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# Social Position as a Structural Determinant of Adherence to Treatment in Women Living with HIV/AIDS

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#### 1. Introduction

Adherence to treatment has been a matter of priority in the control of the HIV/AIDS epidemic. Due to the characteristics of the virus, adherence of at least 95% is necessary for the continuing suppression of the viral load, and to prevent the risk of AIDS progressing (Bangsberg et al., 2000). In view of the chronic nature of HIV/AIDS, and the benefits offered by antiretroviral therapy, a sufficient rate of adherence is essential for world public health. There have been many efforts to control the behavior of people who suffer from HIV, in order to ensure that they follow their treatment instructions carefully. Nevertheless, in the conceptualization, research and intervention on the field of adherence, determinants of a general nature which could affect it have been seen as a minor issue.

Much of the research on HIV/AIDS adherence has been rooted in biomedical and behavioral approaches. Studied variables include age, gender, education (Carballo et al., 2004; Glass et al., 2006; Godin et al., 2005; Gordillo et al.,1999; Ickovics & Meade, 2002; Mocroft et al., 2001; Spire et al., 2002; Sternhell & Corr, 2002), health beliefs, coping styles, self-efficacy, control perception, stress, anxiety, depression (Chesney, 2000; Ingersoll, 2004; Turner-Cobb et al., 2002), pharmacological regimen, side effects, relationship with health care providers, geographical barriers, and social support (Burke et al., 2003; Chesney, Morin & Sherr, 2000).

Despite wide research on this topic, studies have not reach conceptual explanations about the relation between adherence to treatment in people diagnosed with HIV and structural determinants such as social position. Drawn from the current vision studying adherence, its definition has been limited to the degree that patients complete behaviors like following healthcare provider's instructions, taking antiretroviral medication and attending medical appointments. The gender perspective has also been restricted in spite of reports that compared to men, women face additional barriers including delays in medical attention, non-use of antiretroviral therapy, lack of financial support, poor quality of health care, and difficulties related to the doctor-patient relationship (Ickovics & Meade, 2002, Jia et al., 2004).

To complement the current biomedical and psychosocial view to the study of adherence in HIV cases, this chapter presents an approach from the social determinants of health focus. In

particular, the social position category is analyzed as a structural determinant of adherence of women affected by the virus. This proposal emerges before the need to understand not only the role of social position in adherence but also gender determinants that can affect it. An integral comprehension of adherence could promote the application of more effective interventions to achieve hoped for results.

The chapter begins with a section titled *gender*, *social position and health*, where these concepts are defined, and the problem of gender equity and inequity is considered together with their impact in the field of public health. A continuation called an overview of vulnerabilities for women affected by HIV/AIDS is presented giving a description on how women must face up to a wide range of political, economic and cultural determinants. The chapter subsequently shows data derived from a study carried out between 2006 and 2009 with 352 Colombian women who had been diagnosed with HIV. The data is analyzed based on a review of the literature which describes the associations between adherent behaviors and different variables related to social position. According to these results, the following section offers a conceptual proposal of the social determinants of adherence to treatment in HIV/AIDS, applicable to women affected by the virus, as well as describing its components. Finally, the chapter presents conclusions which summarize the arguments made throughout this study for the recognition of social position as a structural determinant of adherence to treatment in HIV/AIDS. It observes that debate, conceptualization and research into adherence are still not enough, and it stresses the need to continue to progress in a direction which would include the probable influence of determinations in a macro social context, such as poverty, inequity, violence, health systems, work, and food security, among others. Readers are invited to understand adherence in an all-embracing sense, to carry out new forms of intervention, focused on social and gender-related equity.

# 2. Gender, social position and health

# 2.1 Gender equity and health

It is well known that the "gender" category has been redefined in terms of a social and cultural construction, and not as a condition which derives from biological pertinence to one sex or another. On the contrary, gender determines different roles in society, which are transformed into inequities in the access to financial resources and the power which is exercised over them. *Gender equity* means fairness and justice in the distribution of benefits, power, resources and responsibilities between women and men (Breilh, 1999; Gómez, 2002; Kottak, 1994). As a counterpart, *gender inequity* represents a group of inequities which are considered to be unnecessary, avoidable, and apart from that, unfair (Whitehead, 1990), and which are associated with systematic disadvantages at socioeconomic level between men and women.

In socioeconomic terms, according to the International Labor Organization, inclusion in economic and social life is determined by gender. Also, this organization acknowledges that although the situation of women who work has improved, progress continues to be slow. In several regions women often face stronger barriers in the labor market, and female unemployment rates exceeded those for males. For example, of all the people employed in the world, only 40% are women; the rate of unemployment is higher in women than in men; employed women tend to be engaged in less productive sectors of the economy, have fewer opportunities to access the social security system, and are frequently receive lower salaries than men. In Latin America, around a quarter of the women are employed in the informal

sector, where their income can vary from day to day, and where the lack of social support systems makes them more vulnerable to market variations. In this region the percentage of women who do not have their own income is between 37 and 50 (International Labor Organization [ILO], 2010).

However, gender inequity is also expressed in socially and culturally constructed gender roles. Women who live in patriarchal societies come up against exposure to what has been called the "triple feminine load", which determines the roles they carry out (Breilh, 1999). The first load consists of conditions such as informal work, with discrimination in tasks and positions; the second refers to the double shift that many women have, as a result of domestic work with their families. This double shift also includes an unequal and sexist distribution of work in the home, where the women look after the children, the cleaning, cooking, shopping among other things. The third load refers to the biological demands made on women's bodies due to their reproductive activity related to menstruation, pregnancy and lactation (Breilh, 1999). These three loads produce physical deterioration and result in having a differential affect on women's health, in comparison with that of men.

