



## ORIGINALES

### Factors affecting adherence to antiretroviral treatment in women with HIV: A sequential mixed model research design

Factores relacionados con la adherencia al tratamiento antirretroviral en mujeres con VIH: Un estudio mixto con diseño secuencial

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#### ABSTRACT:

**Background:** HIV/AIDS is affecting more and more women. Adherence to antiretroviral treatment (ART) is decisive for those infected to achieve quality of life.

**Purpose:** The aim of the present study is to determine the degree of adherence displayed by a group of women with HIV/AIDS and to identify those factors and circumstances which might influence their adherence to ART.

**Method:** A sequential mixed model research design was applied. The subjects studied consisted of 86 women diagnosed with HIV/AIDS and treated with ART.

**Findings and discussion:** Qualitative data were collected from 18 of these women. 59.3% of participants were non-adherents. The determining factors for non-adherence were level of education, age, income, as well as personal and/or interpersonal factors such as socio-familial support, perceived stigma, self-stigma and factors related to disease and treatment. Nursing care should take a gender-focused approach towards those psychological and personal factors inherent in the adherence process.

**Key words:** HIV Infections; HIV; Anti-Retroviral Agents; Treatment Adherence and Compliance; Women's Health; mixed methods.

#### RESUMEN:

**Introducción:** El VIH/Sida afecta cada vez a más mujeres. La adherencia al tratamiento antirretroviral es decisiva en la calidad de vida de las personas infectadas.

**Objetivos:** El objetivo del estudio es determinar el grado de adherencia manifestada en un grupo de mujeres con VIH/Sida, con TAR e identificar los factores y circunstancias que influyen en su adherencia.

**Metodología:** Se ha realizado un estudio con diseño mixto secuencial explicativo. Los sujetos de estudio son 86 mujeres diagnosticadas con VIH/Sida en tratamiento con TARGA.

**Resultados:** Se recogieron datos cualitativos de 18 de ellas. El 59,3% de las participantes son no adherentes. Los factores determinantes de la no adherencia son el grado académico, edad, ingresos, así como factores personales, interpersonales como el apoyo sociofamiliar, estigma percibido y autoestigma y factores relativos a la enfermedad y tratamiento.

**Conclusión:** Los cuidados de enfermería deben abordar con enfoque de género aquellos factores psicosociales e individuales del proceso de adherencia.

**Palabras claves:** Infecciones por VIH; VIH; antirretrovirales; cumplimiento y adherencia al tratamiento; salud de la mujer; metodología mixta.

## INTRODUCTION

HIV/AIDS infection has become a pandemic, with severe consequences for humanity, affecting the lives of 36.9 million people<sup>(1)</sup>. Initially, the epidemic affected mainly men, yet current data shows that 57% of all those with HIV are women<sup>(2)</sup>.

Since the onset of the epidemic a total of 85,720 cases have been notified in Spain, where HIV is mainly transmitted sexually. Incidence in the region of Murcia is lower than the overall nationwide mean for the entire 2009-2015 period, yet higher than for European Union member states / Western Europe<sup>(3,4)</sup>. Regarding those women diagnosed with HIV, 89% of cases in the Region of Murcia are attributable to heterosexual transmission and 5% to injectable-drug use<sup>(3)</sup>.

Adherence (ADH) to antiretroviral therapy (ART) acquires immense importance due to its impact on the immune system, since a sub-optimal adherence leads to therapeutic failure and an increase in morbidity and mortality in those with HIV<sup>(5)</sup>. There are, therefore, numerous studies which raise the need to explore and consider the social contexts of those undergoing ART in order to identify any required adaptations and favour effective adherence<sup>(6,7)</sup>. In this sense, interventions must be designed and planned such that they might be adapted to the needs of specific subgroups, taking into account sociocultural aspects and available support and applying solutions to specific gender-based vulnerabilities in terms of the transmission and development of the disease<sup>(8,9)</sup>.

Women with HIV experience multiple forms of discrimination, both due to their socio-economic status as well as their gender, and are stigmatized by the means of transmission<sup>(10)</sup>, such stigma being associated with the perpetuation of isolation and loneliness<sup>(11)</sup>.

