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RESEARCH

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WOMEN LIVING WITH HIV AND PREGNANCY: UNDERSTANDING THEIR (DE)MOTIVATIONS

Mulheres que vivem com hiv e gestação: compreendendo suas (des)motivações

Mujeres viviendo con vih y el embarazo: comprendiendo sus (des)motivaciones

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ABSTRACT

Objective: to understand the (dis)motivations of women living with human immunodeficiency virus in their decision to become pregnant. **Method:** data collection was conducted from January to February 2022 at a Municipal Health Center through semi-structured interviews with nine women assisted at the unit's Specialized Assistance Service. Data were analyzed using Bardin's content analysis technique, which was organized according to Oliveira. **Results:** there is a certain relevance in the socioeconomic conditions of these women alongside with their knowledge on the subject. These issues, as well as the negative and positive feelings expressed by them, end up having a certain influence on either the desire for pregnancy or the absence of it. **Conclusion:** in view of the different spheres that involve the woman living with HIV, it is the nurse's role to welcome these particular demands, contributing with their autonomy in the decision for pregnancy.

DESCRIPTORS: Pregnancy; HIV; Nursing; Women.

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RESUMO

Objetivo: compreender as (des)motivações das mulheres que vivem com vírus da imunodeficiência humana na decisão de engravidar.

Método: a coleta de dados ocorreu no período de janeiro a fevereiro de 2022 em um Centro Municipal de Saúde, através de entrevistas semiestruturadas com nove mulheres atendidas no Serviço de Assistência Especializada da unidade. Os dados foram analisados pela técnica de análise de conteúdo de Bardin, sendo organizados segundo Oliveira. **Resultados:** há uma certa relevância das condições socioeconômicas dessas mulheres em conjunto com informações sobre o assunto. Assim como os sentimentos negativos e positivos expressos, essas questões acabam por ter certa influência tanto no desejo pela gravidez quanto na falta dele.

Considerações finais: tendo em vista as diversas esferas que envolvem a mulher que vive com HIV, é papel do enfermeiro acolher essas demandas particulares, contribuindo com sua autonomia na decisão pela gravidez.

DESCRITORES: Gravidez; HIV; Enfermagem; Mulheres.

RESUMEN

Objetivo: comprender las (des)motivaciones de mujeres que viven con virus de inmunodeficiencia humana en la decisión de quedarse embarazada. **Método:** la recolección de datos se realizó de enero a febrero de 2022 em um Centro de Salud Municipal a través de entrevistas semiestruturadas con nueve mujeres atendidas em el Servicio de Atención Especializada de la unidad. Los datos fueron analizados utilizando la técnica de análisis de contenido de Bardin, siendo organizados según Oliveira. **Resultados:** existe cierta relevancia en las condiciones socioeconómicas de estas mujeres junto a sus conocimientos sobre el tema. Estas cuestiones, así como los sentimientos negativos y positivos expresados por ellas, acaban teniendo cierta influencia tanto en el deseo de embarazo como em el no. **Conclusión:** frente a las diferentes esferas que involucran a las mujeres que viven con el HIV, corresponde a las enfermeras acomodar las demandas particulares, contribuyendo con su autonomía en la decisión por el embarazo.

DESCRIPTORES: Embarazo; VIH; Enfermería; Mujeres.

INTRODUCTION

The Human Immunodeficiency Virus (HIV) is a major public health issue even after almost four decades of its first cases. It is known that this epidemic can affect all individuals, regardless of sexual orientation or social and economic conditions. This demystifies the initial idea that only some population groups, such as sex professionals, homosexuals, and drug-addicted, were at a higher risk of contracting/transmitting HIV.¹

The so-called feminization of HIV occurred around the 90s, characterized as the increase in the number of infected women and their greater susceptibility to infection. This because of the invisibility faced by women at that time, since governmental actions and goals had a greater focus on homosexual/bisexual men.² When looking at the data from UNAIDS (Joint United Nations Programme on HIV/AIDS) in 2020, there were about 38 million people living with HIV worldwide, of which 53% were women and girls.³