Gender differences in health have been widely documented. There is sufficient evidence of this, and variations in life expectancy, the risk of morbidity and mortality, access to health services and treatment, the use of preventive health services and health behaviors have been found (Gómez, 2002; Payne, 2009). On a global level data shows that men experience higher mortality and a lower life expectancy than women, while women have a greater probability of higher morbidity and more years living with disability (Mathers et al, 2001; Payne, 2006). In the field of public health, for gender inequity to be reduced, what is required is the elimination of differences in the opportunities to enjoy good health, not to become ill, become disabled or die from preventable causes. In the case of women it is necessary to recognize that these differences are a reflection of: 1, different types of needs, 2, better use of health services, 3. differential patterns in the recognition of symptoms, perception of illness, and the way in which attention is sought, which are prevalent in different cultures, geographical regions, and socioeconomic status, and 4. the structural and institutional determinants of the health systems, which differentially facilitate or obstruct access to health services (Gómez, 2002; Weisman, 1998;). This situation is combined with roles as family caregivers, which obliges women, to a greater extent than men, to become familiar with symptoms of illness, and as a consequence, seek more medical attention.

The specific needs of women, their social position, the gender-based roles they assume in certain contexts, and the characteristics of the health systems to which they belong, highlight the importance of directing public policies with a gender mainstreaming approach, to promote their health and wellbeing. Health systems in particular have the commitment to promote gender equity and to reduce the gender gap in their daily operations as well as in the development of health policies.

#### 2.2 Social position

Social position can be defined as the "place" or social stratum of a person in the society in which they live. It is derived from a specific context, which means that the classification of the social position varies between societies with different economic structures (Diderichsen, et al., 2001). Throughout history it has been seen that in every society the most valued resources are distributed are unevenly distributed between the different social positions, and that individuals and families with occupy the more favored positions are those who enjoy them more.

It is important to point out that the concepts of "socioeconomic level" and "socioeconomic status" are often used as synonyms for social position, but they have no explicit relationship with the economic and political forces which explain the lack of social and gender-based equity. Neither can social position be compared with the concept of "social class" in the style of Marx or Weber, since in its most classical sense this concept cannot but accept the transversal capacity that gender has as a category, not only in the differentiation of experiences between men and women, but also between women of different social positions. The relationship between social context and the manner in which people are distributed among certain social positions is a determinant of the health outcomes. At the same time, social position is influenced by other variables, such as the health network to which individuals have access, their academic level, and occupation or "earning a living".

In countries lacking complete universal access to health insurance or health services, people and families must absorb the direct costs of health care themselves (Dahlgren & Whitehead, 2007; Navarro, 1989). Although this phenomenon affects people of all social positions in the same way, their ability to deal with these costs is extremely varied, depending on the socioeconomic situation (Diderichsen, et al., 2001). In general, those who belong to the wealthier sectors are able to absorb more costs, often have private insurance policies, and will probably not get into serious debt in order to pay their health costs. For its part, the economic safety net of the poorest groups is smaller, these people are less likely to be able to pay for private health insurance and they are often obliged to find new sources of income produced by other members of the family, or become seriously indebted. Non-universal health systems may impose impoverishing charges on those who are able to use them, making the already existent inequities in their living conditions even worse (Borrell et al., 2007). Ill-health may commence an ascending spiral of excessive costs as a result of health care and the loss of income derived from work.

Women in particular are limited, as far as opportunities in the labor market are concerned; their ability to pay is less, but despite this they pay more than men for their medical costs. Health financing systems which require high out-of-pocket payments increase their outgoings, when added to their basic needs and use of services (Borrell et al., 2007). Access to health insurance is still more limited, because of the interruptions in their work, due to pregnancy and the raising of their children. Apart from this, the nature of "dependents" in insurance, places them at risk of being unprotected in the event of widowhood, abandonment, marital separation, changes in the employment situation of their partner, or changes in the regulations which govern the coverage of dependents. The fact that over 30% of homes in regions such as Latin America have women as heads of household (Pan American Health Organization [PAHO], 2009) serves as an indicator of their vulnerability. Gender analysts have pointed out that health costs have a devastating effect on economies which are managed by women. When a woman becomes ill and at the same is head of the household, the family income which is destined for food, education and health care for children, is reduced (Payne, 2009). In the case of HIV/AIDS the effects have obviously been financially ruinous (International Community of Women Living with HIV/AIDS [ICW], 2005). It is thus accurate to conclude that the principle of gender-based equity in health, according to which the amount payable would be linked to the people's capacity to pay, is considerably threatened in the case of women, especially in the case of non-universal health systems, and are restricted to social security networks.

For its part, as far as *education* as a determinant associated to social position is concerned, there is sufficient data to show that each unit of increase in educational level or professional hierarchy is accompanied by a corresponding increase in the final health outcomes (Dahlgren & Whitehead, 1992); the probability of survival is greater in persons in social positions with higher educational levels. And with regard to *work/employment*, it has traditionally been suggested that the relationship between employment and health is based on whether people can earn sufficient income to support themselves, have access to resources and be productive (Benach & Muntaner, 2007; Raphael, 2004). The unemployed population presents higher mortality rates, while job security has an effect on life expectancy (Navarro, 2004; Raphael 2003).

In a global context, the growth in the number of women who work outside their homes in paid jobs has brought about qualitative changes in their political, legal, economic and social situation. In the private sphere, employment has an effect on the material conditions in which women live their lives on a day-to-day basis, their ability to negotiate in their marital and family relationships, the possibility of achieving economic independence and in their self-esteem as individuals. Nevertheless, social position as a category of analysis helps in the understanding of the connection which exists between one's place in the world of work, the social and cultural characteristics and the relationship of this position with gender inequities. The working world of women cannot be understood only as employment or unemployment from a traditional approach. This vision does not take into account different occupations and "ways of earning a living" that women have, such as informal and domestic work. The type of work done by women determines gender roles, and as Breilh (1999) has stated, has an impact on women's health with patterns of deterioration which are different from those of men.