Emphasis should be placed on family as one of the most important supportive elements as well as on eliminating conflicts generated by discriminatory processes such as social exclusion and the marginalization of people living with HIV/AIDS in the workplace, school and social environments<sup>(12)</sup> or the increase in violence towards women, all of which highlights the need for research to approach this phenomenon in a holistic and exhaustive manner. The fact improvements in adherence have not been achieved is due to most adherence-to-ART guidelines being based on quantitative research focused on the individual, when many of the barriers described require interventions on a community level, precisely that in which affected people live<sup>(6)</sup>.

Therefore, the main objective proposed by the present study was to determine the degree of adherence to ART by a group of women with HIV/AIDS, as well as to identify and analyse those factors and circumstances which might influence adherence in such women.

## METHODS

### Study Design

A mixed, sequential, explanatory research design was utilized. This methodology begins with the collection and analysis of quantitative data, to continue on an equal standing with the collection and analysis of qualitative data and ending with an interpretation of the results in which associations are established between the quantitative and qualitative data.

### Study Sample

The present study is based on a multifocal approach and was carried out in six public hospitals from six healthcare districts in the Region of Murcia, Spain. The sample was construed according to the following inclusion criteria: women from 18 to 65 years of age, diagnosed with HIV/AIDS, time elapsed to onset of ART of at least 6 months, periodical clinical follow up at reference hospitals. Exclusion criteria were: existence of language barriers, advanced cognitive deterioration, being hospitalized or pregnant at the time of the study.

The sample selection method was probabilistic for the quantitative stage and the sample size was established according to number of patients who collected their medication personally from the hospital pharmacies over the years 2014-2015. Thereby, the total study population was composed of 86 women who met the aforementioned criteria.

During the qualitative stage the study population was composed of 15 women from 18 to 65 years of age, who participated in the quantitative stage and collected their medication from the hospital pharmacies in 2015. Participants were recruited via intentional sampling until reaching data saturation.

### Quantitative Stage

This stage involved a retrospective, cross-sectional descriptive design. It is cross-sectional for the following variables: *Influential factors towards non-adherence in women undergoing ART* and the *Degree of adherence shown by women undergoing ART*. It is retrospective for the variable *Degree of adherence according to the hospital pharmacies' (HP) dispensing records*. In order to obtain data during the qualitative stage the following instruments were utilized:

**1. Questionnaire on Adherence to Treatment in Women with HIV/AIDS (CAT-M VIH)<sup>(13)</sup>**: this is a questionnaire on adherence, comprised of closed-ended questions with a Likert-style ordinal response scale, constructed and validated previously in women with HIV/AIDS, the latter consisting of closed, dichotomous and/or multiple

responses organized into three sections: Socio-Demographic Data, Clinical History and Treatment Adherence Records.

**2. SMAQ adherence questionnaire:** A brief questionnaire containing 6 questions to be asked directly to the patient regarding their medication-taking habits that considers patients with a therapeutic compliance of 95% or greater, to be adherent<sup>(14,15)</sup>. This instrument has been validated for the Spanish population<sup>(16)</sup>.

**3. Blood tests:** results for viral load were collected from medical records as an indirect measure of adherence to ART and reinforcement thereof<sup>(17)</sup>, and of confirmation of suspected insufficient therapeutic compliance<sup>(18)</sup>, CD4/CD8 blood cell counts were utilized for HIV-infection staging, establishing the need for prophylaxis and eventual discontinuation<sup>(19)</sup>.

**4. Hospital pharmacy ART dispensing records:** providing information on the withdrawal of patients' medication from the hospital pharmacies and on the continuity of treatments, as well as on changes to new combinations of ART<sup>(14)</sup>.

### Qualitative Stage

The qualitative design involved an interpretative phenomenological approach in order to comprehend women living with HIV/AIDS, thus building a group perspective based on particular experiences of their unique yet collective realities. In this stage participatory and selective observation were utilized during in-depth interviews. The results were recorded in a field diary to relate and interpret their meanings. A conversational method via semi-structured interviews was applied using topics of interest to be explored. The questions were verified previously by key informants and experts in the field. The interviews were conversational, non-directive, non-judgmental and flexible in order to adapt to each participant's discourse such that the interviewee might discover, via phenomenology, the motivation behind their behaviour. The interviews were held in a private, amicable and relaxed environment, for which a multipurpose room was arranged in the participant recruitment services department. The mean duration of the interviews was 45 minutes.