Regarding sexual and reproductive health, many women end up being repressed due to gender inequality factors.⁴ Because of the lack of information and precarious support, women living with HIV find it difficult to fully exercise their sexuality and reproductive choices. For that reason, it is necessary to provide a welcoming environment so the woman can feel comfortable to expose her doubts and anxieties.⁵

This study is justified based on the reality of several women living with HIV who have their reproductive health repressed because of their condition. Many do not know that nowadays there is the possibility of having children safely, due to lack of information and prejudice from health professionals.⁶ The dis-

comfort that some professionals feel when discussing the sexual and reproductive desires of people living with HIV interferes negatively in the discussion about safe conception and contraception and the appropriate methods for such, which increases the risk of HIV transmission to partner and/or baby.⁶

The general objective of the study is to understand the (dis) motivations of women living with HIV in their decision to become pregnant.

METHOD

This is a descriptive exploratory study with a qualitative approach. The research occurred in a Municipal Health Center (CMS) located in the state of Rio de Janeiro, with women being monitored in the Specialized Care Service (SAE) of the site, from January to February 2022. A total of nine women who met the inclusion criteria participated: women aged 18 years or older, in reproductive age, and living with HIV. Those unable to answer the questionnaire coherently and independently were excluded.

In the SAE care context and with respect for the ethical criteria expressed in Resolution 510/2016 of the National Health Council (CNS),⁷ the selected women signed the Informed Consent Form (ICF) to participate in the study, being a non-profit voluntary participation. According to the CNS Resolution nº466/2012,⁸ this study was submitted to the Committee for Ethics in Research (COEP) of the Rio de Janeiro State University (UERJ), being approved on December 3, 2021, with opinion number 5.143.064. For data collection, the participants were interviewed based on a semi-structured script in a room of the health service, having the audio recorded for later transcription. To maintain the par-

participants' anonymity, alphabet letters (A to I) were assigned to identify the interviews in the study. The age range of the participants was between 22 and 38 years.

The data from this study were analyzed using Bardin's content analysis technique,⁹ being organized according to the model proposed by Oliveira.¹⁰ At first, the registration units (RU) were defined, being these excerpts from the participants' speeches considered relevant to the research objective. Each RU was aggregated to a meaning unit (MU), allowing a description of the characteristics pertinent to the content expressed in the participant's speech through a word or phrase. Then, the frequency with which each MU was expressed in the different interviews was observed, as well as the amount of RUs that each one had. From these steps, the data were grouped into categories according to a proposed theme, each consisting of subcategories, as well as their units of meaning (MU) and their respective numbers of registration units (RU) and percentage.

RESULTS

Chart 1 reproduces the first category of analysis, highlighting the main socioeconomic factors that seem to have some influence on the decision to become pregnant. Therefore, we observe that external factors (34% of the category's RUs) stand out, mainly because of the limitations imposed by socioeconomic conditions.

The second subcategory, of equal importance (34% of the category's RUs), highlights the influence of information on the decision to become pregnant. We observe that the data point to

the relevance of information about proper treatment and safe pregnancy for choosing pregnancy.

The third and fourth subcategories, representing 16% of the category's RUs each, show the prejudice and the partner's influence exerting some authority on this woman's decision. It is possible to observe that the prejudice resulting from the impossibility of breastfeeding discourages the choice and the partner's desire to have children motivates it.

Chart 2 composes the second category of analysis, where it is possible to observe women's feelings when thinking about a possible pregnancy. The first subcategory (54% of the category's RUs) focuses on issues involving motivation, or the lack of it, showing that the desire and the non-desire for pregnancy are close by representing 35 and 31% of this subcategory, respectively. However, the other meaning units point to motivation and desire to get pregnant.