# 3. Overview of vulnerabilities for women with HIV/AIDS

As has already been mentioned, conditions of gender inequity place women in positions of disadvantage in comparison with men, making them more vulnerable. The vulnerability approach has attracted attention with regard to the structural conditions which place women in a position of risk, beyond that of their "irresponsible" individual behavior in relation to HIV infection. Women must face a broad spectrum of political, economic and cultural determinants which affect the way in which they can protect themselves against infection, deal with the virus once they have been affected, or look after family members who are affected. In fact, a meta-analysis of research carried out in the field of social epidemiology in HIV/AIDS between 1981 and 2003 revealed that to be a woman is one of the determinants of structural violence and discrimination related with the infection (Poundstone et al., 2004).

Some of the conditions of vulnerability of women infected with HIV are described below.

**Poverty.** It is no secret that HIV has spread uncontrollably throughout the world, but not by chance; on the contrary it is intensified within the ranks of the poor and those who are powerless, such as women (Farmer, 2000). In this way, poverty has become a structural determinant which is clearly connected to the epidemic, and acts as a booster of the virus. Women in situations of poverty have few opportunities with respect to education, work, nutrition, and housing. They run a greater risk of infection and have limited care options at their disposal once they have been diagnosed with HIV. In this case inequity by social position is exacerbated by gender inequity.

On an individual level, research has revealed that women with HIV/AIDS, who are financially vulnerable have less chance of using a condom, terminate a possibly dangerous relationship, have access to information about sexual health care, and a greater possibility of relapsing into high-risk behavior to obtain financial resources (Marcovici, 2002). Women who have no work and are financially dependent on their partner are exposed to sexual relations in which the man takes the decision on whether to use a condom (ICW, 2005); those who are employed in the informal sector and have some income may be more empowered with regard to the taking of decisions about their sex life, have more flexibility but at the same time less stable opportunities of earning money, and when they become ill receive no financial assistance. In all cases, diagnosed women who live in poverty have less chance of being able to use health services, counseling or medication.

Ethnicity. HIV/AIDS-related inequities with ethnic connections have been reported in some literature (Poundstone et al., 2004). Going beyond individual behavior the ways in which the virus is concentrated in certain ethnic groups involves complex processes of economic and social deprivation, socialization patterns, socially inflicted trauma, ties with the illegal drugs trade, and limited access to health care and prevention services. An example of this can be found in the United States, where HIV/AIDS affects a disproportionate number of black women who are isolated and stigmatized by poverty, forming part of an ethnic minority, their association with the sub-culture of injectable drugs, or because they live in areas where the infection is prevalent. In this way contextual or structural determinants share a role in the socialization of patterns which contribute to ethnic inequities in HIV/AIDS. With regard to adherence, a small number of studies have revealed that this is lower in persons of African descent and that the data is not consistent (Glass et al., 2006). To the best of our knowledge, no studies have been found that relate specific ethnic characteristics to adherence among women.

**Migration and wars**. The migration of a population plays an important part in the spread of HIV through migration processes, human trafficking, and urbanization. Female migratory workers are vulnerable due to the pressures of poverty, the lack of information and access to services. The temporary nature of some of their couple relationships and long periods spent away from their families can lead to greater sexual activity of a commercial nature. Illegality can present a greater host of problems and generally, in these situations women do not have the necessary documentation to remain in the host country legally, and may encounter difficulties in receiving medical care, or can be reluctant to request these services for fear of being deported.

Studies of migration processes have revealed that human-trafficking<sup>1</sup> markets increase women's vulnerability to HIV/AIDS infection. In Latin American countries such as Colombia it has been estimated that about 35.000 women have left the country, to escape from the violence and inequitable conditions, and have been recruited for sexual work (Ward, 2002).

With regard to processes of urbanization, HIV/AIDS is a classic example of an urban health problem. Young women who move far away from their rural homes to seek work in factories in towns and cities become more vulnerable to infection. They become exposed to

<sup>&</sup>lt;sup>1</sup> Understood as the capture, transportation, movement, acceptance or receiving of persons, resorting to threats or the use of force or other forms of coercion, abduction, fraud, trickery, the abuse of power, or a situation of vulnerability, or the payment of receiving of money or benefits to obtain the consent of a person who has authority over another, with the purpose of exploitation (UN, 2000).

the possibility of sexual exploitation in their work places and the loss of social support previously given by their families and communities. Internal conflicts, wars, the militarization of certain areas tend to increase migration, and are directly or indirectly related to HIV/AIDS. Wars break down social networks, destroy medical infrastructure and increase poverty and social instability (Hankins et al., 2002). Also, prostitution increases with the presence of military personnel in urban and rural areas.

**Sexual, physical and psychological violence**. Gender-related violence is understood as any act or threat of violence which results in detriment and/or suffering of physical, sexual or psychological health of women. Unfortunately the wielding of power by men over women leads to different forms of violence, which increases their degree of vulnerability.

Sexual violence increases the risk of HIV infection at the moment of abuse. Studies reveal that those who have been victims of physical ill-treatment or sexual abuse during childhood are more likely to present high-risk sexual behavior, and have difficulty in negotiating sexual relationships with their partners which involve adequate care (Marcovici, 2002). This type of violence can be perpetrated by partners or families; rape in marriage and in all forms of couple relationships is generalized and widespread. The political relationship of tenancy and property relationship in conjugality makes what happens in these relationships valid, in spite of the implicit health risks. Thus, it is probable that many women do not have safe sexual relations because their partners do not consider it necessary; in fact, is probable that a woman could have sexual contact against her wishes and as a consequence endure forced coitus. There are significantly high rates of infection by HIV among women who have been subjected to physical abuse or sexual aggression, or are dominated by their partners (Dunkle et al., 2004).