### Data analysis

The quantitative data was analysed via basic descriptive methods. The comparison of qualitative variables between groups was performed via the Chi-squared method. The degree of concordance between the methods utilized for classifying patients according to adherence was calculated via Cohen's Kappa index. The statistical analyses were performed using the SPSS V23.0 software for Windows. Statistical significance was established at  $p < 0.05$ . The qualitative data analysis was based on a latent content approach. The four stages of the analysis were as follows: textual transcription of interviews, organizing and processing of data by identifying the arising coding and context units in order to grasp the exact meaning of each coding unit the reduction of data via the regrouping of codes that provided meaning plus identifying categories and subcategories and the interpretation of data via the search for intragroup relationships as well as relationships between groups of meanings. Subsequently, the data arising from both methods were compared and integrated as is recommended in mixed methods, such that during the interpretation, the qualitative data helped explain and complemented the quantitative data.

## Ethical considerations

During the data collection process, all the related information required was provided to participants in a socio-culturally appropriate format. Furthermore, participants were informed of their right to decline to respond to any given topic, as well as the option to withdraw from the interview at any time without penalty. All data obtained underwent strict confidential handling and signed "Informed Consent" forms were procured from all participants. Likewise, their permission was requested to record the interviews in audio format. Following transcription, all recordings were destroyed.

This study has been approved by the Ethical Clinical Research Committee of the University of Murcia and each Hospital in which data collection took place.

## Quality criteria

Credibility, transferability and traceability were applied as quality criteria to ensure scientific rigour. Thereby, veracity and credibility of the data were confirmed via the corroboration of experts and participants, transferability via transparency and protocolization of the entire process and traceability via the detailed description of sociodemographic traits of the informants, as well as inclusion and exclusion criteria and the selection process. Furthermore, a methodical data triangulation was performed by gathering information sourced from women from a range of geographical and healthcare areas, comparing and contrasting the results obtained using both quantitative and qualitative tools.

# RESULTS

## Sociodemographic Characteristics

The sample of the quantitative study is 86 women with HIV/AIDS undergoing ART and that of the qualitative study is a subsample of the quantitative of 15 women with adherence problems to such treatment. The participants are between 20 and 65 years old and have a mean age of 45.5 years for the quantitative sample and a mean of 42.2 for the qualitative sample.

As can be seen in Table 1, the participants in the quantitative sample have a majority level of primary education followed by secondary / high school, 45% are active, 35 have dependent children and 77 are in charge of housework. On the other hand, the profile of the participants with adherence problems (qualitative phase) consists of a woman with basic level studies, with low economic resources (€ 500-700 / month) and with paid jobs (10 participants with work activity recognized) who reconcile with household chores (14).

**Table 1. Sociodemographic Characteristics**

Characteristics	N=86(%) quantitative study	N=15(%) qualitative study
<b>Marital Status</b>		
<b>Single</b>	15(17,4)	2(13,3)
<b>Married</b>	20(23,3)	1(6,6)
<b>Widow/Widower</b>	14(16,3)	4(26,6)

<b>Divorced</b>	17(19,8)	2(13,3)
<b>Partner</b>	20(23,3)	6(40)
<b>Cohabitation</b>		
<b>With partner</b>	24(27,9)	7(46,6)
<b>With partner and children</b>	17(19,8)	1(6,6)
<b>With parents</b>	7(8,1)	2(13,3)
<b>With children</b>	21(24,4)	4(26,6)
<b>Alone</b>	17(19,8)	1(6,6)
<b>Education</b>		
<b>None</b>	18(20,9)	3(20)
<b>Primary school</b>	34(39,5)	5(33,3)
<b>Secondary school</b>	28(32,6)	5(33,3)
<b>University studies</b>	6(7)	2(13,3)
<b>Employment status</b>		
<b>Working</b>	39(45,3)	10(66,6)
<b>Welfare</b>	18(20,9)	3(20)
<b>Pensioner</b>	29(33,7)	2(13,3)
<b>Personal income/month</b>		
<b>Less than 500 €</b>	39(45,3)	6(40)
<b>500-700 €</b>	23(26,7)	5(33,3)
<b>Greater than 700€</b>	23(26,7)	4(26,6)
<b>Nil</b>	1(1,2)	0
<b>Origin country</b>		
<b>Spain</b>	68(79,1)	12(80)
<b>others</b>	18(20,9%)	3(20)
<b>Dependent children</b>	35(40,7)	9(60)
<b>Housekeeping</b>	77(89,5)	14(93,3)