The second subcategory (29% of the category's RUs) highlights the feelings about the decision to become pregnant. It can be observed that the fear of not being able to see the child grow, and the suffering caused by the impossibility of offering breast milk to the child are more expressive, representing, respectively, 25% of the RUs in the subcategory.

The third category is expressed in chart 3, showing a certain influence of HIV on the decision to become pregnant. The concern about transmitting HIV stands out (70% of the category's RUs), especially when it relates to the child.

In the second subcategory (30% of the category's URs), it is possible to observe that HIV largely does not play an important

Chart 1 – Socioeconomic and sociocultural aspects that may interfere in the decision to become pregnant. Rio de Janeiro, RJ, Brazil, 2022

Subcategory	Theme/US*	RU**/ Theme	%RU/ Theme	Category	RU/ Category	%RU/ Category
External conditions (68 – 34%)	Financial condition has a negative influence	31	46%	1	201	41%
	Country/world situation influences negatively	18	26%	1		
	Prioritizes professional life	16	24%	1		
	Unemployment has a negative influence	3	4%	1		
Information influencing the decision to become pregnant (68 – 34%)	Knowledge about treatment efficacy	21	31%	1		
	Knowledge about resources for safe pregnancy	15	22%	1		
	Seeks information	13	19%	1		
	Did not receive professional orientation	10	15%	1		
	Received professional orientation	9	13%	1		
Prejudice (33 – 16%)	Prejudice due to the impossibility of breastfeeding	17	52%	1		
	Prejudice has a negative influence	10	30%	1		
	Prejudice due to lack of information	6	18%	1		
Partner influence (32 – 16%)	Partner does not want children	13	40%	1		
	Partner wants children	9	28%	1		
	Don't want to depend on partner	5	16%	1		
	Don't want to overburden the partner	5	16%	1		

*US: Unit of signification. **RU: Registration unit

Source: The Author, 2022

role in the decision to become pregnant (52% of the subcategory's RUs), but still has a certain influence (48% of the subcategory's RUs).

DISCUSSION

When addressing external factors to woman who live with HIV regarding her decision to become pregnant, it is observed that the financial condition is the most mentioned. It is expressed in a negative way, since the participants highlighted this aspect as a major limiting factor. When thinking about the costs involved in taking care of their own child, many women end up reflecting on the subject, choosing to put pregnancy as a future possibility. In addition to this, some women cited the country's crisis due to the Covid-19 pandemic and the widespread violence in Brazil and around the world.

[...] pandemic, everything stopped. I had to stop working, so in financial terms it limited me a little [...] having a child now would limit me financially. (Participant G, 30 years old).

I think it's the world today [...] the violence that can happen later. So I have a little bit of fear of having another child because of this. (Participant I, 27 years old).

These elements contribute to the fear of raising a child nowadays, which makes us think that the fact of living with HIV (and its particularities) may not be the only and/or the main aspect taken into consideration when deciding whether to become pregnant or not. When talking about a low socioeconomic status, it is possible to state that this situation contributes to women having a greater vulnerability to HIV infection.¹¹ Little was found in the scientific literature on the relationship between financial status and pregnancy. However, it was possible to verify that this situation can interfere with the quality of life of women

Chart 2 – Feelings of women living with HIV about pregnancy. Rio de Janeiro, RJ, Brazil, 2022

Subcategory	Theme/US*	RU**/Theme	%RU/Theme	Category	RU/Category	%RU/Category
(Dis)motivations to get pregnant (99 – 54%)	Want to become pregnant	34	35%	2	183	38%
	Don't want to become pregnant	31	31%	2		
	Don't see any impediment to becoming pregnant	12	12%	2		
	Want to get pregnant because she likes children	11	11%	2		
	Want to get pregnant by planning	11	11%	2		
(dis)motivations sentiments (53 – 29%)	Fear of not being able to keep up with your child's growth	13	25%	2		
	Fear of not being able to breastfeed causes suffering	13	25%	2		
	Fear of getting pregnant due to health problems	12	22%	2		
	Influenced by previous bad experience	7	13%	2		
	Concern about your own health	5	9%	2		
	Feeling of fear at the thought of becoming pregnant	3	6%	2		
Safety/ Happiness (31 – 17%)	Feels responsible for the treatment	19	61%	2		
	Feeling safe because she has not transmitted HIV to her child	8	26%	2		
	Feeling of happiness at the thought of becoming pregnant	4	13%	2		

