hegemonic discourses and to have an impact on the construction of our social reality. Specifically, the article studies the influence of cultural productions around HIV/AIDS, a discourse that is still laden with stereotypes and prejudices today. I include textual analysis of two small "grassroots" documentaries that target and contest dominant media representations of the epidemic, reflecting on how Ellen Spiro's early documentaries disrupt these representations, as well as of AIDS activism and education.

2. Methodology

This article studies the documentaries by Ellen Spiro through the lenses of cultural anthropology and textual analysis. As researcher Nieves Febrer asserts (2010), non-fiction is a more concrete form of representation and narration of the reality around us; and documentaries narrate, organize and give meaning to the human experience. However, both fiction and non-fiction are the result of convention –that is, are unequivocally constructed–. Documentary cinema is understood here as an elaborated process of construction of signifiers that, later on, can be equally deconstructed. This article is aligned with Febrer's approach, which highlights two crucial characteristics of the documentary: its reflexivity, which blurs the frontiers between reality and its representation; and its behavior as a cultural object, subject to multiple interpretations and constant re-elaboration.

Regarding the textual analysis, my approach embraces the feminist practice of content analysis, as defined by Patricia Lina Leavy. According to Leavy (2007: 224), "by investigating culture in general, and popular culture more specifically, dominant narratives, images, ideas and stereotyped representations can be exposed and challenged", and "feminist researchers employ content analysis in very unique ways and ask questions that would otherwise go unexplored". This feminist research based on content analysis is crucial for three main reasons: first, to understand what meanings are embedded into our cultural products; second, to carry out a critique that explores the problematic aspects of those meanings; and third, to open the door to social change. For feminist researchers, the deconstruction of cultural norms found in popular products can serve as a political weapon, since it can demonstrate the ways in which patriarchal society, whether consciously or not, structures the media messages that accompany our lives (Mulvey, 2010: 57). Following Michelle M. Lazar's explanation of feminist critical discourse analysis, I assert that the goal is "to show up the complex, subtle, and sometimes not so subtle, ways in which frequently taken-for-granted gendered assumptions and hegemonic power relations are discursively produced, sustained, negotiated, and challenged in different contexts and communities" (142).

3. The HIV/AIDS epidemic: A cultural production

HIV/AIDS is not an epidemic that exists outside culture. When speaking of HIV/AIDS, we must remind ourselves that science is also the product of culture –it does not exist outside of the realm of discourse, but has been shaped by cultural production that manifests in multiple ways– We know AIDS only "in and through the practices that conceptualize it, represent it, and respond to it" (Crimp, 1998: 3). American sociologist and historian Cindy Patton goes as far as entitling one of her books *Inventing Aids* (1990), reflecting on the constructed nature of the epidemic. Similarly, scholar of medicine and women's studies Paula Treichler highlights that the epidemic is "cultural and linguistic as well as biological and biomedical". (Treichler, 1999: 1-2).

The understanding of AIDS as constructed through language and particularly through the discourses of medicine and science (Treichler, 1999: 11) is aligned with French philosopher Jacques Derrida's view, according to whom there is nothing outside the text, i.e. we only exist and conceive our reality within the margins of discourse. However, untangling the work that discourse achieves is complex. For American literary critic and academic Lee Edelman, discourse might not be as efficient in the fight against AIDS. Following Edelman (1994), if the ACT-UP motto asserts that silence about the epidemic results in death –"Silence=Death"–, it necessarily follows that discourse protects against death –"Discourse=Defense"–. He wonders, however, whether this correlation is necessarily true: Edelman argues that we must be wary of our constructions even when they attempt to contest dominant representations, since "no matter the explicit ideology they serve, they will carry within them the virulent germ of the dominant cultural discourse" (Edelman, 1994: 91). Producing and contesting meaning do not by definition defend against HIV/AIDS, according to Edelman. He may be right when he asserts that "there is no available discourse on 'AIDS' that is not itself diseased" (Edelman, 1994: 92): we know that there is no discourse outside the dominant cultural discourse. Nevertheless, I prefer to focus on another aspect that Edelman also points out: the fact that discourse is the only defense with which we can counteract discourse.

