

UNCERTAINTY OF PREGNANT WOMEN LIVING WITH HIV ON ANTIRETROVIRAL TREATMENT

IVONNE ROSARIO ROMERO GUZMÁN¹, DENNYS ISABEL MUÑOZ MONTERROZA²,
LUCELLY BENITEZ CHEIJ³, KOMAL ABDUL RAHIM⁴, ANIBAL ARTEAGA NORIEGA⁵,

Recibido para publicación: 19-02-2021 - Versión corregida: 10-05-2022 - Aprobado para publicación: 8-06-2022

Romero-Guzmán I.R., Muñoz-Monterroza D.I., Benitez-Cheij L, Abdul-Rahim K, Arteaga-Noriega A., **Uncertainty of pregnant women living with HIV on antiretroviral treatment.** *Arch Med (Manizales)*. 2021. 22(1):89-98. <https://doi.org/10.30554/archmed.22.1.4179.2022>

Summary

Objective: *determine the level of uncertainty of HIV pregnant women in antiretroviral therapy and their relationship to the variables age, occupation, marital status, years of study and weeks of gestation. The experience of living with HIV confronts the individual with certain complex situations or processes, where psychosocial implications may arise. For its part, pregnancy with HIV has been described as an experience governed by fear and uncertainty related to the risk of infection and the effect of antiretrovirals on the unborn child, which could represent a risk to physical health and emotional of the dyad.* **Materials and Methods:** *observational, descriptive study with an analytical component. The population consisted of all pregnant women diagnosed with HIV and antiretroviral treatment, who attended a check-up at an IPS in the city of Montería (Fourteen).* **Results:** *65% of pregnant women with HIV, on antiretroviral treatment, presented a high level of global uncertainty, 14% regular and 21% low.* **Conclusion:** *the pregnant women with HIV in antiretroviral therapy participating in the study presented a high level of uncertainty, especially regarding the prognosis, treatment and diagnosis. Of the variables analyzed, the relationship of uncertainty with age and weeks of gestation was evident.*

Key words: *uncertainty, pregnancy, HIV seropositivity, Anti-HIV Agents.*

- 1 Nurse. Specialist in Health Audit. Master in Nursing. Lecturer University of Sinú Elías Bechara Zainúm. Montería, Colombia. ORCID: <https://orcid.org/0000-0002-4626-0081> Mail: ivonneromero@unisinu.edu.co
- 2 Nurse. Magister in Public Health and Health Planning. Lecturer University of Sinú Elías Bechara Zainúm. Montería, Colombia. ORCID: <https://orcid.org/0000-0002-4020-8231>. Mail: dennysisabelm83@gmail.com
- 3 Nurse. Specialist in Epidemiology. Lecturer University of Sinú Elías Bechara Zainúm. Montería, Colombia. ORCID: <https://orcid.org/0000-0001-7522-519X>. Mail: lucelybenitez@unisinu.edu.co
- 4 Nurse. Bachelors in Science and Nursing. The Aga Khan University Hospital, Pakistan. ORCID: <https://orcid.org/0000-0002-0790-6644>, Email: komalrahim44@gmail.com
- 5 Nurse. Master in Public Health Candidate to Doctor of Epidemiology and Biostatistics. Lecturer Remington University Corporation. Medellin, Colombia. ORCID: <https://orcid.org/0000-0002-6612-1169> Mail: anibal.artea@uniremington.edu.co

Incertidumbre de las gestantes viviendo con VIH en tratamiento antirretroviral

Objetivo: *determinar el nivel de incertidumbre de las gestantes VIH en tratamiento antirretroviral y su relación con las variables edad, ocupación, estado civil, años de estudio y semanas de gestación. La experiencia de vivir con VIH enfrenta al individuo a ciertas situaciones o procesos complejos, en donde pueden presentarse implicaciones psicosociales. Por su parte, la gestación con VIH se ha descrito como una experiencia regida por el miedo y la incertidumbre relacionada con el riesgo de infección y el efecto de los antirretrovirales en el hijo por nacer, lo que podría representar un riesgo para la salud física y emocional de la diada. Materiales y Métodos:* estudio observacional, descriptivo con componente analítico. La población estuvo conformada por todas las gestantes con diagnóstico de VIH y tratamiento antirretroviral, que asistieron a control en una IPS de la ciudad de Montería (Catorce). **Resultados:** 65% de las gestantes con VIH, en tratamiento antirretroviral, presentó un alto nivel de incertidumbre global, 14% regular y el 21% bajo. **Conclusiones:** las gestantes con VIH en terapia antirretroviral participantes del estudio presentaron un alto nivel de incertidumbre, especialmente frente al pronóstico, tratamiento y diagnóstico. De las variables analizadas, se evidenció relación de la incertidumbre con la edad y las semanas de gestación.