## Quantitative Findings

### Clinical characteristics and HIV/AIDS treatment

Table 2 shows the clinical characteristics and HIV/AIDS treatment details. Within the clinical traits it is noteworthy that 79.1% contracted HIV via sexual transmission, 73.3% were in stage A1 of the disease and the viral load of 76.7% of participants was undetectable.

**Table 1. Clinical and treatment characteristics (n=86)**

<b>Characteristics</b>	<b>n (%)</b>
Family members with HIV	
Current partner	10(11.6)
Children	3(3.5)
Previous partner	32(37.2)

Others	6(7)
None	35(40.7)
Mode of transmission	
Sexual	68(79.1)
Needles or other sharps	9(10.5)
Blood	3(3.5)
Other	6(7)
Clinical stage	
A1	63(73.3)
A2	14(16.3)
A3	9(10.5)
B-C	0(0)
ARTs treatment	Media (DT)
No. of medications (1-4 drugs)	2.0 (0.8)
No. of active substances (1-4)	3.2 (0.7)
No. of tablets/day (1-4 tablets/day)	2.6 (1.4)

Regarding treatment, the mean number of medications administered was 2.0 (SD=0.8) with a mean consumption of 2.6 (SD=1.4) tablets per day and a mean number of active ingredients of 3.2 (SD=0.7). In terms of viral load, there was a significant difference ( $p=0.008$ ) between adherent and non-adherent patients, with detectable viral loads being significantly more prevalent in non-adherent than adherent patients (33% and 8.6% respectively).

### **Adherence to antiretroviral treatment**

The analysis of adherence to ARTs treatment via the SMAQ questionnaire showed that 41.9% of participants infected with HIV were non-adherent while the analysis of the hospital pharmacy registries concluded that 40.7% of participants were non-adherent. This produced a degree of concordance between both instruments of 63.95% with a Kappa coefficient of 0.257 ( $p=0.017$ ). If a participant is non-adherent by at least one of the two methods, she was classified as non-adherent. Thus, 59.3% of the HIV-infected women who participated in the study were non-adherent.

### **Factors influencing non-adherence to antiretroviral treatment**

Table 3 displays demographic and clinical variables in terms of non-adherence prediction, thus determining univariantly that participants with university studies are less likely to be non-adherent than those with no education or primary school

education at most (OR=0.10, p=0.040). Income also proved to have a significant effect in that women earning more than 700€ per month were less likely to be non-adherent than those with an income of less than 500€/month (OR=0.09, p<0.001). The remaining variables showed no statistically significant effects. On a multivariate level, the variables which proved to have a significant effect were: age, education and income. The older the age the lesser the likelihood of being non-adherent among the sample subjects (OR=0.92, p=0.032).

**Table 2. Effects of demographic and clinical variables in predicting non-adherence to ARTs**

Demographic Variables	Univariate Analysis		Multivariate Analysis	
	OR (95%CI)	p-value	OR (95%CI)	p-value
Age	0.97 (0.92 – 1.01)	0.130	<b>0.92 (0.85 – 0.99)</b>	<b>0.032*</b>
Education				
None/Primary	Ref.			
Secondary	0.56 (0.22 – 1.44)	0.228	0.60 (0.17 – 2.13)	0.430
University	<b>0.10 (0.01 – 0.90)</b>	<b>0.040*</b>	<b>0.36 (0.01 – 0.78)</b>	<b>0.023*</b>
Personal Income				
Less than 500€/month	Ref.			
500-700€/month	0.40 (0.13 – 1.26)	0.117	0.75 (0.18 – 3.07)	0.691
More than 700€/month	<b>0.09 (0.03 – 0.31)</b>	<b>&lt; 0.001***</b>	<b>0.16 (0.03 – 0.86)</b>	<b>0.033*</b>

Note: OR = Odds Ratio, \*p<0.05, Ref. = Reference value

### Qualitative Findings

Based on the quantitative results analysed in the first stage of the present study, a subsample of women with difficulties in adhering to treatment was selected in order to identify factors associated with poor adherence to ARTs. Four main categories arise from the analysis of these semi-structured interviews.

