

MUJER Y SALUD

Oral Testimonies: the Other Face of the HIV Story

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ABSTRACT. Women's needs are different from men's; the research and services related to HIV/AIDS have been focused in men's needs. The implication of this approach is that it has had very serious consequences for women who live with HIV/AIDS. It has resulted in health professionals failing to understand the emergence of the symptoms, the complications, the necessary treatments, and the complex patterns of progression of the disease. Oral testimonies are an alternative methodology for the

development of theoretical and intervention models that incorporate issues pertaining to the life-styles and world-view of women with HIV and other socially alienated people. Through the testimonies of three women living with HIV the author discusses concepts such as social stigma, family, spirituality, and human solidarity and denounces the oppression, exclusion and dehumanization experiences that these brave women have experienced as a result of living with this condition. *Keywords: Testimonies, Women, HIV*

HIV/AIDS official story started in 1981. By 1983, the first woman with HIV/AIDS had been identified, and by 1984 reports that confirmed the existence of an equal proportion of men and women with HIV/AIDS started to arrive from countries in Central Africa. Nevertheless, the story was constructed as one that affected essentially males. We, women were left out. The consequences: a devastating experience, and a new space for social and political struggle. There was also the fact that HIV/AIDS emerged by striking social groups already outcasted, with lifestyles that threatened the social order. There was a profound ignorance that generated stereotypes and myths about the values, beliefs and lifestyles of these social groups. As a consequence, the investigation of the HIV/AIDS phenomenon faced difficulties in incorporating the multiple ways of interpreting the diverse cultural spaces that constituted it.

Scientific research, like other areas of knowledge, is not necessarily objective nor free of values, but frequently

reproduces the ideologies and myths of the historical time and cultural space where they are conceived. In our culture, institutionalized power, authority and domination by men frequently results in acceptance of a male vision of the world. A male vision is also observed in scientific research, it is reflected in the selection of the problem to be studied, the methodological approaches, the selection of participants, as well as in the interpretations and applications of the findings. The research on HIV/AIDS among women has focused on women as carriers of the infection- women prostitutes and pregnant women- instead of regarding women as human beings who live and die with the condition. The implications of this approach has had very serious consequences for women who live with HIV/AIDS. It has resulted in health professionals failing to understand the emergence of the symptoms, the complications, the necessary treatments, and the complex patterns of progression (1).

Living for Life: Testimonies of Brave Women

One of the main controversies resulting from the approach used by many texts on HIV/AIDS is that they ignore the main characters of the story. The testimonies of women who live with HIV/AIDS offer authentic explanations from their perspective. The testimonies have

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been defined as authentic narrative told by spectators who are prompted to talk because of the urgency of the situation, and then become main characters. The oppression they experience leads them to express an alternate proposal to the "official story".

To George Yudice (2), testimonies are a challenge to the official discourse since they reject the official discourses or the prevalent frames of world interpretation. It is a means for the common people to start fighting on the public arena, from where they have been excluded and forced to represent the stereotypes assigned by the elite. Jean Franco (3) says that testimonial texts cover a spectrum between biography and oral history, but the word testimony has religious and legal connotations. Furthermore, it has a public event witness and participant subject implicit. To Franco, testimonial literature has constituted an important genre for the rescue of the oppressed woman's power. The distinct trait of these stories is that an "abnormal" event prompts the subject to take over the public space and acquire a new identity. To Timothy Murphy (4), testimonial papers represent healing spaces and can have the effect of making it easier for others to talk about HIV/AIDS independently from the political, sexual or cultural agenda. Testimonies, according to Murphy, belong to the moral and political conscience continuum that moves activism during the epidemics, and bears an important function for individual protection. Therefore, testimonies constitute a central part of any moral analysis of the epidemics. It is an important way to challenge public mythology with respect to the multiple issues involved.