Palabras clave: *incertidumbre, embarazo, seropositividad para VIH.*

Introduction

Human immunodeficiency virus (HIV) remains one of the most serious public health problems worldwide, according to the World Health Organization in the world there are approximately 37.9 million people with HIV and there were 77,000 deaths related to this cause, the result of deficiencies in health services [1]. In Colombia, there has been a decrease in the mortality rate, however, the number of new cases has increased considerably, in 2017 there were a total of 9,399 new cases diagnosed and an estimated 83,000 people had the disease [2] in 2018.

For pregnant women with HIV, in 2018 the High-Cost Account 761 was reported, higher compared to the previous year of 674, with an age range between 15 and 49 years. The proportion of pregnant women with HIV, among the total number of pregnant women per department, showed Córdoba, as one of the territorial authorities with the highest

concentration, presenting 70 pregnant women with HIV from a population of 13,724 pregnant women [2].

The experience of living with HIV confronts the individual with certain complex situations or processes, where changes in family dynamics, changes in role may occur, in some cases their daily work is affected, adaptation to a new health condition, which leads to assistance to routine controls, examinations and treatment. All these changes may have psychosocial implications [3], where while HIV is currently considered a chronic disease, social stigma still persists so in some cases there is social isolation or fear of communicating the diagnosis to its close ones [4].

HIV gestation, on the other hand, has been described as an experience governed by fear and uncertainty related to the risk of infection and the effect of antiretrovirals on the unborn child, which could pose a risk to the physical and emotional health of the day [5-6].

Uncertainty has been described as the inability of the individual to understand the meaning of the elements associated with the disease, especially when faced with diagnoses related to death or loss of autonomy, generating a negative impact on the well-being of the person, even rushing the process of the disease [7].

The theory of uncertainty about the disease provides foundation for research in subjects experiencing chronic diseases by addressing the integrality of the individual and the emotional responses that occur [8], allowing the nursing professional to understand people's experience in the face of diagnosis, symptomatology, treatment and prognosis of the disease. This theory has been widely used in hospital and outpatient care for cancer patients [9], cardiovascular diseases [10,11], respiratory [12], fibromyalgia [13], pregnant people [14], among others; allowing to deepen the psychosocial aspects associated in the care of these patients and guide nursing care to the real needs and expectations of the user and the family.

Therefore, the timely identification of uncertainty in the pregnant women with HIV positive, in antiretroviral treatment, by the nursing professional, is relevant for the design of intervention strategies, aimed at adapting the pregnant party and her family to the new health condition.

In this sense, the purpose of this study was to determine the level of uncertainty of HIV pregnant women in antiretroviral therapy and their relationship to the variables age, occupation, marital status, years of study and weeks of gestation.

Type of study

Observational study, descriptive with an analytical component.

Population

Through convenience sampling in January to June 2019, all pregnant women with HIV diagnosis and antiretroviral processing, who

attended control at an IPS (health care provider institution) in the city of Monteria (Fourteen), Colombia, who met the criteria for inclusion, being over 18 years of age, pregnant in antiretroviral treatment and in current control were invited to participate, and who agreed to participate in the investigation voluntarily. The total number of pregnant people in antiretroviral processing in this IPS was taken as a reference for the sample the previous year.

Analyzed variables

The analyzed variables were: age (number of years), marital status (single, living together, separated), years of study, occupation (housewife, employee, independent), weeks of gestation and the level of uncertainty (low, regular, high).

Instruments

Two instruments were used for the collection of information, a questionnaire that researched sociodemographic variables (Age, Marital Status, Educational Level, Occupation) and the clinical variable weeks of gestation. The scale of uncertainty against Merle Mishel's illness was also applied, which has been used to determine the factors that influence the uncertainty that the person experiences in the events related to the disease. This instrument has been used in various studies to determine the uncertainty in the face of chronic pathologies, being translated into several languages. In Latin America it has been used since 1987 when it was validated in a study in Chile, showing high levels of reliability. In Colombia, facial and content validation was carried out, as well as organization by scale dimensions in 2012 [15]. It has also been used to evaluate the uncertainty regarding diseases such as diabetes mellitus, [10] in a female population diagnosed with cancer [7, 16] and adaptation and validation was recently carried out to assess the uncertainty regarding diagnostic procedures [17]. This scale contains 29 Likert

questions of 1 to 5 points and ranges from very disagree, disagreement, indifferent to, agree, to very agree; a score of 5 of each question reflects a high level of uncertainty, except in questions 6, 7, 10, 12, 21, 22, 25, 27 and 29, in which the score is reversed. You can get a maximum score of 145 points and a minimum of 29 points. A score < 59 points is low level of uncertainty (NI); regular corresponds to 59-87 points and ni high: >87 points [10].