What this means is that we might be less powerless to counteract discourse than we may think. Although media technologies are not neutral –on the contrary, they have been used through history to codify, intentionally or not, different conceptions about gender, race, class and sexuality–, there are ways to problematize the construction and inclusion of the normativities coded in our media and cultural products, and to negotiate the meanings we receive. We understand that the messages we receive from our media are burdened with our society's values, judgments, and expectations. These constructions are incorporated not only into our cultural or media products, but also into the discursive dimension of an epidemic such as HIV/AIDS. Nevertheless, media is not a monolithic and all-powerful model, but has the potential for resistance, dissonance, and readings against the grain. As Inderpal Grewal and Caren Kaplan assert in the classic *Scattered Hegemonies*, "a cultural flow such as CNN has an undeniably hegemonic effect, but it would be a mistake to see such flows as unidirectional or uniform" (Grewal and Kaplan, 1994: 13).

This reasoning is aligned with the foundational theories developed by Stuart Hall. What he described as processes of "encoding" and "decoding" in 1980 already reflects the dual semiotic charge in cultural products: they are loaded with cultural meanings and signifies –encoding–, but need to be read and deciphered in multiple ways by the audience –decoding–. I agree with Stuart Hall when he reads the audience as having a certain agency: although he cautiously asserts that the media tends to serve to classify the world within the discourses of dominant ideologies, he also notes that this is contradictory work, since counteracting tendencies are also manifested. As Hall acknowledges, the media industry tends to serve the interests of dominant ideologies and groups, and resisting them is not an easy task. Hegemonic messages constitute pervasive forces, which determine specific readings and prevent others from emerging. However, sometimes audiences react to cultural products in complex and critical ways, and are capable of renegotiating the meaning of the media products they consume, and even of offering oppositional readings. This consequently means that our cultural and social constructions can be challenged and contested, and media can be used as effective sites of resistance and self-care. The early work of Ellen Spiro is a clear instance: she has done admirable work in order to resist and negotiate dominant narratives of the HIV/AIDS epidemic.

4. Discourses around HIV/AIDS: Marginalizing and resisting

Since the beginning of the epidemic, there has been a myriad of discourses around HIV/AIDS –see Treichler's catalogue, 1999: 12-13–. From a governmental act of genocide that attempts to eliminate "undesirable" populations (Epstein, 1996: 221) to God's judgment of a society that has disobeyed his rules, HIV/AIDS has been created and developed in conjunction with ideologies and political, social and economic forces (Crimp, 1998: 8). These forces, for instance, initially associated the virus with the four H's –homosexuals, heroin addicts, Haitians, and hemophiliacs–, while women were systematically excluded from trials and the possibility of treatment (Susser, 2009: 24). Many cultural and scientific discourses about the HIV/AIDS epidemic in the late eighties further marginalized those who were infected with the virus, especially vulnerable populations such as women of color and drug users. In many instances, some media, especially mainstream television and mainstream print, have spread fear and suspicion, and increased stigma. In the early days, media efforts to "put a face on AIDS" resulted in depictions of volunteers as "earnest gay men, perky white women, or grandmothers", while scientists and physicians "were frequently represented as serious white men, who sometimes appeared to be gay". Scientific publications, for instance, often articulated pre-existing stereotypes in a new, objective-sounding language (Patton, 1990: 26). If we take into consideration that individuals based many of their early opinions on AIDS on the information they received through different media (Cohen, 1999: 152), the mechanisms through which television, magazines, and newspapers perpetuated discrimination and stigma are clear.

Other media, however, have served the opposite purpose: they have been used to contest mainstream narratives, to challenge dominant representations of marginalized communities, and to increase social awareness. As Paula Treichler points out, the question is how to disrupt and renegotiate the powerful –and I would add pervasive– cultural narratives surrounding AIDS (Treichler, 1999: 37). The videos made by the activist group *ACT UP* are a representative example, since they attack the aforementioned dominant representations of the epidemic and of people with AIDS and aim to replace them with alternative representations (Epstein, 1996: 220).