In her work *Tapestries of Life*, Bethina Aptheker (5) offers another point of view. She argues that oral stories or traditions teach women ways of life and ways to survive. These stories constitute ways of representation. They contribute to recognize women strategies to deal with, survive, construct and change the parameters of their existence in their own terms, and not in contrast with male strategies. Above all, the testimonies of women can teach us the multiple ways of resistance and survival that they have used to make their voices heard. These ways of resistance are not necessarily feminist nor political, that is, they do not emerge from the understanding of any theory, and they are not up to date with the political experience. This experience exists outside of the political parameters, and out of the reach of any of the traditional definitions of progress and social change. Oral testimonies make it easier for women with HIV/AIDS to reveal their condition. They offer them the opportunity to express their feelings of anger, fear, and pain. This is a big step of psychological liberation. Also, they constitute an instance of human solidarity since they are a way to help others,

and at the same time receive the support that they need. For some of them, testimonies are also a space for social liberation because they facilitate the challenging of the ideologies, myths and metaphors that the 'official discourse' supports about HIV/AIDS. The testimonial experience, offers the opportunity to denounce the oppression, exclusion, and dehumanization experiences that they have lived.

Perspectives and Explanations About the Health/Illness Phenomenon

Oral testimonies can be considered as an alternative methodology for the development of theoretical and intervention models that incorporate issues pertaining to life-styles and world-view of women and other social outcasts. Moreover, oral testimonies can teach health professionals other perspectives and explanations about the health/illness phenomenon. The video/film "*Viviendo para la vida: testimonios de mujeres valerosas*", as we will see in this section, has provided the opportunity to many health professional to meet the other face of the HIV story. Such testimonies also have offered the opportunity to reflect about their own feelings and prejudices.

Social stigma. Historically, women have been the object of oppression and violence through prejudice and discrimination in the diverse cultural spaces. During the last decades, we have questioned the alleged theorists and the social and cultural practices that have perpetuated our situation. We have developed new proposals that allow the acknowledgment of our humanity, we have started to discover that we are strong persons, capable of being committed to life, and that we have an enormous hope to continue fighting. On the other hand, HIV/AIDS and its ideological sequels make us face a new situation of oppression, moves us to a new social and political space, and triggers the emergence of a series of prejudices that stigmatize women who live and die with HIV/AIDS. The profound roots that support stigmatization allow for this process to have a great power of oppression.

For many women living with HIV, social stigma is not a new experience since, in other occasions, they have been in the 'hole'.

"I know the other side of addiction...of the coin...someone who can afford her addiction versus someone who has to hustle on the street to maintain her addiction. And that was the very tough part because I had to do a lot of things that I didn't like, but I had to because I had a need. This...was stronger. And it was then, that I went into prostitution and other criminal

activities and I stayed living at La Perla.

Then I reached the lowest point in the twelve years of strong addiction that I had, I reached the lowest point where I felt worthless, I felt that my self-esteem was on the floor, that I wasn't worth anything, that the things I had accomplished...I had lost everything...my job, my apartment...my daughter, my family...my friends, and I'm very sad and very lonely...I was in a state in which nothing mattered to me anymore. I didn't care about my life."
(Lizzie)(6).

Disclosure of HIV/AIDS diagnosis. The disclosure of the diagnosis is difficult for both genders, but there are unique situations faced by women. Many women with HIV/AIDS depend on public institutions, they are in charge of children, and need the support of family and friends. Fears of institutional repression, of losing their children, their partners and of their family rejection, forces them to keep silent. Economic dependency and the responsibility to care for others complicates the decision of revealing the diagnosis (7). One of the first questions women ask themselves when they receive the results of the HIV/AIDS test is: To whom do I have the obligation to reveal the HIV diagnosis? At a time when a person is emotionally weak, with a lot of fear and specially guilt, the fear of reactions that will cause isolation and abandonment makes them keep silent. To reveal the diagnosis could be an important step in breaking the stigma associated with HIV/AIDS. Nevertheless, the daily experience from the 'hurricane eye' (the medical space), leads to an understanding of the need not only to respect the decision to keep silent, but in occasions, to suggest silence to protect lives. Even though for many women the possibility of facing HIV/AIDS was a possibility that they considered plausible, the moment of HIV diagnosis constitutes one of the most devastating experiences which they have to deal with.

"Then, well, since then to me, well, I was already an extraterrestrial...like something out of this world, something abnormal...something that was going to be rejected...I had felt rejected all my life, but now more, this was the last straw...then...I took up that load...but I remained the same, I didn't care about my life, if I was going to die or not..." (Carmen)(6).

Challenging the AIDS/Death metaphor. AIDS/DEATH has been a metaphor representative of HIV/AIDS. And death prevails not only in the person's conscience, but in all social spaces. As the number of survivors increases, one starts to consider the need to learn to live with HIV/AIDS. This has made us redefine the

notion of HIV/AIDS. For some women, HIV/AIDS is a new dirty trick of the many that life has provide them with. For many, the HIV diagnosis means a new opportunity to reach goals and make fundamental changes. Death is no longer something imagined that one day will reach us, now it is a certitude, now every day is a-gift of life, and it is important to enjoy and value it entirely. Death becomes one more challenge in their lives.