Process

After obtaining the corresponding endorsements for the research, the pregnant women who were on antiretroviral treatment of this institution were contacted and the details of the study were explained, giving the possibility of accepting or not participating in it. Then an appointment was made with each of the users, in the premises of the health institution and in a private room of the interview and a warm and comfortable atmosphere was provided for the participants. Each of the questionnaires was applied by the researchers in the months of January and to June 2019.

Statistical analysis

The information was processed through IBM-SPSS 25 (IBM Corp). Descriptive, central trend and dispersion measures were used to analyze the data. Non-parametric tests were used for the analysis of the relationship between the study variables taking into account the sample size (<30). The relationship between qualitative variables was made by Fisher's exact test and the relationship of quantitative variables to the overall uncertainty score was made through Spearman's correlation.

Control of biases

The instruments were captured by the participants in conjunction with the researchers to avoid errors in the interpretation of the information. As it is a small population, it was decided to admit all pregnant women enrolled in the health institution.

Ethical considerations

The research is ethically supported by the ethical principles contained in the guidelines of the Council of International Medical Sciences Organizations (CIOMS) and Resolution 008430 of 1983 of the Colombian Ministry of Health. The study was classified as a minimum risk.

Consent was obtained informed by the participants. It was approved by the Scientific Committee of the IPS where the research and authorization of the Ethics Committee of the Faculty of Health Sciences of the University of Sinú Elías Bechara Zainúm- Sede Montería was carried out.

Results

The sample consisted of 14 participants with an average age of 31.5 years and 7.4 years of study. 43% live as a couple and 58% are housewives. Regarding the weeks of gestation, it ranges from 21 to 37 weeks, with an average of 31.5. (Table 1).

Table 1. Sociodemographic characteristics of the participants (n=14)

Variables		Frequency	Percentage
Marital status	Single	3	21 %
	Lives	6	43%
	Separate	5	36%
Current occupation	Housewife	8	58%
	Used	3	21%
	Independent	3	21%
		Average	Standard deviation
Years of study		7.4	3.2
Age		31.5	5.3
Weeks of gestation		31.5	4.9

Source: own elaboration.

In terms of uncertainty against the disease, 65% of pregnant women with HIV, in antiretroviral processing, had a high level of overall uncertainty, 14% regular and 21% low. See Figure 1.