Stigma and discrimination. The stigma associated with HIV is a considered as a second epidemic because of the impact it has on the lives of people and societies. This occurs with anyone who is diagnosed with it, irrespective of age, gender or ethnicity. Discriminatory acts include the denial of education, denial of or destitution from employment, the obligation to take an HIV test as a condition of employment, travel or any other activity. Allied to this, there is a lack of confidentiality, detention, deportation, condemnation in the communication media, rejection by family, friends and community, and physical aggression, including murder (Foreman et al., 2003). Stigma has a negative impact on social interaction, emotional well-being and self-esteem.

Discriminatory actions on the part of institutions and health-care providers affect adherence, and can take the form of delayed treatment, the withholding of treatment, treatment given inadequately, the delay or withholding of care in other ways (eg. the presentation of food, hygiene etc.), premature discharge, objection to receiving a patient by the health-care center, inadequate attention to bedridden patients, or to those in outpatient centers, tests carried out without the patient's consent, the violation of confidentiality within and outside the health system, difficulty in giving a diagnosis, inappropriate comments and behavior, for example, shouting, foul language, etc., and the use of excessive precautions among other things (Foreman et al., 2003). Any of these acts can have transcendental physiological or psychological consequences for the person being treated.

In a qualitative study it was found that the stigma caused by HIV/AIDS is as shocking as the diagnosis itself. In particular, women are not worried by the possible psychological changes, or by the death that the diagnosis implies, but by the attendant psychosocial consequences. This fear becomes a barrier to the adherence to treatment and to maintaining and improving their health (Carr & Gramling, 2004).

# 4. Social position and HIV/AIDS treatment adherence: The case of Colombian women living with HIV/AIDS

Research conducted between 2006 and 2009 by the author of this chapter, identified and analyzed the relationship between social position and adherence to treatment in a sample of 352 Colombian women living with HIV/AIDS in five major cities in that country (Cali, Bogotá, Medellín, Pasto and Villavicencio). The purpose of this study was to broaden the individual point of view of adherence in HIV/AIDS, and to advance towards the development of an alternative concept from a social determinant perspective. The research project was approved by the institutional review boards of the National University of Colombia (Universidad Nacional de Colombia, UN) and Javeriana University in Cali (Pontificia Universidad Javeriana Cali, PUJC). Written informed consent was obtained from all study participants.

A mixed method approach with a qualitative and quantitative cross-sectional design was applied. In the phase of formative research, semi-structured interviews (SSI) were conducted with 7 national experts in the field. The qualitative component of the study included 10 focus groups discussions (FGD) with a total of 83 women; in-depth interviews (IDI) were conducted with 14 of these participants. Another 269 women completed a sociodemographic and clinical questionnaire, an adherence to treatment questionnaire, and a social position survey designed according to the Colombian socioeconomic structure. Content analyses were applied to analyze the qualitative data and logistic regressions used to analyze the quantitative data. The general results show significant statistical associations and qualitative patterns between adherence and social position. Women in a medium and high social position were more likely to present higher adherence behaviors than women in low social position (See table 1).

	Regression coefficient (b)	Wald test statistic	DFa	<i>p</i> -value	OR (95% CIb)
Constant $(b_0)$	-1.7427	18.0960	1	< 0.0001	NAc
Low social position $(b_1)$	1.7319	15.8323	1	<0.0001	5.651 (2.408–13.262)

<sup>&</sup>lt;sup>a</sup> DF = degrees of freedom. <sup>b</sup> CI = confidence interval. <sup>c</sup>NA = not applicable.

Table 1. Univariate logistic regression analysis of the association between low adherence to treatment and low social position (versus medium and high social position) among 269 HIVpositive women in five Colombian cities

The findings of the study show the importance of social determinants in adherence, and make clear that the way in which women with HIV occupy a place in the social hierarchy and in a specific context, is linked to critical processes which advance or obstruct adherence to treatment. The social position was determined by a group of characteristics which occur jointly in the Colombian context and define it. These characteristics were: place of residence (urban or rural), official socioeconomic stratum in Colombia<sup>2</sup>, educational level, type of affiliation to a health system or type of access to health services 3, labor profile or "way of

<sup>&</sup>lt;sup>2</sup> The official socioeconomic stratification classifies Colombian citizens in six levels: 1-2 (Low), 3-4 (Middle) and 5-6 (High).

<sup>&</sup>lt;sup>3</sup> The General Colombian Health System has two main types of health care coverage: Contributive and Subsidized. In addition, a special category called "Vinculados" (meaning "Attached") exists for

earning a living"<sup>4</sup> (referring to considerations of gender, income level, access to property, and access to credit with banks).

Described below are the characteristics of adherence to treatment in the women who took part in the study, broken down into three levels, according to their social position. The information shown is taken mainly from the qualitative phase of the study.

# 4.1 Low social position and HIV/AIDS treatment adherence

"Having AIDS is horrible and being a woman alone and with children is worse!

There is never enough money.

Besides food, it is difficult to pay transportation to go to the doctor"

(HIV-positive women, age 29, FGD)

The findings of the study showed that the lives of Colombian women with HIV/AIDS of low social position or in poverty conditions are compromised by limited access to economic and financial resources. Women placed in the lowest social level were women with no formal education, or had some degree of primary schooling, had limited access to subsidized health services, had an occupational profile which included being housewives, in some cases heads of family, with principal financial responsibility for the home, were manual workers, factory workers, self-employed or farm workers. They had incomes of less than US \$200, did not own their own home and had no access to credit. The precarious nature of their lives was related to the difficulty they experienced in adhering to treatment once they had been diagnosed with HIV.

The conditions of poverty were reflected in the unsatisfactory response to these women's basic needs. In nutritional terms, they reported serious limitations, with negative consequences for their adherence. These were women whose incomes were insufficient to provide adequate nutrition – many of them ate one meal per day and apart from this shared their small rations of food with their families and in particular with their children. Some women chose not to take their antiretroviral medication in order to avoid gastrointestinal disorders, and to literally have an "empty stomach".