Video production was crucial for AIDS activism. It constituted a prime example of a new form of political expression, as video maker and writer Alexandra Juhasz analyzes in *AIDS TV: Identity, Community, and Alternative Video* (1995). The early documentaries by Ellen Spiro exemplify this phenomenon, in which new accessible technologies enabled the creation of low-budget, community-produced video work. Camcorder AIDS activism sought to challenge mainstream representations of the epidemic and empower those who suffered from it. The documentaries *DiAna's Hair Ego* and *(In) visible women* by Spiro shared this goal.

5. *DiAna's Hair Ego: AIDS Info Up Front:* Black hair and AIDS

The documentaries *DiAna's Hair Ego: AIDS Info Up Front* and *Invisible Women* are fantastic examples of niches of opportunity and empowerment that can be used to resist and to contest dominant narratives. They both incorporate a strong, vivacious and cheerful oppositional stand toward mainstream representation of AIDS and those affected by it. Those seeking information and advice regarding safe-sex practices and HIV/AIDS are presented "with clips of hair salon patrons under hair dryers and with shampooed heads in sinks" (Montgomery, 1995), which highlights the humorous tone of the documentary. Ellen Spiro portrays a serious disease through a positive lens, joining DiAna's efforts in advocating for safe sex practices, optimism, and hope.

The performative style that characterized non-commercial documentaries in the decades of the eighties and the nineties pervades *DiAna's Hair Ego*. In this sense, the documentary seeks to establish a different relationship with the spectator, rendering the conventions visible and highlighting their representational nature. What is a stake in this type of non-fiction is not the "historical world", but the construction of the reality it captures and its representation (Febrer, 2010: 9). The very own Ellen Spiro is seen on scene: her image is reflected on the mirror of the hair salon and captured by the camera.

It is worth noting that DiAna's prevention campaign in her salon and portrayed in the documentary is mostly directed to black women, "which makes up the majority of local AIDS cases" in Columbia, South Carolina (Video Data Bank). In the early years of the epidemic, different groups had different access to HIV/AIDS information, prevention and treatment, and black gay men and black women were amongst the most vulnerable populations. In those first years, when DiAna's work starts, African American men and women were removed from images and discussions around HIV/AIDS (Cohen, 1999: 182), and the access to information and prevention was difficult. Mainstream media's representation of AIDS left unfilmed images of single low-income females of color. Hence, "the low-income woman of color hoping to negotiate both safer and non-procreative sex sees no model of herself in mainstream AIDS documentary" (Juhasz, 1990: 33).

In contrast, DiAna's work, as depicted by Spiro, takes place in a black beauty salon, and it addresses the needs of her community, mostly black and female. Black beauty salons have historically been spaces of cultural and social significance for black women, and oftentimes have been key for social change. For Tiffany M Gill (2010: 2), who has explored the reach of activism in the black beauty industry, these sites must be understood as "providing one of the most important opportunities for black women to assert leadership in their communities and in the larger political arena". In spite of their seemingly frivolous appearance, black salons have played a major role in providing a "fruitful and important base for black women to launch some of their most significant agitations for social and political change" (2010: 3-4).

5.1. Individual? efforts

DiAna's Hair Ego shows us how small efforts can have a strong impact on the community: DiAna's hair salon becomes a shelter for those seeking information and advice regarding AIDS prevention, and the efforts of DiAna herself are deeply felt in the town of Columbia, in South Carolina. Douglas Crimp (Crimp, 1998: 5) makes a fair point when he says that activist art has been key to the survival of those affected by AIDS, but I would agree that "engaged" art practices can take many forms[2], and they can all be efficient in the fight against AIDS. The prevention work shown in *DiAna's Hair Ego*, for example, is mostly the result of DiAna's resolution to make a positive impact on her community through games, informative fliers, workshops, or music. It started with small interventions: when she realized her community was lacking or was receiving incorrect information about HIV/AIDS, she started to offer brochures and free wrapped condoms to her customers, and she screened educational tapes in the salon's television monitor. DiAna worked during repressive times "to teach a sex-positive and compassionate response to the AIDS crisis" (Video Data Bank), and her efforts soon developed and grew: she started lecturing around the state, addressing AIDS and sexuality with a "refreshing directness and humor" (Montgomery, 1995).