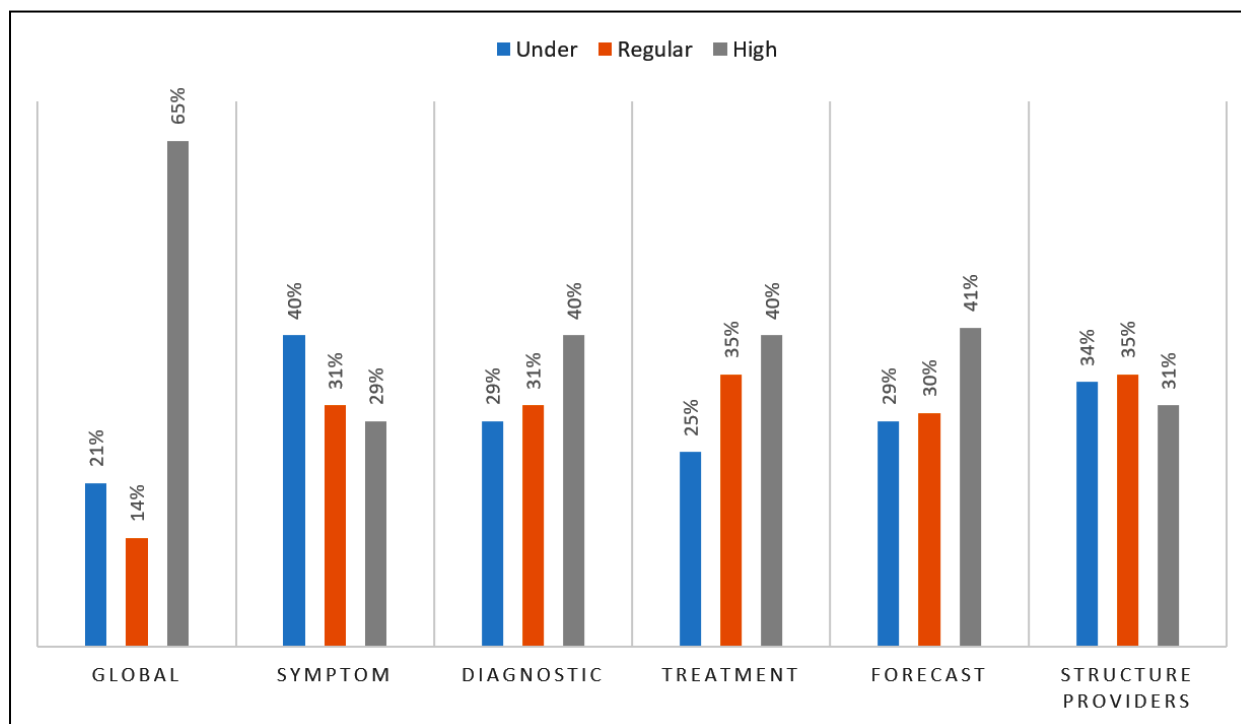


Figure 1. Level of global uncertainty and by subscales of pregnant women living with HIV on antiretroviral treatment. Source: self-made.

In assessing the level of subscale uncertainty, high levels of uncertainty were found against prognosis (41%), treatment (40%) diagnostics (40%).

The high level of uncertainty of pregnant women versus prognosis is based on questions that cannot predict how long their disease will take by 100%, they do not know when they will feel better at 42.8% and 100% states that they cannot predict the course of their disease.

With regard to treatment, 85.8% of pregnant women with HIV, in antiretroviral processing, do not know when there will be changes in HIV and for 37.8% it is complex to understand this. In diagnostic-related questions, 57.1% of pregnant women have many unanswered doubts.

In assessing the subscale against structure suppliers, the pregnant women stated that the explanations received seem confusing to them at 28.5% and do not understand the explanations 42.8% of them.

The level of uncertainty in pregnant women in the face of symptoms was unclear when they will feel better at 64.2%, 85.7% do not know what pain means for their health condition.

About the association between qualitative variables and the overall level of uncertainty through Fisher's exact test, it was obtained for marital status (Value 1,601; $p = 1.0$) and for occupancy (Value 4,593; $p = 0.334$), so the null hypothesis is accepted, there is no association between these variables and the level of uncertainty, with the p -value being greater than 0.05.

Finally, to identify correlations between uncertainty against the disease and quantitative variables, years of study, age and weeks of gestation, correlation analyses were performed with Spearman's Rho statistic, from which a positive correlation of uncertainty was obtained with age ($r = 0.961$; $p = 0.000$) and weeks of gestation ($r = 0.883$; $p = 0.000$). While for the variable years of study a minimum correlation

level is established ($r -0.156$), being a negative correlation, i.e., inverse, so, less years of study, the higher the level of uncertainty in pregnant women with HIV in antiretroviral processing. However, a significance level was obtained ($p = 0.595$), so it is concluded that it is statistically non-significant.

Discussion

Living with the HIV virus is recognized as an experience that confronts the individual with physical and spiritual suffering, which creates stressful situations and can even lead to neurotic disorders or vulnerability in such patients [18].

In this sense, being pregnant and HIV positive is a complex situation that has a great impact in all areas of the pregnant world. A high degree of uncertainty was observed in the sample studied, consistent with what has been reported by previous studies in which pregnancy has been identified to create uncertainty related to the well-being of the fetus and mother [19, 20]. This situation can have negative consequences on the development and health of pregnant women and their families [21]. Likewise, suffering is accompanied by uncertainty in the face of disease related to lack of support, social stigma and self-blame [22].

Regarding the sociodemographic characteristics of HIV pregnant women in antiretroviral processing participating in the study, they are similar to what Meza *et al.* reported in her study on stress level in Mexican HIV-positive pregnant patients, where she reports an age of 27.7 ± 6.9 years (average \pm DE), with years 9.2 ± 3.0 of studies, equivalent to full basic education. Housewife women predominated (71.2%) and who live together in pairs (59%) [23].

