MUJER Y SALUD

Redefining Empowerment and Sexual Negotiation for Women Living with HIV.

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ABSTRACT. The HIV/AIDS epidemic has presented many challenges to both: researchers and care providers. In addition, the concepts and models of human behavior needed a re-examination in response to this pandemic. We are redefining both empowerment and sexual negotiation for women living with HIV. Empowerment is defined as a process of awareness throughout which women recognize their capacity to achieve individual and social changes. This process involves a mental and spiritual awareness that will enable them to focus on their physical, psychological and social aspects. For women living with HIV, this is also a strategy for survival. For women living with HIV, sexual negotiation is a straightforward issue: it is either safer sex or nothing. Safer sexual practices then are a consequence or by-product of the process of empowerment. To facilitate this process our approach is directed to the individual, in an attempt to reach the inner power source that all human beings share.

The HIV/AIDS epidemic has challenged not only the scientists and researchers but all of us; it has challenged our society in many aspects. We have been forced to reevaluate our current health care system and its inequalities and our views about sexuality, gender and sexual education. We were urged to re-examine our position about clinical research in women of reproductive age and in pregnant women to allow for access to new drugs and to gather essential gender-related information about the pharmacologic effects of such drugs. We re-examine our health care interventions to women and their families with one goal: to improve them. The HIV epidemic has therfore compelled us to review our theoretical models and human behavior conceptualizations (1).

In describing the experiences of the early years of the epidemic we are trying to set the background for our response to the epidemic. When we started the Multidisciplinary Womens HIV Clinic at the University Hospital back in 1987 we realized that these devastating and painful personal experiences were the most important to address; it was those human beings that needed our rescue. The perspective had to be personal, if we were going to respond at all. We believe that once you strengthen a critical mass of individuals, then you can impact society; it is in this rescue of the individual that we must concentrate. We work on the "personal" knowing that eventually we may reach the "societal".

The concepts of Empowerment and of Sexual Negotiation will be reexamined and redefined. This redefinition is necessary because we are dealing with a different world: the World of Women Living with HIV. We will list some of the issues incorporated in our analysis although we recognize that the list changes constantly because of historical and scientific developments. We will make a distinction between individual vs social approach, the relationship with sexual negotiation and safer sexual practices, the concept of "special needs" or the need to customarize the approach to fit the specific cultural, knowledge, social, gender and political sensitivities of a given group.This is to be contrasted with the notion that human beings share some universal traits, essence and needs, and these may transcend the "special needs" of some specific groups. Finally, we will describe briefly our intervention model.

One of the strongest messages of the Women's Movement has been that women are "different", that we (women) have a different perspective, approach and even language. Therefore the theories created to explain our experiences and the models developed for interventions have to be women centered (2, 3). Such statements and arguments have also been utilized to describe and justify

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interventions or studies in minority groups: we have to adapt or modify our theories and interventions knowing the specific traits of their culture, beliefs, traditions and perspectives. Even though we as human beings share many characteristics that are universal and transcend gender and culture, we also recognize the uniqueness of human beings as well. Therefore we need to find a comfortable space from which we can generalize the human nature but from which we could also make the distinctions for what we define as gender, ethnicity, social class and so forth, and then reach out to the uniqueness of each individual.

Traditionally, women have played the most important role as health care providers for the family. Women have the personal burden of caring for themselves, their children and their partners. Thus we as women feel that the society is well served when we think and act for others first. Any provider of services for women will acknowledge that compliance with the medical treatment may be affected by these "responsibilities to others". It is because of this ideology that the HIV epidemic has placed such a higher burden on women. A significant proportion of women have acquired the HIV infection heterosexually and unkowingly have transmited the infection to their children during pregnancy or delivery. Women are less likely than men to abandon an HIV positive partner (4). They often place the care of their partner or their children before their own care (5) and women with AIDS are more likely than men to present with opportunistic infections as the onset of disease (6). Women living with HIV have specific issues that need to be acknowledged if we want to adapt any intervention model to them. They are immersed in a distinct world which may be responsible for their HIV acquisition risk and may also be responsible for their difficulties coping and living successfully with HIV. Issues surrounding the sexuality of women living with HIV such as: their right to be sexual entities, to have satisfactory and healthy sexual life and their rights for reproductive decision-making in the presence of a chronic illness perceived as a terminal condition. These issues are almost always surrounded by guilt; this guilt, planted and reinforced by society is deeply rooted within the self. It is one of the major hindrances to self-love and forgiveness, it cannot be ignored, as if non-existent, it should be dealt with an up-front attitude, especially when we are dealing within the sexual context.