Nobody works in isolation, and neither did DiAna. She took on the task of educating the black community in Columbia, South Carolina with her partner, Dr. Bambi

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[2] For Crimp, engaged art practices are collective endeavors that are employed by the collectives' members as an essential part of their activism.

Sumpter, and they created the South Carolina AIDS Education Network (SCAEN). The documentary itself is not an isolated endeavor either: Ellen Spiro was responsible for the direction, production and cinematography. She acknowledges her mediation in the construction of this story, as she "didn't shy away from images that show her reflection in the shop's mirrors" (Gever, 1993: 214). She did not work alone either, but needed the collaboration of the people showcased in the documentary, such as DiAna, Bambi and the customers, who are shown signing, commenting, or participating in the different activities organized by the SCAEN, such as the safe-sex workshops. Their voices convey the narrative in this documentary, since Ellen Spiro does not provide voice-over narration. She does not include non-diegetic music either (Holmlund, 1997: 42), but lets the diegetic sounds[3] speak about the story.

5.2. Impact: Activism

DiAna's activism fostered the creation of the South Carolina AIDS Education Network (SCAEN) in 1987, which originated and operated in her beauty salon. The 2012-2013 Concordia University Community Lecture Series on HIV/AIDS describes the efforts of the SCAEN in their YouTube video, which shows DiAna discussing *DiAna's Hair Ego* and her latest activist endeavors:

> Run by volunteers and funded by donations from salon clients and visitors looking for a way to help, SCAEN has provided one-to-one AIDS information to more than nine thousand people living in South Carolina, fostering projects such as AIDS Busters, which served to bring safer sex information directly to Columbia's youth, and an AIDS education and support hot line run from DiAna's own home. In 1989, DiAna joined forces with *ACT UP* to stage a State House rally for the rights of people with HIV/AIDS in South Carolina. A filmmaker borrowed footage from the rally and from DiAna's salon to make the short film *DiAna's Hair Ego*, which was honored by the American Film Institute and the International Public Television Conference (INPUT) in Dublin. (CUTV)

6. *(In) Visible Women:* Dancing with HIV/ AIDS

As professor of Anthropology Ida Susser asserts (2009: 40), historical, social, and economic discrimination, as well as biology itself, have framed the experience of women in the epidemic of HIV/AIDS differently than for men. Through cultural production, through discourse, women have often been rendered invisible. Not only them –injection drug users and disempowered children–, "many of whom were African American and Latino/a, found themselves silenced, invisible, and neglected in the early years of this epidemic" (Cohen, 1999: 146). The three women featured in this documentary are not complacent with the responses from organisms and institutions toward women with HIV/AIDS. In a time when their needs were rendered invisible and deemed insignificant, the protagonists of *Invisible Women* raise their voices to be heard in their respective communities: through poetry, art, activism, and dance, they explore notions of female invisibility and complacency in the face of AIDS.[4] Different Latinx and women of color, amongst which we find mothers and drug users as well, are represented in a positive light.

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[3] Diegetic sound or diegetic music refers to the world of the film, and it can be heard by the protagonists in the story. Non-diegetic sound, however, is added during post-production and does not refer to the story. Consequently, the protagonists cannot hear it. Non-diegetic sound is commonly used as background music for the visuals, and it establishes the tone and emotional force of the image (i.e. it tells the audience how to feel).

Mainstream representation of women with AIDS during the eighties in shows such as *Life, Death and AIDS* –NBC Special– or *AIDS Hits Home* –CBS Special– classified women in two categories: safe *versus* dangerous women. "A new group has now been labeled as the source of the disease", Juhasz argued: "Women, but not all women, only those considered to be outside the limits of social respectability" (1990:28). This hierarchy responded to the urge of mainstream media makers at the time: they needed to blame women for the spread of the disease, while at the same time perpetuating the myth that the middle-class, white male spectator did not need to worry about becoming infected (26). By separating women into these two categories, mainstream media fostered a depiction of women as "contained threats: an oxymoronic representation that allowed them to register simultaneously as iconographic site of danger and as easily controlled subject" (25).