Within sociodemographic aspects, schooling has been considered as a variable that allows understanding of the evolution and prognosis of the disease, which decreases uncertainty, stress and promotes the adoption of healthy be-

haviors and adherence to treatment [18]. Within the results of this research, the association found was not statistically significant. Not so with the age at which it correlated with the level of uncertainty of the pregnant women studied, contrary to what was observed in previous studies on uncertainty against the disease in chronic patients [7].

In relation to marital status, no association was found with the level of uncertainty, contrary to what has been exposed in previous studies, where partner living has been identified as a positively influencing factor in the face of diseases, especially HIV, which may be related to perception of support, favoring quality of life and emotional well-being in this population [24]. Social support, especially family support, has also been reported to be a strategy in reducing uncertainty, facilitating the acquisition of information compression skills and acceptance itself [25].

In the subscale analysis, high levels of uncertainty were identified against the diagnosis and prognosis of the disease, similar to what was observed by Rubiano and collaborators in his study with pregnant women with HIV, where 68.1% of participants reported high levels of uncertainty against diagnosis, reporting great emotional burden upon notification of the diagnosis and the accompanying process, such as confirmatory tests and medical checks [26]. Likewise, the experience of diagnosis framed in suffering by the likelihood of transmission and harm to sons and daughters, the complexity of treatment, the face of death and social rejection [27] has been described.

In this sense, it has been highlighted within the experience of HIV gestation, indifference and abuse, generated by the hostile environment that sometimes the same health professional provides to pregnant women, deepening fear and uncertainty [28, 29,30].

Despite advances in the treatment and management of the disease, now regarded as

a chronic disease, stigma and discrimination become apparent [31] which influences HIV-positive women in the decision to be breastfed [32].

With regard to antiretroviral processing, the pregnant women in the study stated that it is complex to understand and that they have many doubts about it. Although it is widely recognized that antiretroviral treatment in HIV-positive pregnant women improved pregnancy outcomes and child survival [33], there are economic, cultural and social factors that affect lack of adherence, so addressing uncertainty is critical to ensuring the effectiveness of treatment [34]. Uncertainty with treatment is related to adverse effects, changes in schemes, barriers to the health system, lack of economic resources, among others [35]. For some people it is a complicated process by lifestyle changes and understanding the importance of adhering to treatment, which means continuous learning for the maintenance of life and well-being [36,37].

Finally, there is a strong relationship between the weeks of gestation and the level of uncertainty, where the higher the week of gestation, the higher the level of uncertainty. It is recognized in the literature that during pregnancy, high psychological burdens are experienced that can affect the outcome of childbirth or the development of the fetus, increasing the possibility of pre-term delivery, low birth weight and lower score in the Apgar test [38,39], which raises the need to create strategies that prioritize health care to this population beyond biomedical schemes, which involves recognizing all aspects involved in gestation, providing more resolute and comprehensive health systems, addressing the psychosocial risks faced by HIV-positive pregnant women and the impact it can generate [40].

Conclusions

Pregnant women with HIV in antiretroviral therapy participating in the study had a high

level of uncertainty, especially in the face of prognosis, treatment and diagnosis. Of the variables analyzed, there is evidence of a link between uncertainty and age and weeks of gestation.

The results of the present study allow the nursing professional, through the application of the Theory of uncertainty in the face of the disease, to provide comprehensive care by identifying uncertainty in pregnant women with HIV, in antiretroviral treatment and, in turn, deepen the approach who suffers from a chronic communicable disease, from the perspective of recognizing their individual care needs. Likewise, provide a frame of reference that contributes to the application of novel intervention proposals that contain social reinclusion, decision-making and reconceptualization of the experience of the disease as an opportunity, in the different practical scenarios; where the support of the nursing professional facilitates adherence to treatment and effective coping.

Limitations of the study: Among the limitations of the study is the size of the sample, it is recommended that future research expand the study population reaching other specialized care centers for pregnant women living with HIV.

Conflict of Interest: authors have no conflict of interest.

Sources of funding: funded by the University of Sinú Elías Bechara Zainúm by internal call, this article is based on the project Mutagenic effect of exposure in the womb to antiretroviral therapy.

Authors contribution:

Data Collection: Ivonne Rosario Romero Guzmán, Dennys Isabel Muñoz Monterroza

Data analysis: Komal Abdul Rahim, Lucelly Benitez Cheij, Anibal Arteaga Noriega

Manuscript Writing: Komal Abdul Rahim, Anibal Arteaga Noriega

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