"...And I thought that I was going to die because when they tell you that you got the virus, you think that you are going to die tomorrow and I kind of took life more seriously. I told myself that I had little time left to live and wasn't going to continue to waste it..." (Carmen)(6).

"I have been hospitalized many times, but thank Goodness, I've learned to live with what I have, because I can't change that. The only thing that I can change is my way of thinking, and my way of living with that. That is, I can't let that bring me down to the point of making me want to die because I felt worthless. Now after this diagnose, I want to live...(Lizzie)(6).

"I was the one who had to motivate him to test me, because I felt very bad and it was a big shock for him and everybody else. You feel like running, you feel afraid, but you don't fear the virus as much as you fear the people, who have turned into beasts...cruel towards people with AIDS...(Cora)(6).

The family. In our culture, the family is considered the most important support net in times of sickness and in situations of crisis. Even though not everyone with HIV/AIDS can count on the support of their families, the significant persons in their lives have an important role in it. The notion of the family occupies another level of discussion, the impact of HIV/AIDS on the family has generated great concerns. Families that live with HIV/AIDS face the obligation of having to deal with social stigma, isolation, fear of infection and the handling of death. However, in our culture some families apparently overcome all this process of dehumanization, and frequently respond to the opportunity to heal old wounds, and reinstate lost bonds.

"I had left a girl about 7 years old, they gave me a 15 year old teenager and I thought that everything was going to be just peachy: "Your mother is rehabilitated, and now we are going to be happy and everything is in the past". But that was not reality. The reality is that there are wounds and it's not easy, it's not easy for

a teenager, who has just been reunited with her mother, to know that she can lose her because that is the way she thinks... (Lizzie)(6).

Spirituality. HIV/AIDS has lead us to examine other realities that confront us with multiple contradictions. One of the main characters of this story confronted me with the accusation: "when I was at la Perla as a drug user and prostitute, living for death, the professional people, the feminists or the socialist were not the ones who offered me help, it was the Reverend". She confronted me with the reality of her life, and with a contradiction of mine: How do I deal with a religious space in which in one hand constructs an oppressive discourse, and on the other offers the only available help for many women?

Through religious groups, some women find a space to develop their spiritual life. The human spirit can be the greatest force in the human arsenal. For some women, the development of this human dimension has been what has allowed them to go on.

"...takes me to my Reverend's house, to church and I tell him, and he tells me, well, what you have to do is to go on living. Thanking God, and going on living. Don't get your nose out of joint, and well, that's what I did. I didn't start to think in terms of time, of how much time I have left. Because I feel that the time that God has given me, has been a gift, because had I stayed at La Perla, in the condition that I was, I wouldn't have lasted more than a couple of months." (Lizzie)(6).

"The faith that I have put in everything in my life, comes from God, is what keeps me going on. Furthermore, I say that all the things that I have accomplished are blessings that God has given me, because he gave me a husband, I have a car again, I have some dogs that I love dearly... Then, well, with religion, with God I have stayed positive towards life, is like I have hope, when there's love, because above all God's things, there's love and with love...well, I think that has been the cure for the disease. (Carmen)(6).

"...And I believe that AIDS for me, hasn't been death, as I was telling you a moment ago, but a gift from God. Because through AIDS, I have been able to be a better human being, through AIDS, I have been able to erase prejudice and to love human beings for what they are and not for their actions, and above all, I have gotten very close to God..."(Cora)(6).

Human solidarity. For many women a HIV/AIDS diagnosis represents a new opportunity to value life, and share the knowledge acquired. One of the characteristics that has differentiated our gender, is the immense capacity for human solidarity. Through servicing other, we give meaning to our own lives.

"My future plans are to continue serving, the time that I have left to live, to continue serving people with HIV, lending them a hand, giving them support, going to appointments with them. Because...well, someday I'm going to need the help of another volunteer..." (Lizzie)(6).

"...and I started to render service...Because I find myself in a stage where I'm not looking for me but I'm giving instead from what's mine to others and I think that has been the most important part of my life. To know that I'm not trash, a worthless being, despised but that I was useful and now, this had to happen, but is like that, life is like that, you don't know why things happen, I know that now I want to live more, I don't have the condition in mind all the time, I simply live life." (Carmen)(6).