#### Personal factors

Personal factors which influence adherence to treatment are associated with socio-demographic (table 1) and cognitive-emotional aspects. The latter are unique and



differ from one subject to another, although certain common elements are to be found which will be highlighted subsequently.

Regarding cognitive-emotional aspects, these were closely associated with interpersonal factors and the appearance of self-stigmatization factors. The feelings and emotions generated on being diagnosed as HIV-positive and associated experiences limit interpersonal relationships and alter the “everydayness” of participants. In this sense, the main feeling identified in the participants of the present study was fear, although other feelings also emerged, such as resentment, rage, rejection, betrayal or anger (Table 5).

Moreover, fear stood out as a determinant for maintaining proper adherence to ART. Fear of the progress of the disease, of infecting third parties and of others learning of their serostatus leads them to becoming incapable of collecting and taking their medication on a regular basis. This in turn produces behaviour aimed at concealing any activity that might associate them with HIV, including visits to the Hospital Pharmacies to collect ARTs.

*“You have to have a little bag for medication hidden inside your handbag/suitcase so no-one can see which medication you’re taking in case they ask: “What’s that you’re taking?””* MVIH7

*“I can’t hand the box (of ARTs) to just anyone because it says so on the box and you know yourself with a mobile phone number in no time... they’ll rob you of everything”* MVIH13

**Table 3. Feelings associated with VIH**

<b>Fear</b>	
<b>Of the disease</b>	<i>“At the beginning I didn’t realize, I was scared like many people.”</i> MVIH5
<b>Of the disease progressing</b>	<i>“To think I won’t be able to fend for myself conditions me tremendously, that is to say, I’m, I’m not just afraid, I’m terrified and maybe it’s that added secrecy of saying: I’m going to be ill and won’t be able to say why.”</i> MVIH7
<b>Of revealing one’s serostatus</b>	<i>“My son doesn’t know because he’s still too young. Should I tell him? I don’t know what I’ll say. How can I tell him? How will it affect him? When I get sick for whatever reason, I don’t know, or my illness gets worse. What am I going to tell him?”</i> MVIH7
<b>Of infecting other people</b>	<i>“I’m very careful with her (sister) in this regard, because she grabs anything of mine. For example, my toothbrush, my razor... in the bathroom.”</i> MVIH1
<b>Of the future and death</b>	<i>“The first thing I asked was: “so when am I going to die?”</i> MVIH2 <i>“My fears are mostly centred on the future, on what will become of me tomorrow”</i> MVIH7
<b>Resentment</b>	
<i>“I don’t deserve it, mostly because (my ex-partner) has ruined my life and everything!”</i> MVIH6	
<b>Rage</b>	
<i>“It makes me furious, because it’s real. (...) there are those who bring it on themselves”</i>	

*and those who don't ...) I have never taken drugs yet I have to live with this disease."*  
MVIH8

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#### **Rejection**

*"I hear people commenting "Look, look, look, that person has AIDS (...) I see how they reject him, they reject those people and they glare at them." MVIH9*

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#### **Betrayal**

*"I could never have imagined such a thing... that this could ever happen in my household, nor to him; well, I did think it could happen to him (my husband), yes I did actually." MVIH12*

*"I have no idea because I was completely deceived (...) even his mother knew and they said nothing about it." MVIH3*

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#### **Anger**

*"Then the doctor told me, they did it all (the tests) and I got angry with him (husband), with my mother-in-law as well." MVIH15*

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### **Interpersonal factors**

The main interpersonal factors which have a negative impact on adherence to ART are: socio-familial support, self-stigmatization and perceived socio-familial stigma. Socio-familial support can be a factor which favours adherence to treatment when it is positive:

*"My cousin came to Madrid to tell me I had HIV and had to take medication (...). "You have to take this medication and live a normal life" and I said: "Oh, well that's that then! Take medication" (...) I was taken to an association in Murcia to get informed (...)." MVIH2*