The approach of Ellen Spiro is radically different from mainstream television, for it seeks to pave the way for community identity and self-empowerment. Jeannie Pejko, one of the protagonists of *Invisible Women*, is a Latina mother with HIV/AIDS who fights for the rights to treatment and prevention for women with AIDS and her families. "I've got family. They're not infected. But because they are not educated, my sisters and brother don't even know they are at risk", she claims (Spiro and Alvarez, 1991: 18.47). The depiction of Pejko, also a member of the activist group ACT-UP, contests the representation of mothers in mainstream AIDS documentaries, "the minority, poor and guilty, single mother of sick babies, and the white middle-class married mother of innocent victims" (Juhasz, 1990:35).

Marina Alvarez, who co-directs the documentary, is also featured. She openly talks about her disclosure and how she became politically active, joining ACT-UP. "I'm Marina Alvarez and I'm HIV positive, and there is nothing wrong with that. How other people perceive it… that's their problem", she asserts (Spiro and Alvarez, 1991: 2.20). In her interview, she makes clear that the government is not addressing the issues that affect women with AIDS. Marina introduces Irma McClara, the third woman included in the documentary, as having a special aura. Irma McClara is a dancer, and she uses dancing as a healing strategy, as something that gives her strength to continue her fight. McClara also denounces the situation of women with AIDS in prison, where they are "isolated, stigmatized, and humiliated", and where their confidentiality is "constantly violated". "I say this from experience", McClara says (Spiro and Alvarez, 1991: 22.50).

Invisible Women's inclusion of dancing as a healing mechanism and a way of resisting the narrative of tragic is an example of opposing mainstream, condescending or melodramatic narratives regarding HIV/AIDS. The art and practice of dancing can take both hegemonic and subversive forms, as the early work of scholar Angela McRobbie in the eighties shows. In *Dance and Social Fantasy* (1984), McRobbie sheds light on the negotiation that operates through dance, exploring the meaning dance has for women and girls. As McRobbie eventually asserts, it is a channel that despite its limitations offers opportunities for bodily self-expression and control, and for female pleasure and sensuality –aspects that are clearly seen in *(In)Visible Women*–. In the aforementioned work, McRobbie also discusses the contradictory nature of the representation of dance in films such as *Fame* and *Flashdance*. For McRobbie, the two films follow a common trend in popular entertainment, by offering images of "overwhelming conformity" with Hollywood's treatment of women and other images which seem to disrupt that same treatment (1984:150).

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[4] A longer summary of the documentary is available at the Video Data Bank: http://www.vdb.org/titles/visible-women

Art, dance, community AIDS education and AIDS activism are the preferred operational channels for the protagonists of the documentary. Spiro does an excellent job at including representations of these fiery, persistent women who seek to be recognized by medical professionals and policymakers as affected by AIDS, who fight to obtain resources for marginalized communities suffering from AIDS, and who attempt to raise awareness and prevention.

Ellen Spiro's work follows the approach of non-commercial community video in the United States in the eighties and nineties. In this sense, the treatment in *Invisible Women* is similar to the work by Not Channel Zero in *Black Women, Sexual Politics, and the Revolution* (1992), a video that examines "how African American women deal with issues of poverty, abortion, battering and lack of health care, and addresses how women's roles in community struggle and activism are often overlooked or ignored" –Third World Newsreel–. Music and audiovisual resources –in this case, around hip hop– also play a crucial role in the documentary by Not Channel Zero, which emphasizes the representation of black women in music videos.

Just like *DiAna's Hair Ego*, *Invisible Women* incorporates only a few questions from the filmmaker and lets the protagonists tell their own stories. It constitutes performative work, characterized by the negotiation between the author and reality. During the nineties, "new subjectivities" are incorporated into documentaries, and new ways of representing identity can be observed (Febrer, 2010:9-10). In *Invisible Women*, Spiro deploys a handful of strategies widely used at the time, specifically in non-fiction projects outside the mainstream industry. These new resources encompass conventions from genres like the melodrama and the telenovela, and can be seen in works such as the experimental documentary *Privilege*, by dancer and filmmaker Yvonne Rainer (1990) and *El diablo nunca duerme*, by Mexican filmmaker Lourdes Portillo (1994).