Empowerment and safer sex. The concept of empowerment has been brought up in the context of HIV prevention, specifically in negotiating safer sex; the idea is to "empower" a person and enable him or her to perform a specific task. Some behavior modification models use the term empowerment within a framework of power issues that need to be addressed usually by allowing conflict to occur and then focusing on the solution of that conflict.

Self efficacy is also a major element for some models. There is a gap between an individual's perception of self efficacy and the actual process of negotiation and engaging in safer sex. To close this gaps many intervention strategies and models have been attempted unsuccesfully. This lack of effectiveness has been more dramatic for the aspects dealing with sexual practices and sexual negotiation for risk reduction. In the minds of many researchers these two concepts (empowerment and sexual negotiation) are usually tied together. You attempt to empower a person so that he or she can be able to negotiate and get involved in safer sexual practices. We believe that they couldn't be farther apart, especially for women living with HIV. The fact that women living with HIV are a special group is the main reason for re-defining these two concepts, but the fact that they very intensively belong to the category of living human beings facilitates a more universal type of approach.

We believe that for women living with HIV the issues of life are much more intense. For them, sexual negotiation as defined by some groups (you give something in order to get something) is seen from a different perspective. There is nothing to negotiate, it's either safer sex or nothing.

Individual and social approaches. Social scientists have either focused on the individual as a target for change or focused on the society. Sometimes it seems that the two approaches are in conflict, one being more personal, the other more political. It also reminds us of previous debates: nature vs. nurture (inhereritance vs. environment); we think both approaches have their theoretical and practical advantages and disadvantages and may not be antagonist at all. Our definition and our model evolved from the actual experiences of women living with HIV. One of the most distinctive aspects of this epidemic and undoubtedly the most painful to those with HIV was the severe social isolation that came with the diagnosis. Perhaps using the term social isolation may be an euphemism: it was much more than that. It was a lack of physical contact with other human beings (health care professionals included), abandonment, mistreatment, a gigantic sense of guilt placed on those acquiring the infection and on top of that, a sense of hopelessness because of lack of effective treatment and of a cure. This "Lack of Cure" was perhaps the single biggest reason for the irrational fear that motivated these attitudes and behaviors so painful and inhumane.

Re-defining empowerment. We define empowerment as a process of awareness throughout which women

recognize their capacity to achieve individual and social changes. This process involves a mental and spiritual awareness that will enable them to focus on their physical, psychological and social aspects. For those living with HIV, this is also a process for survival. Nathaniel Branden, PhD has defined this awareness process as the art of 'living consciously' and we quote:

> "Living consciously is a state of being mentally active rather than passive. It is the ability to look at the world through fresh eyes. It is intelligence taking joy in its own function. Living consciously is seeking to be aware of everything that bears on our interests, actions, values, purposes, and goals. It is the willingness to confront facts, pleasant or unpleasant. It is the desire to discover our mistakes and correct them. Within the range of our interests and concerns, it is the quest to keep expanding our awareness and understanding, both of the world within. It is respect for reality and respect for the distinction between the real and the unreal. It is the commitment to see what we see and know what we know. It is recognition that the act of dismmissing reality is root of all evil" (7).

In acknowledging this state of awareness we are taking the first steps towards confronting our reality and beginning the process of switching our priorities. Women need to understand they have to place themselves as priority as a step towards caring for others. Christiane Northrup in her book Womens' Bodies, Womens' Wisdom expresses a concept we all know to be true: that in order to improve womens health, we need to improve their lives and their living conditions: "Nothing will change in a womans' outer circunstances until she learns to value her own life and her own gifts as much as she has been taught to value and nurture the lives of others. As a friend of mine says: If you want to be one of the chosen, all you have to do is choose yourself" (2).

Our strategy, therefore doesn't pretend to change any sexual behavior. As a first step, our strategy is directed towards facilitating their awareness so that they can for the first time perhaps, start living. It is a strategy for life and living; they need to switch their priority and place themselves first. They need to understand that you cannot love another human being unless you love yourself first; this is not egoism, it is self acceptance and more than survival, it is a strategy for living. As a consequence, when women learn to live consciously, they may take steps to change their sexual behavior. But that is a consequence or a secondary effect. It doesn't happen until after improvements in lifestyles, adherence to medical treatments and changes in their support network. Sexual practices will change but usually after other changes have taken place.