In this regard, support and comprehension within couples prevents concealment issues, reducing levels of self-stigmatization and normalizing the disease process:

*"The person who really supported me in every sense was my partner: by talking with me, advising me and not leaving me for even one second, by supporting me with the treatment" MVIH1*

Nonetheless, it can also act as a detrimental factor for adherence when it is negative, directly influencing the emotional stability of the participants, occasionally becoming an incentive for concealing their serostatus, even if this meant complicating the collection of medication:

*"To look for support ...is something you can't do (...). You can't talk with everyone or look for support openly, it's better they don't know." MVIH7*

*"Regarding work, because practically I can't ... actually, I can say "I have a Doctor's appointment", yet the less absent I am, it would seem, less explanations I have to give (...) due to my profession, since I attend to members of the public, the less people know the better." MVIH11*

Conversely, the processes of labelling and assimilation of beliefs and prejudices related to HIV/AIDS, both by infected women and by their social, familial and working

environments, directly and negatively affect ongoing optimal adherence to ART. The belief that everyone rejects, or would reject, others due to their serostatus, drives women with HIV/AIDS to seek concealment strategies for the entire range of situations they must face regarding their illness and ART.

*“I cleaned up the blood, I put on a glove, I did what I had to do to stop the bleeding and carried on working!” MVIH2*

*“Every time I go to have blood tests done, I have to come up with an excuse (...).*

*Every time I have to go and collect medication, I have to make up an excuse (...).*

*Each time I go to the Doctor, I have to make something up” MVIH7*

### **Factors related with HIV/AIDS**

The acceptance of and attitude towards this illness to a large extent determine adherence to ART, but it is also directly related to the acquisition of habits such as self-care and caring for one's surroundings which complement pharmaceutical treatments.

The presence of HIV/AIDS permeates the feelings and emotions of the women who suffer from it throughout their entire their lives. All of these factors, together with their attitude towards HIV and ART will come to determine adherence. Participants are to be found with either positive or negative coping mechanisms and it is difficult to discern between feelings of acceptance, conformity or resignation towards the situation. Nonetheless, the participants have adapted to living with the illness, despite having developed defensive attitudes towards the social prejudices which drive self-stigmatization and perceived socio-familial and socio-workplace stigma. This leads them to conceal the illness, to minimize it and even attempt to forget they have HIV:

*“There are worse things and by worse things I mean, there are people who can't even move or anything.” MVIH5*

*“I think I have adapted to it (HIV) (...). Up until now I'm doing fine. I have assimilated it.” MVIH1*

The degree of acceptance of the illness displayed by some participants and resignation by others, led them to incorporate new lifestyle habits, encouraged by professional advice, in order to keep healthy:

Nutritional self-care: *“I try to eat well, I take vitamins and I always say you have to work, because by working one remains keener.” MVIH1*

Mental-health self-care: *“Many a time I jump on my motorcycle and head to the countryside for a spin or I go window shopping to distract myself, so as not to think, so as not to think.” MVIH9*

Medical check-ups, blood tests and pharmacological reviews: *I continue to have blood tests” (...). I visit the doctor on my own, I have the tests done and go alone (...). My*

*chest x-ray is fine, bone tests are fine, it's all fine, it's just that "I've got this and I've got to keep an eye on it." MVIH8*

*Sexual health: "Now I know that this isn't ... one has to take care when it comes to sexual relations, just like other diseases which are caught more often" MVIH5*

Such routines are also associated with taking care of one's surroundings, mainly to avoid disease transmission.

*Caring for the family: "We had the (HIV) tests done on my son as well but he came up negative (...) I have a daughter who is fine, I had her tests done and she's fine." MVIH8*

*Caring for healthcare professionals: "When I go to the doctor, it (having HIV) is the first thing I tell them, the dentist even, that's right, the very first thing, I always tell them straight up." MVIH15*

Conversely, those participants who have not accepted the fact they have the disease develop ineffective (negative) coping mechanisms. This finds them not developing the self-caring attitudes necessary for a proper and effective adherence to treatment:

*"I have never accepted it" (...). "It's difficult to accept it (...). The first year I had it, I shut myself indoors, not even a window open; everything totally shut." MVIH1*

*"No, accept it (HIV)? I will never accept it, ever, because I don't deserve it, because I didn't do anything to bring it on myself." MVIH6*

### **Factors related with ART**

The prognosis and quality of life of HIV patients depend on the degree of therapeutic compliance with ART. Along these lines, the importance of and adherence to treatment were analysed as factors related with ART, as was attitude towards ART and perceived efficacy.