*US: Unit of signification. **RU: Registration unit

Source: The Author, 2022

Chart 3 – The woman living with HIV and the possibility of becoming pregnant. Rio de Janeiro, RJ, Brazil, 2022

Subcategory	Theme/US*	RU**/Theme	%RU/Theme	Category	RU/Category	%RU/Category
Concern about transmitting HIV (71 – 70%)	Concern about Transmitting HIV to their Child	61	86%	3	102	21%
	Concern about transmitting HIV to partner	10	14%	3		
Facing HIV (31 – 30%)	HIV has no influence on choice	16	52%	3		
	HIV influences not to become pregnant	15	48%	3		

*US: Unit of signification. **RU: Registration unit

Source: The Author, 2022

living with HIV, and that it can be a factor that makes them more vulnerable, leading to an emotional imbalance.¹²

With regard to information and guidance about pregnancy in the context of HIV, most of the study participants expressed knowledge about the effectiveness of treatment in preventing mother-to-child transmission and the possibilities of a safe pregnancy. The fact of finding HIV during a previous prenatal seems to indicate greater chances of receiving information related to the subject. However, even those who did not receive guidance from professionals said they sought information on their own.

[...] I know that there are resources, right. Today I already search, I already try to know things, right. And I know that there are resources for this, so the child can be born healthy. [...] if I get pregnant today, I know that my child can be born healthy. (Participant C, 38 years old).

[...] nowadays I am no longer (afraid) because of the understanding I have about what you explain to me [...] (Participant D, 33 years old).

[About the information she has] It's based on videos that I saw [...] I looked it up on my own. (Participant G, 30 years old).

Understanding what women think about the subject is of utmost importance to draw a line of care for their reproductive and sexual choices. Although there are reports that show that women have some knowledge, it is known that this is not the reality experienced by all of them.⁵ This is expressed in the speech of some of the interviewees, among whom it can be observed a desire to fill the gap that is formed due to the lack of information perceived by these women.

It depends a lot on who assists you, you know, wanting to explain [...] today you are talking to me, but there are doctors who don't even look at you. They just look at your result and goodbye and blessing, until the next appointment. (Participant E, 30 years old).

[About finding it important to receive orientation] To know about the risks, right, if there is any risk of passing it to the child, how life is after pregnancy. (Participant F, 22 years old).

It should be considered that, even if the woman seems to be informed, it is still the role of the nursing professional to discuss this topic with her, to promote the alignment of her desires and open space for the clarification of any doubts. Information, besides being important for women living with HIV to exercise their autonomy, also enables the creation of a bond with the professional. By paying attention to her particularities and being willing to answer her demands, whether related to pregnancy or not, a comfortable environment is created so that the woman feels at ease to express herself.¹³

About the desire for pregnancy, we noticed that this is present in part of the participants, being expressed in a significant way.

Similarly, it can be observed that other women do not present this intention. Regarding the feelings that permeate the desire or not for pregnancy, we observed that the fear of not being able to watch the growth of the child is something mentioned by the women, since they fear that they will die and leave the child abandoned. One study¹⁴ illustrates this issue as an incentive factor for adherence to treatment. In addition, the expectation of having a healthy child ends up resulting in a state of suffering, since the woman living with HIV fears transmission or even the end of her own life because of the virus.¹³

But I wonder until when I can be here to guide him, to watch him grow. Until when, you know, and this is the fear. This scares us, we don't know if we will be able to create them, you know. (Participant C, 38 years old).