One of the greatest difficulties mentioned by these women belonging to a low social position was in obtaining money for transport to medical centers and to pay the excessive administration fees of the health insurance companies. Out-of-pocket expenses increased when they had to make a number or "trips" to attend medical appointments, collect

economically disadvantaged people who are not formally recognized by the two main coverage types. The Subsidized and the "Vinculados" systems include the poorest sector of the population in Colombia. <sup>4</sup> Three profiles of female work were analyzed in the case of Colombian women: Profile A, made up of workers, factory workers or manual workers in companies not of their ownership, farmers, self-employed workers (e.g. car watcher (guard), street salesperson, cook, washerwoman and maid). Profile B, includes owners of small businesses, or small traders, (e.g. bakeries, butchers, dressmakers, hairdressers, store, etc.), semi-salaried with regular income from commissions from sales (e.g. cosmetics or underwear salesperson, working from a catalogue), women who work in public or private companies with operational functions with employment contracts, (e.g. secretary, receptionist, office assistant), and independent professional with an undergraduate degrees. Profile C, made up of company owners and managers with their own business, independent workers with postgraduate degrees, and women working for public or private companies with administrative, technical duties, or those involving control and supervision with employment contracts (e.g. manager, director, head of department).

medication, or go for tests. Added to this was the cost of travelling from urban or rural areas far from their homes. Every journey meant more expense, which affected the family finances, more so when the women were heads of family who in many cases had to pay for food, housing, services and their children's education.

Conditions such as poverty, unemployment, exposure to violence, the lack of education and the difficulty in satisfying basic financial needs for food, clothing, housing and access to public services, were explanations of why some women in a low social position decided to sell their antiretroviral medications once they had obtained them from the health system, just to satisfy their basic needs. There were also cases where their partners forced them to sell these medications.

The low educational level of these women affected their understanding of HIV/AIDS, its treatment, and the consequences of not taking medication, or taking it incorrectly. All of these living conditions resulted in tendencies towards low adherence, resistance to medication, exposure to opportunistic infections, and the risk of mortality.

By way of a summary, Figure 1 shows the living conditions and adherence behavior in this group of women.

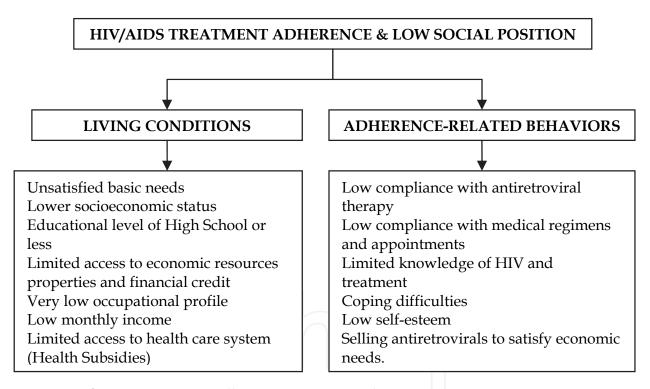


Fig. 1. HIV/AIDS Treatment Adherence & Low Social Position. HIV-Positive Women. Colombia - South America. 2007-2010.

# 4.2 Medium social position and HIV/AIDS treatment adherence

"In general, women from a medium social position adhere to treatment more easily than poor women and even better than women from a high economic status. They have characteristics such as a degree of economic independence which does not imply they are rich women living on their money but they work and become good patients who adhere well" (HIV/AIDS National Expert -Physician-. SSI)

For women belonging to the medium social position, the results of the study indicate that they share similar living conditions and socioeconomic characteristics. Some were financially independent and were heads of household, while others produced income from their jobs to contribute to the upkeep of the family. On receiving the diagnosis, the initial effect on these women was one of dismay, anger and sadness, but these were also women who showed a positive attitude in coping with the illness and the treatment. In contrast with the women of a low social position, these women were more aware of the benefits of adherence to treatment. In other words we were dealing with women with complete or partial financial independence, who maintained an active role in the upkeep of their homes after their diagnosis, and they took responsibility for the new situation regarding their health. The "economic/financial power" that working women with their own income are supposed to have places them in a relational sphere of exercising their autonomy, and of recognizing themselves as persons who are capable of dealing with a diagnosis such as that of HIV.

The social position of this group of women has given them access to formal education and the ability to understand the complexity of antiretroviral treatment, and the benefits of following it correctly. Activities aimed at seeking information about HIV/AIDS -once this had been diagnosed- were highlighted in this group. They stated that they usually began to read, carefully selecting what they read, became skilled at choosing reliable information, attended workshops and conferences, and those who had access to it, consulted Internet. In all cases, explanations offered by these women about HIV/AIDS and its treatment, were more detailed, complex, and in the most outstanding cases, analytical and critical in comparison with women from low social positions. Thanks to the quality of life enjoyed as a consequence their social position, these practices which benefited their adherence may be added to "the power of accumulated knowledge".

The knowledge of HIV and antiretroviral therapy in this group of women resulted in their being more able to negotiate the type of therapy with their doctor, and discuss any recommended changes with health-care personnel. These women were familiar with the antiretroviral medication, the corresponding doses, and their possible adverse effects. They knew how to interpret the results of the tests, relating them to their compliance with the therapy.

The *empowerment* evident in these women of medium social position manifested itself in their defense of their rights as users of the health system. In fact, of the three groups of women, it was this group of medium social position who most exercised their health rights in this regard, even taking into account the fear and stigma associated with HIV. They went as far as to initiate legal action to be able to ensure opportune and continuous access to treatment, direct and active communication with their doctors and health-care personnel, and compliance with their appointments, without fear of being identified as HIV carriers. The defense of these rights was linked to the knowledge they had of how the health system worked, and for this reason they were able to have medical attention, and access to medication in a relatively stable and uninterrupted manner.