It was thereby found that the greater part of the participants reported having received information on ART from qualified professionals, the importance of proper adherence and the consequences in terms of disease progression associated with low or non-adherence.

*"The Doctor said to me: ...you will have to take medication, this medication will be your lifeline (...). If you follow the treatment properly ... you have a chance at a somewhat longer life (...). I had already been informed very well about the disease, about what happens when you do certain things, if you don't take the medication, what happens step-by-step, basically everything." MVIH3*

*"Everyday (I take ART) in the morning. I was told: if you take it in the afternoon, then in the afternoon it is, if you take it in the morning, then in the morning it is, but never ever change the time." MVIH9*

Nonetheless, there was one case reported of not having received sufficient information regarding the dose and timing of the treatment, which led to self-administration errors.

*“When I started with the pills, the first time I took them they didn’t explain how I was supposed to take them properly (...) I took them all in one go, I became very unwell with high fevers!” MVIH2*

As such, correct professional healthcare information and education can have a positive effect on both adherence to and proper administration of ART.

Furthermore, the information received by the study participants favours positive attitudes towards ART and the perception that treatment is effective. In this regard, most participants reported trusting in ART and perceived its effectiveness:

*“I am aware that without this medication I would be as (good as) I am (...). It’s enough for me to know I’m doing fine, because the Doctor tells me so, and besides the Doctor, I see the blood tests and I know I’m doing well, because my defences are up quite a bit.” MVIH1*

Notwithstanding, although the attitudes towards and the perception of the efficacy of ART was positive among the majority of the participants as well as the treatment being considered responsible for their wellbeing, despite their illness, in some cases contradictory statements were noted with regard to adherence to ART, raising some suspicion as to a possible low adherence. This is based mainly on statements revealing delays in dosing regimen, the existence of leftover tablets and sporadic omissions in administration.

Improper dosing regimen: *“(…). When I have a drink, I take my medication a little later than normal so as to not mix it with the (alcoholic) drink, but I never skip taking it, I never skip a day.” MVIH1*

Surplus medication: *“I’m handling the treatment well, I mean, I take it (the medication) (...). There are months I go and months I don’t because I’ve got pills to spare, I say: “Why bother going all that way? (...). One tablet every night and that’s that, that’s my day-to-day...” MVIH13*

Dosing omissions: *“I keep up with my medication. My Doctor told me it was long term and I can’t stop taking it, I have to follow instructions to the letter (...). Well, I’m carrying on, although sometimes I forget and then pick it up again, and so on, but I’m still on it.” MVIH15*

Further important factors related to adherence to ART are side-effects and simplifying treatments. In this regard, reducing the number of pills on a daily basis can be seen to favour adherence: *“At first you have to take up to a dozen pills, I had forgotten, now, thank God, one is enough (...) I have never had any side-effects, none whatsoever, and mine’s (viral load) undetectable” MVIH8.* Likewise, the side-effects associated with treatment pose a barrier to proper adherence: *“In the mornings I wake up quite poorly, I get terrible acid reflux and I told the Doctor I couldn’t go on like this, I went 2 - 3 days without taking the medication because I wasn’t tolerating it.” MVIH1*

## DISCUSSION

To be informed of a HIV diagnosis creates a strong emotional impact in women which in turn produces shock, denial, surprise and fear. Participants reported such an impact greatly limits interpersonal relationships and alters daily life. Among the feelings that pervade the lives of those interviewed, fear of unknown aspects of the disease, of worsening health, of the physical manifestations of HIV, of the discovery of their serostatus, of facing their future and of infecting third persons are all to be emphasized. Furthermore, an unfounded sense of guilt worsened stress levels in these female participants, which is considered a predictor for low adherence. In this regard, emotional impact, psychological anguish and depressive symptoms which develop during the illness, are associated with a drop in adherence<sup>(11)</sup> Further elements highlighted by participants in the present study were stigma and self-stigmatization. Stigma is another factor associated with low adherence<sup>(20)</sup> and although there is no statistically significant association between stigma and gender, there tends to be a greater presence of self-stigmatization among women<sup>(20)</sup>. The issue of seropositivity being related with behaviour construed as immoral finds women with HIV presenting reported perceived stigma from friends, family and healthcare professionals<sup>(21)</sup>. Regarding the latter statement, ignorance of the disease causes HIV to be associated with promiscuity and drug use. As such, some women see their reputation questioned and feel obliged to clarify to the contrary.