The testimonies of women offer different perspectives and different points of view. They can identify new research areas and program needs (8). By ignoring the experience of women, one ignores the situation they live in, and specially as it is presumed that their needs are similar to those of men's. This adds up an additional harmful element to their position of exclusion.

"Women don't have anything, or almost nothing. For men, there's everything...for men there places...the shelter, but for women, women addicted to drugs, women prostitutes, people don't want to deal with that kind of woman. There are very few places where she can go. But, more than anything, I'm afraid for the mothers. The woman who's infected and has kids and who despite being a prostitute, doesn't want to be separated from children. The end is separation from the children, because she takes care of children first..." (Cora)(6).

The denunciation. Women have lived in oppression, and we know that it is not enough to denounce it, but that it has to be transformed. At present, HIV/AIDS has lead us to examine our ideologies about life, death, friendship, and human solidarity. It forces us to question the cultural, political, and economical structure that determines the right to live at the present.

Women with HIV/AIDS have had to face multiple manifestations of stigma, prejudice, and discrimination. They have had to deal with the denial of basic services of physical, psychological and social attention. They have faced the isolation, rejection, and abandonment and have had to suffer the loss of privacy, and the restriction of their human rights.

“I want to tell health professionals not to be afraid of patients with HIV or AIDS, because patients perceive that immediately...When people are afraid of them, when they don't want to operate them and I have seen it. In the time that I have been working with other patients, I have seen it in different hospitals here in Puerto Rico—I'm not going to mention any places—where there has not been a doctor, a surgeon that wants to operate a person, because of the fear, and that person was about to die, until the family intervened and a Courageous doctor came and performed the operation and that person lasted several months more after that. Another thing that I would like to tell them is to continue their education regarding this condition. To not stop. Every day, new information comes out, everyday new data comes out. Be up to date about the condition. Get educated to the maximum so you don't believe any myths and are not afraid to approach the patients. Same to the dentists, I know many who don't want to treat people with HIV and everyone should be treated as a possible virus carrier (transmitter). Because not everyone is going to give information about what HIV is. You know...and take the universal precaution measures. And another thing that happens in the hospitals of this country, is that sometimes it seems incredible that there are patients who are isolated, who have tuberculosis, who have AIDS, and there aren't any gloves, there aren't any diapers, even when the nurses don't want to change them and you go there and find them dirty, and you go to the counter and ask for some gloves and diapers, they tell you there aren't any. That means that we have to improve in that aspect and you, the health professionals are the ones who have to deal with that area...and help the patients.” (Lizzie)(6)

I want you to remember that we are human beings, that they (Health professionals) swore

to serve human beings not their actions. I think that they are also exposed, not because of us, the AIDS patients, but because they have to admit what has been their sexual behavior to understand that maybe one day, they will be the ones with AIDS. And that they should not see in us a way to make money, but our need for them, the need of not being just another file number and the need of being hugged and given hope to die with dignity.” (Cora) (6).

We, health professionals are humans inserted in a social context that constructs and reproduces ideologies that stigmatize people with HIV/AIDS. The profound roots of the ideologies, beliefs, myths, and prejudices that support stigmatization makes it very hard to eradicate. Recognizing stigmatization and identifying, and eradicating these practices, could be for all a new beginning.

Resumen

Las necesidades de las mujeres son diferentes a las de los hombres. La investigación y los servicios relativos al VIH/SIDA se han enfocado en las necesidades de los hombres. Las implicaciones de este acercamiento es que ha tenido consecuencias serias para las mujeres que viven con el VIH/SIDA. Ha resultado en profesionales de la salud fallando en entender la aparición de síntomas, las complicaciones, los tratamientos necesarios y los patrones complejos de progresión de la enfermedad. Los testimonios orales son una metodología alterna para el desarrollo de modelos teóricos y de intervención que incorporen cuestiones pertenecientes a los estilos de vida y a la visión de mundo de las mujeres viviendo con VIH/SIDA y otras personas marginadas socialmente. Mediante los testimonios de tres mujeres viviendo con VIH/SIDA se discuten conceptos como estigma social, familia, espiritualidad y solidaridad humana. Se denuncia la experiencia de opresión, aislamiento y deshumanización que estas valientes mujeres han enfrentado como consecuencia de vivir con esta condición.

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