Testimony as an empowerment strategy. One of the strategies that we have found extremely useful for attaining or rescuing our control (this is how we translate empowerment) is the testimony. First, let us acknowledge that there is a difference between disclosure and testimony. Disclosure can be limited to significant others or close family members, there is an implicit expectation that the "secret" will be kept. Testimony on the other hand, involves public expression and acknowledgment of the situation. The implicit expectation of the secrecy is vanished because you cannot control how large numbers of individuals may respond or react, it is therefore an opening into the world. Both disclosure and testimony might be threatening situations to women living with HIV. The fear of disclosure is rooted in the possible consequences or dangers women may face when revealing their diagnosis. They face the possibility of losing their children and families and of being rejected and isolated. They also may face domestic violence and even death (8). In order to disclose their diagnosis women need to feel safe, anticipate acceptance or non-rejection and expect some support. A large proportion of women living with HIV do not disclose their diagnosis to their immediate family just to "protect them from suffering". They isolate themselves and abandon themselves, they may not seek life saving treatments just to protect significant others from having to suffer the stigma of the condition. They are killing themselves for the sake of others. This is another reason why the priority shift is essential.

Oral testimonies can facilitate disclosure, they offer an opportunity to express anger, fear, pain and they also constitute a space for human solidarity and social support. There are also some beneficial biological effects associated to testimonies such as in the blood pressure, muscle tension, immune function and others (9). Oral testimonies have been used by Latin American women historically to denounce repression and marginalization. They transcend social class and education. Examples are: Rigoberta Menchú from Guatemala, Isabel Allende from Chile, and many others. Oral testimonies beyond being a therapeutic modality are also part of our cultural tradition. They facilitate this awareness and priority shifting because when women think their message is important, it is because their lives are important. Their message is a reflection of their lives and now it has a new meaning and transcendence.

The intervention. With this in mind, we designed an intervention project with the goal of helping empower

women living with HIV. It consists of three workshops or seminars in which the participants are exposed to the concept that the healing process needs a balance between body, mind and spirit and in order to improve or restore the health in one area we may need to also work the other areas. Because of this philosophy they are exposed to different techniques so they can select the most appropriate one. On the first workshops, we discuss different aspects related to the healing process. The activities begin with a meditation about the different stages of human development, we conceptualize the healing process as a balance in body-mind-spirit. We talk about the effect of hope/hopelessness on the immune system and in the disease. We discuss about the importance of re-defining hope in the present moment and talk about the management of emotions and the role of a support system. During the afternoon, the participants develop and act a life theater in which the issue of disclosure is discussed and dramatized. At any point of the presentation participants can move in and substitute any of the actresses in order to try a different strategy to complete the goal, this way, the same problem can be shown or dealt with by different approaches.

On the second workshop, we focus on the different aspects related to the immune system such as laboratory tests, antiretroviral medications and their rationale as well as the signs and symptoms of disease. We also answer questions about different myths related with HIV/AIDS. In the afternoon we discuss issues about sexuality and sefer sex. A meditation and visualization exercise always begins the workshop and we close with an exercise to promote solidarity: "a collective's hug". On the third day, we present information and demonstrations about lifestyles, nutrition, Reiki (hand healing) and aerobics. A special component is the participation of medical students during the workshops, they have the opportunity to share with the patients and also to provide support to them. This opportunity is an extraordinary experience and has helped to change their beliefs on the issues surrounding the misconceptions about people living with HIV.

Our past experience with a successful model has enabled us to focus on the topics or issues for which there is a greater need or greater difficulty as an individual to work out. We also developed the expertise to carry out the workshops in such a manner that they are non threatening to the participants and examined some of the reasons behind our rationalization for new definitions. We have emphasized that we work with the personal to reach the societal, that we understand that the awareness that leads to conscious living leads also to empowerment. This leads to a healthier lifestyle and by consequence to personal changes to facilitate living with HIV and thus, living. Let us remind ourselves that we all live with HIV: some with it inside, and some of us with it outside.

Resumen

La epidemia de VIH ha presentado muchos retos para lo/as investigadores y proveedores de cuidado de salud. Además, los conceptos y modelos de comportamiento necesitan ser reexaminados para respoder a la pandemia. Proponemos la re-definición de los conceptos de "empowerment" y negociación sexual para las mujeres viviendo con VIH. Empowerment se redefine como el proceso de toma de conciencia, mediante el cual la mujer reconoce su capacidad para alcanzar cambio individual y social. Este proceso involucra una toma de conciencia mental y espiritual que le capacita a enfocar en los aspectos físicos, psicológicos y sociales. Para las mujeres que viven con VIH este proceso es también una estrategia de sobrevivencia. Para las mujeres viviendo con VIH la negociación sexual es un asunto claro y obvio: se tiene sexo más seguro o ninguno. Las prácticas de sexo más seguro entonces son consecuencia o resultado del proceso de empowerment. Para facilitar este proceso nuestro acercamiento es directo al individuo, en un intento de alcanzar el recurso de poder interno que todo los seres humanos compartimos.

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