Throughout the documentary, the non-diegetic music links the interviews and footage excerpts together, setting the optimistic tone with Latin upbeat songs. However, Ellen Spiro includes the telenovela and melodrama tropes especially in the advertisements at the end of the documentary, and that are specifically targeted to a Latinx audience. This resource is brilliant. One of the ads incorporates common tropes from Latin American telenovelas –suspenseful music, black and white cinematography, over-the-top expressiveness, melodramatic dialogue– to raise awareness about the possibility of contagion from heterosexual unprotected sex, and urges women to use condoms regardless of their feelings for their partners: "I love you, but I don't love you enough to die for you", the female actress says. The other ad features Celia Cruz, a highly respected celebrity in the Latinx community around the world, informing the audience about the 40,000 people who had hitherto been infected with AIDS in the US, 30% of which were Hispanic. "AIDS does not discriminate according to sex, class, or race", Celia Cruz says. Celia Cruz, a Cuban-American singer considered “the queen of salsa”, passed away in 2003, but her influence was –and still is– enormous for the Spanish-speaking community.

6.1. Impact: Activism

The documentary includes footage from ACT-UP demonstrations, and many of the women shown are involved in the collective. The video is also linked to other activist projects as well, such as *The Artist and Homeless Collaborative* and *The Fear of Disclosure Project*. The video includes paintings made at *The Artist and Homeless Collaborative –A & HC–* as well, a project founded by the visual artist Hope Sandrow in 1988. Artists, art professionals as well as women, teenagers and children living in New York shelters are involved in the project, that tries to combat the adversities associated to homelessness through art and activities such as poster design, installations, life-drawing sessions, sculptural self-portraiture, lectures and discussions (Finkelpearl, 2001: 439).

Invisible Women is the second video in *The Fear of Disclosure Project*, initiated by Phil Zwickler in 1989 and produced by him together with Jonathan Lee. These videos sought to explore the act of revealing an HIV-positive or AIDS diagnosis, how disclosure affected those living with the virus and their communities (Rosenthal, 2005: 122-123). Besides *Invisible Women*, the project included four other videos: *Fear of Disclosure*, *No Regret*, *Out in Silence* and *Not a Simple Story* (Hallas, 2009: 263).

7. Summary and brief conclusions

Ellen Spiro’s early documentaries in the context of HIV/AIDS are grassroots works that do not seek to conform, but to disrupt mainstream representations of the epidemic. They are non-fiction narratives, since they reflect on the real lives of those who are represented. Both *DiAna’s Hair Ego: AIDS Info Up Front* and *(In) Visible Women* are small-scale projects, created with limited resources and reach. Both documentary films are also explicitly activist and they constitute examples of engaged activist art. *DiAna’s Hair Ego* is linked to the work of the SCAEN, and *In (Visible) Women* is linked to *ACT UP, The Fear of Disclosure Project* and *The Artist and Homeless Collaborative*.

These community-based documentaries are meant to challenge normative conceptions of HIV/AIDS and of people living with HIV/AIDS. They do not operate according to the mainstream market’s rules: they have a smaller budget, but they also have more room to problematize and criticize dominant discourses around AIDS. Since they are not subject to the expectations of the mainstream audience and the pressures and constraints from the industry, their margin to disrupt is wider. As Juhasz asserts, women can protect themselves from controlling images and institutions by taking control of representation and contribute to the social construction of women and AIDS (1990:43), and Spiro’s work meets this goal. These documentaries, however, can inadvertently embed other normativities, and sometimes this problematic is inescapable. For instance, DiAna’s efforts as shown in *DiAna’s Hair Ego* were perpetuating the dichotomy between “safe” and “unsafe” sex practices, a polarized view that could translate into a distinction between “safe” and “unsafe” people –those who engage in safe practices and those who do not–, and can further stigmatize and marginalize certain groups.