Based on the above, we can affirm that the "place" in Colombian society of women belonging to the medium social position, puts them in a situation of being well able to consider themselves privileged when they have to accept HIV diagnosis. This is a social group in which the pattern of an *empowered woman* converges with conditions of economic and financial possibilities, which, although not the best situation, is very favorable for adherence on the part of this sample in the study.

Figure 2 summarizes living conditions as well as adherence conduct in women of a medium social position who took part in the study.

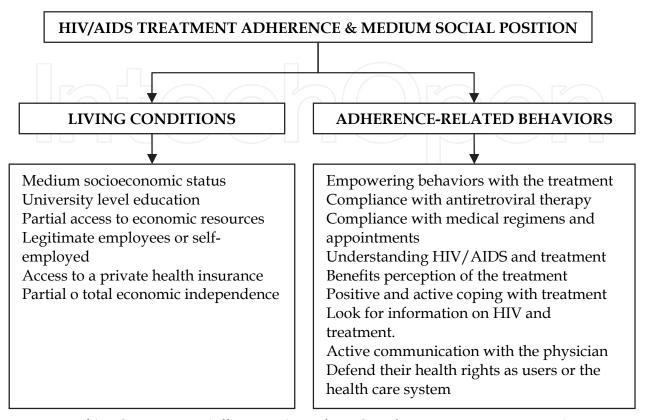


Fig. 2. HIV/AIDS Treatment Adherence & Medium Social Position. HIV-Positive Women. Colombia – South America. 2007-2010

# 4.3 High social position and HIV/AIDS treatment adherence

"I do even the impossible and pay what is necessary to hide my diagnosis.

Nobody must know! It would end my career.

I take my medication religiously to not get sick and that no one notices that I have HIV"

(HIV-positive women, age 36, IDI)

Women from a high social position with HIV/AIDS who took part in the study had no financial difficulties and therefore enjoyed a satisfactory life style. These were women with university education up to postgraduate level, with property, access to credit with banks, and with professional profiles of company owners and management positions in different companies. These conditions favored adherence when beginning antiretroviral therapy. In spite of this, significant findings from the study show how these women lived with HIV,

In spite of this, significant findings from the study show how these women lived with HIV, the social role they tried to maintain after being diagnosed, and how difficult it was for them to accept being HIV-positive, in comparison to the experience of women from the lower social positions. They presented chronic stress as a result of the diagnosis, which in itself represented a threat to their health.

In the first place, it is important to mention that women who occupy a high social position are generally affiliated to private health insurance companies as well as having complementary health plans. Nevertheless, some of these women reported that they would

prefer to pay for their HIV treatment themselves, so that their HIV-positive status would not be registered in the health system. They even went as far as to invest money in visits to private consultations with specialists in other Colombian cities. Women from a high social position felt that they would not be seen consulting certain doctors, whose medical experience may associate them with HIV treatment, and at the same time reducing the threat to the confidentiality of their diagnosis. In all of this the financial cost involved was unimportant; what was important for them was the need to maintain secrecy.

In comparison with women of low and medium social positions, women belonging to a high social position thought of HIV/AIDS as more of an "illness" of which they should be ashamed; they considered that for society it is not the same to talk about another illness, however fatal this may be, as to talk about HIV/AIDS. Also, for them, to become "ill" means to depend, be helped and attended to, which goes against their personal and professional model of an independent woman. At the same time they had strong convictions about the possible discrimination, rejection, and pity associated with the diagnosis; some women even said that they would move away from the city in the event of their state of health being revealed. They were extremely afraid that their families would find out about the HIV diagnosis; also that the image formed around them would be destroyed, and moreover that their sexual practices could be questioned. For this group of women the emotional cost of the diagnosis caused them suffering which at times was exhausting.

To maintain secrecy about their diagnosis, these women limited the number of people who knew about it to a minimum, preferring to deal only with their own physician, and avoiding contact with the other health-care providers. When in the waiting room of the clinic they resort to strategies in order not to be identified by their name, and carefully plan ways of covering up HIV/AIDS in the event of illness, hospitalization or death. Under no circumstances do they take part in support groups or become involved with organizations which help HIV-positive people. Although they limit their possibilities of receiving comprehensive health care, the secret of their diagnosis – their closest ally – would not interfere with adherence to their treatment.

Conserving their physical appearance, image and personal aesthetic formed an essential part of the secret and was a motivating determinant in adherence. This is a case of women who were aware of the need to protect their bodies and take care of their health to hide HIV from their family and from society. Their self-care behavior included a healthy and balanced diet with vitamins, practicing yoga and taking natural remedies.

In spite of all this, women in a high social position in our study, who had many advantages bestowed by their status in Colombian society, developed a profound conviction about the importance and benefits of adherence. Although they came up against stigma-related threats, they marshalled all of their personal and material resources to care for their health.

Figure 3 shows the living conditions and adherence behavior among women of a high social position.

# 4.4 Discussing the results of the study in Colombia – South America

In the first place, the general trend found in the study was that HIV-positive women and in antiretroviral treatment belonging to the highest social position were more likely to present higher adherence, and the conditions of poverty or low social position in women served to increase –up to five times– the probability of non-adherence.