Of the participants in the present study, 79.1% contracted the disease via sexual transmission related with their partner concealing their serological status from them. These data reflect the greater biological and social vulnerability of women to becoming infected with HIV<sup>(19)</sup>. In addition to biological vulnerability, the present study reflects the social and workplace susceptibility of women who live with HIV/AIDS. Although legal coverage exists in Spain<sup>(22)</sup>, study participants detected discriminatory situations in the workplace and discriminatory situations related with the violation of their confidentiality. These situations and the stigma in the workplace perceived by the participants, generate situations of hiding the disease, fear of being fired, stressful situations linked to injuries in the workplace, hiding medication, medical appointments or fear of taking the ART in public, making ADH very difficult <sup>(23)</sup>.

The aforementioned issues and the stigma in the workplace perceived by the participants, lead to the concealment of the disease, a fear of being dismissed and of other stressful situations associated with injuries in the workplace. Such scenarios produce high levels of psycho-social suffering in seropositive women and the stigma associated with HIV perpetuates isolation and solitude as a refuge for concealing ones serostatus<sup>(11)</sup>. Thus, self-stigmatization and fear of discrimination hinder the initiation of relationships and the creation of social support networks.

Social support is the most relevant factor for adherence and an essential aspect of coping and commitment skills for improving adherence to ART<sup>(24)</sup>. In the study participants, social, family and work support has been described as insufficient or non-existent, which may be one of the precipitating elements of therapeutic non-compliance of 59.3%. Within the social support concept, positive personal relationships improve the experience and acceptance of the disease and in turn improve adherence to ART. However, negative experiences on a community and family level compromise adherence due to ruptures in the social fabric and difficulties

within the family microsystem<sup>(25)</sup>. Reason why, social health care should focus its efforts not only on the individual but also in their social environment<sup>(6)</sup>.

The need to establish strategies to promote and / or improve ADH is evident, applying the gender perspective to avoid bias in health care <sup>(26)</sup> and establishing programs focused on improving self-esteem and strengthening the attitude towards the disease through emotional support <sup>(27)</sup>.

### **Study Limitations and Strengths**

In general terms, sample size may be a factor limiting the extrapolation of results. Therefore, in the quantitative stage, data from several instruments were utilized and cross-referenced in order to confirm the outcomes. further limitation to the quantitative stage which is to be highlighted is that the SMAQ questionnaire overestimates adherence since it is self-referring<sup>(14,28)</sup> and lies in the SMAQ questionnaire presenting a limited scoring system and a predisposition to please. Furthermore, the pharmacy registry overestimates adherence given that it assumes patient take the medication registered therein. Nonetheless, the combination of both methods enables the degree of adherence to be adequately analysed<sup>(29)</sup>.

Likewise, in the qualitative stage theoretical data saturation was achieved. In this stage, it was also not possible to discard certain social desirability bias in which participants might modify their responses for the sake of better appearances, mainly supported by the self-stigmatization processes described in the results. Notwithstanding, there was an element of trust in the relationship between the interviewer and the participants given that the former was a pharmacy staff member and was familiar with their adherence status, which facilitated a more open dialogue on matters of personal motivation and gender with regard to adherence to treatment.

### **Implications for Future Research and Practice**

Generally, nursing care should not be limited to a biological and social level, but should also involve the existential sphere, in order to respect patient dignity and help compensate for the deficits produced when a person's health is lacking. In this sense, healthcare for women with HIV/AIDS should be oriented towards developing educational and guidance protocols with gender and cultural considerations in order to address the psycho-social factors involved in adherence processes. Approaching social determinants of health such as socio-economic and educational status are noteworthy elements to be developed in the endeavour to improve ADH.

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