The groups represented in Spiro's documentaries are mostly women of color: the black community of Colombia in South Carolina is showcased in the documentary *DiAna's Hair Ego*, while in *(In)Visible Women* the focus centers around Latinx and women of color, mothers and drug users, who have been some of the most vulnerable populations in the HIV/AIDS epidemic. Both the documentaries seek to have a real effect in the real world: first, they contest dominant narratives about HIV/AIDS portraying those with the disease with a positive light, showing a different "face" to the epidemic. And second, these works also serve as a tool for political activism, since they spread information about the protagonists' efforts and denounce the inability of the governments and institutions to address the problems of women with AIDS or the lack of information about HIV/AIDS in communities of color.

Alexandra Juhasz explains in *The Contained Threat* that up to 1990 the representation of AIDS had been largely an attempt to muster control. AIDS became, in this sense, one more 'moral' imperative to control women through their sexuality. A new kind of sexual conservatism and a re-inscription of the monogamous, if not the procreative bed was encouraged (30), as media insisted that women could still have sex, but only "the right kind". Juhasz argues –and this author agrees– that mainstream AIDS documentary fostered "a quick return to the constraints before women's liberation: monogamy, marriage, and children" (27-28).

Radically opposed to these productions are Ellen Spiro's documentaries. In her early work Spiro took a strong, vivacious and cheerful oppositional stand toward mainstream representation of AIDS and those affected by it, empowered vulnerable populations –black and Latinx women, mothers, and drug users– and made their stories visible. Furthermore, she proposed a new, empowering way of depicting the populations affected by the epidemic. Her approach was aligned with what Alexandra Juhasz calls "the ongoing work of feminists: to create alternative practice which contributes to an emergent culture of sexual and personal freedom" (1990:44). That's exactly what Spiro did. And she did it in video Hi-8 and in less than thirty minutes.

8. Acknowledgement

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9. Annex: Film details

DiAna's Hair Ego: AIDS Info Up Front: Black hair and AIDS

Directed by: Ellen Spiro
Produced by: Ellen Spiro
Cinematography: Ellen Spiro
Release date: 1989
Running time: 29 minutes

Awards and grants[5]:
1991
First Prize, National Black Programming Consortium Prized Pieces
Juror's Award, Black Maria Film and Video Festival
Silver Apple Award, National Educational Film and Video Festival
Golden Gate Award, San Francisco International Film Festival, Honorable Mention
Australian International Video Festival, Honorable Mention
Australian International Film and Video Festival, Honorable Mention

1990
Atlanta Film and Video Festival, Best Activist Video Award
Louisville Film and Video Festival, Special Merit Award
Charlotte Film and Video Festival, Silver Medal Award
International Television Association, Finalist, Videofest '90s

1988-1989
Art Matters Inc., Unrestricted Fellowship
New York State Council on the Arts
Media Arts Grant Media Bureau, Finishing Funds

Summary: *DiAna's Hair Ego: AIDS Info Up Front* is a documentary film about HIV/AIDS that introduces us to the efforts of the hairdresser DiAna to educate her community about the epidemic. Her beauty salon in Columbia, South Carolina, becomes a center for information about HIV/AIDS and safe-sex practices and prevention of the epidemic. The documentary compiles, among other bits of visual information, footage excerpts from DiAna's presentations about AIDS at local conferences, working as a hair stylist in her salon, conducting role-playing exercises about safe-sex practices, and asking schoolchildren about their questions about AIDS.

(In) Visible Women: Dancing with HIV/AIDS

Created by Marina Alvarez and Ellen Spiro
Photography/editing: Ellen Spiro
Release date: 1991
Running time: 25 minutes

Awards, Festivals & Screenings: San Francisco International Lesbian & Gay Film Festival 1992 - Audience award for best video

Summary: The documentary *Invisible Women*, distributed by Deep Dish TV, features three female HIV-positive activists while they discuss their disclosure to others and how they became politically active. The documentary also presents poetry by Carmen Reyes and paintings by *The Artist and Homeless Collaborative*. The video also shows political demonstrations by *ACT UP* which focus on relevant issues to

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[5] Information from Ellen Spiro's webpage. Available at http://ellenspiro.com/hair.html

HIV-positive women[6]. It specifically shows stories of Latinx and Black women affected by HIV/AIDS.

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[6] Information from the Stanford University Libraries' Catalogue.

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