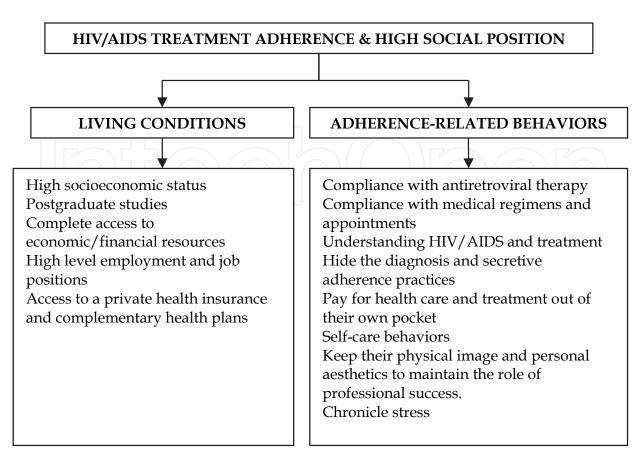


Fig. 3. HIV/AIDS Treatment Adherence & High Social Position. HIV-Positive Women. Colombia. 2007-2010

The relationship between socioeconomic status and adherence in HIV/AIDS-related cases is a subject which has been covered in different ways and with diverse results in scientific literature. In their sociodemographic descriptions, the majority of authors include variable income levels as the closest variable to social position. In general, socioeconomic variables are measured as independent factors, and as was the case in this study similar reports measuring social position as a group of conditions which act together to determine the place of HIV-positive women in Colombian society have not been found. Neither has the link between social position and the specific features which characterize adherence in the different groups been clear.

Although the relationship between the poverty of women and HIV/AIDS has been recognized as an essential determinant of the dynamics of the epidemic (Farmer, 1996; Herrera & Campero, 2002; Rao, 2004; Wingood & Diclemente, 2000), adherence among this population is a topic on which there has been little research and the results are not consistent. A systematic literature review of 116 studies presents the conclusion that even though there is a positive trend in relation to adherence in various chronic illnesses and some areas of socioeconomic status, for example income, education and occupation, there is insufficient evidence about statistically significant associations between socioeconomic status and adherence among patients with HIV/AIDS (Falagas, 2008). On the contrary, other studies carried out with men and women reveal associations between a deficient financial situation and non-adherence (Carballo et al., 2004; Castro, 2005; Chesney, 2000;

Chesney et al., 2000; Gifford et al., 2000; Glass, et al., 2006; Gordillo, 1999; Ickovics & Meade, 2002; Kleeberger et al., 2001).

The truth is that poverty accounts for a higher probability of social disadvantages associated with risks to adherence. In this study the relationship between the conditions of women of a low social position and low adherence was clearly seen. As far back as 1996 it had been reported that poor women with HIV/AIDS undergoing antiretroviral therapy, by comparison with samples of men with the virus, are more exposed to delays in being diagnosed, access to the health system and the corresponding care, which contributes to a bad prognosis and evolution of HIV (Daily et al., 1996). The problem of the lack of access to economic/financial resources due to their low social position, reduces their ability to obtain and continue with treatment (Amaro et al., 2001; Rao, 2004), or to satisfactorily maintain any type of therapy.

Some of the afore-mentioned variables have been analyzed independently by other authors, who have presented similar findings to those of this study. There is data on academic income and unemployment-related levels.

Regarding levels of education and adherence, as is the case with this study, some authors (Goldman & Smith, 2002; Golin et al., 2002; Kalichman et al., 1999; Kleeberger et al., 2004) have demonstrated significant associations. Results of research also illustrate the way in which adherence of women of higher social positions benefit from access to formal education and the cultural baggage accumulated in these social groups. High levels of education contribute to the ability to deal with the HIV diagnosis, serve in the taking of decisions, facilitate the search for information on access to health-related resources, and are advantageous in understanding HIV and its treatment. On the other hand, low levels of education, as with women of a low social position, produce patterns of vulnerability associated with low adherence. Allied to the other conditions which are typical of the lives of poor HIV-positive women, low education level can trigger a bad prognosis and the high risk of death from AIDS.

With respect to income level, some authors have suggested that there are associations with adherence (Carballo et al., 2004; Ickovics & Meade, 2002), and propose that it would be reasonable to argue that attention to basic needs is more beneficial than direct attention to adherence. In particular, women of a low social position could receive social support for the satisfaction of their basic needs.

This is also especially important in the case of unemployed women. Some authors contend that unemployment could contribute to reduced intention or capacity to continue taking antiretroviral medication, in keeping with the doses and times prescribed (Adler & Newman 2002; Fong et al., 2003). Bearing in mind that work is a central category of social position, it is necessary to develop new studies that will show the possible effects on adherence of employment/unemployment and the working/occupational situation of HIV-positive people. In the case of women, gender considerations should be taken into account with regard to the particular characteristics of women's work, and according to their social position.

The findings of the Colombian study also showed that in women of medium social position a pattern of empowered behavior converges, which favors adherence. In this regard, new approaches to the problem of HIV have referred to the importance of the "empowerment" category, identifying six sources of fundamental power for the support women with HIV: information and education, skills, access to services and prevention technologies, access to

financial resources, social capital and the opportunity to be heard in the taking of decisions at all levels (Gupta, 2000). These proposals coincide with the characteristics of the group of women of medium social position who took part in the study.

Other authors have dealt with the topic of the empowerment of HIV- positive women, from interventions based on microfinance to reduce violence against women, social exclusion, obtain access to health services, and promote mental health (Kim et al., 2007; Mohindra et al., 2008). The authors estimate that providing women with financial benefits such as access to credit services would contribute to their empowerment, increase their self-esteem, self confidence, their ability to resolve conflicts and take decisions. In any event, it would be well worthwhile to investigate more deeply the relationship between empowerment and adherence with future studies which would conserve the social nature of the concepts, since, as has been pointed out, empowerment means a change in unequal relationships between genders on a social level; strengthening prevention networks, the promotion and defense of social, economical, cultural, sexual and reproductive rights; change those life styles which place women at the risk of HIV infection, and fight against the stigma associated with the diagnosis (Herrera & Campero, 2002).

And it is precisely the social stigma which is the main characteristic associated with women of high social position in the study. Some authors relate HIV stigma and discrimination with socioeconomic and gender-related inequities (Altman, 2007); others have focused on the psychosocial consequences it produces (Arregui, 2007; Carr & Gramling, 2004; Pecheny et al., 2007; Ruiz-Torres et al., 2007). It has been said that women are the population most subjected to rejection and discrimination when diagnosed with HIV, also that they suffer from more discrimination than men (Arregui, 2007). In this study it was found that the perception of social stigma on the part of women of a high social position indirectly contributes to adherence. Although this is paradoxical, these women have adherence-related practices which with the purpose of conserving their appearance and in this way hide HIV from their families, their immediate social circle, and society in general. This self-care conduct has the result of favoring adherent practices.

This does not mean to say that the experience of stigma is a positive one for HIV- positive Colombian women of a high social position; for them, the moment of diagnosis is crucial in their biography since HIV is not only a medical diagnosis but on the contrary, begins to define their personal identity (Altman, 2007; Carr & Gramling, 2004; Pecheny et al., 2007). The first personal dimension to be affected by the HIV/AIDS-associated stigma is that of self-image; the woman first reflects every prejudice and rejection learned in society in herself. She is invaded by rational and irrational fears, and silence can take control of her life (Arregui, 2007). Thus, the main challenge of the women of high social position who took part in the study was to keep their diagnosis a secret at all costs. As previously mentioned by other authors (Pecheny et al., 2007), among the reasons for not revealing their diagnosis are avoiding embarrassment and shame, being able to keep to their daily routine, avoiding potentially discriminating situations, the fear of being treated differently and rejected, being the object of ridicule, suspicion and ill-intentioned comments in their social environment. According to reports in literature and the findings of the study, among the consequences of this perceived stigma are the deterioration of interpersonal relationships, negative emotions such as anxiety, depression and guilt, a low level of social support, isolation, difficulties with family relationships, and the deterioration of relationships with health-care providers (Ruiz-Torres et al., 2007).

#### 5. The social determinants of adherence to treatment of HIV/AIDS

Based on the evidence presented, adherence to treatment can be considered as a dynamic process, which moves in a continuum between critical processes related to general determinants and critical processes related to individual determinants.

The critical processes related to general determinants are illustrated in Figure 4 and include consideration of the *social position* as a structural determinant of adherence. In every society and socioeconomic context value must be placed on the characteristics which jointly make up and define the "place" or social stratum of the person living with HIV/AIDS. In the level of the *health system*, the health right to continuous and opportune treatment and comprehensive care by qualified health care providers are necessary conditions for adherence on the part of those who suffer from the virus. For its part, the "mode of living" (Almeida-Filho, 2000; Breilh 2003), represents a bonding category between general determinants and the complex behavior of treatment adherence. This category can be considered as a related group of practices connected especially with adherence, influenced by people's living conditions, socio historical processes, the dynamics of gender pertinence, and the influence of social position.

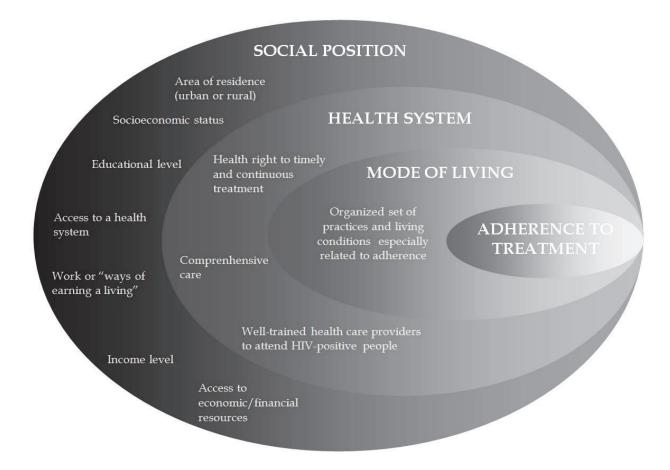


Fig. 4. Critical processes related to social determinants of treatment adherence in people living with HIV/AIDS.

The critical processes related to individual determinants of adherence cannot be understood isolated from the general determinants described above, but rather, subsumed in them. The life course trajectories taken through life lead to different forms of facing up to HIV/AIDS and its treatment, and also, gender roles and their impact on adherence must be taken into account.

Contrary to biomedical and individualistic traditions, and from an approach of the social determinants of health, which offers a framework of theoretical, epistemological and praxiological comprehension on the health-related processes of social life (Breilh, 2003), adherence to treatment can be considered as a *complex behavior promoting adaptation*, psychological adjustment, appropriate health care, and quality of life during the HIV/AIDS infection process, determined by mode of living, social position, and the health care system. With this concept of adherence it is possible to broaden the vision, and attend to the specific matters which are imposed by the general determinants such as individual influences. The critical processes described here, not only when conceptualizing but also when investigating and intervening adherence to HIV/AIDS treatment.

#### 6. Conclusions

The limited understanding of adherence to HIV/AIDS treatment, which is traditionally defined in an individual, biomedical and psychosocial context, and the evidence of the rates of low adherence which still occur in some populations affected by the virus, indicate that an approximation of adherence in relation to other categories of social analysis, and integrated with individual categories, could be useful to advance in the arguments of the negative effects of non-adherence. It is probable that if this concept is understood from the point of view of social determinants of health, new interventions could be proposed and better policies and plans for attention could be developed, with strategies aimed at social and gender-based equity.

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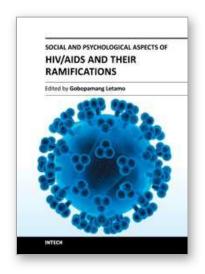
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This book has assembled an array of chapters on the social and psychosocial aspects of HIV/AIDS and their impact on HIV/AIDS and related behaviours. The book addresses key areas of HIV and AIDS, including, but not in any way limited to, care-seeking behaviour, adherence, access, psychosocial needs and support services, discrimination and the impact the epidemic has on various sectors of the economy. The book has seventeen chapters; seven chapters deal with social aspects of HIV/AIDS, four with psychosocial aspects of HIV/AIDS, and the remaining six chapters with the impact of social and psychosocial factors on HIV/AIDS and related behaviours. The book is an essential reading for academics, students and other people interested in the field of HIV and AIDS.

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