Still about the feelings involved, we have the impossibility of breastfeeding and the suffering that comes with it. Breastfeeding is something that, socially, is defined as a woman's role when she becomes a mother. The act of breastfeeding can be characterized as one of the most important events in a mother's life, often being classified as the fulfillment of a dream. Thus, an expectation is created for this moment to happen, not only in the woman, but also among people around her.¹⁵ However, due to the high risk of vertical transmission, breastfeeding is strongly contraindicated for women living with HIV. Given the expectation faced by these women, the impossibility of breastfeeding causes suffering for not being able to feed their child with their own milk.¹⁶

And it is also a difficult issue our acceptance for not being able to breastfeed, because every mother idealizes what? To breastfeed, to have this contact with the child, in the beginning we think this way, I will stop being a mother if I can't breastfeed the child [...]. (Participant I, 27 years old).

[...] not being able to breastfeed weighs a lot. [...] I think it is part of pregnancy, the child feels the mother's milk. (Participant F, 22 years old).

This factor can be found in the scientific literature as something stressful for women living with HIV, causing them to doubt their bond with the child. It is also pointed out the emergence of possible questionings caused by the impossibility of breastfeeding, causing the woman to fear having her diagnosis exposed by feeding her child with something other than breast milk.⁵ The prejudice related to HIV also appeared in many statements. It is known that even today, despite the evolution of treatment and several forms of prevention, HIV still generates fear in part of our society. Therefore, women living with HIV fear being the target of discrimination that many people still reproduce.¹⁷

The problem that I mostly think is the prejudice a little bit from people who don't understand the subject to see one time or another that I can't breastfeed. [...] This is the thing I do, I kind of have to live hidden in a certain way, breastfeed with a bottle and things like that [...]. (Participant D, 33 years old).

I think people today are a little ignorant [...] very prejudiced, you know? [...] this (prejudice) scares you a lot. (Participant E, 30 years old).

A study¹⁸ shows how prejudice is capable of interfering in the life of women living with HIV: its presence in their daily lives causes them to be stigmatized in various social environments, which may cause an emotional imbalance. Thus, it is necessary to welcome this woman in this situation and work with her so that it is not something painful and discouraging.

Although the prejudice linked to the HIV diagnosis affects women in a negative way, not all of them see it as something that will prevent pregnancy. When talking directly about HIV, the concern about transmitting the virus to the child was quite frequent. Pregnancy, which represents a milestone in a woman's life, ends up being a period of changes and adaptations, whether physical, social, or emotional. By combining this process with the fact of living with HIV, the woman is faced with a deep fear that her child will end up presenting the same condition at birth.^{13,19}

And the fact of having this problem, of carrying HIV now [...], no matter how advanced everything is, we always have a doubt. [...] We always have a cricket in our minds. So that is what would weigh today for me, because I wouldn't think only of myself, I would think of the child, my thought is the child. (Participant C, 38 years old).

Only fear of passing to the child [...] even when I discovered pregnancy, I was very scared, scared all the time, fear of passing, I think it was my greatest fear all the time. (Participant H, 26 years old).

The woman is able to feel certain security when she is informed about her rights and the whole process of pregnancy, and it is the duty of the nursing professional to guide her about the issues that involve this process.²⁰ Among the participants, we noticed that having previous knowledge about the effectiveness of the treatment in the prevention of transmission and knowing that the pregnancy is safe makes them calmer when thinking about having a child.

When looking at women who have experienced a pregnancy while living with HIV previously, one can see that there is a certain feeling of security for not having transmitted to the child. However, it is important to emphasize that the fear of a possible transmission is still greater than previous experiences and understandings that these women have, suggesting that the lack of information is not configured as a problem faced by them when considering a pregnancy. The concern about transmitting HIV to the child showed as one of the greatest fears among the participants of the study. It can be said that there is a feeling of anguish related to the possibility of being responsible for making another person have the same condition as her, regarding HIV. It is verified that this fear leads the woman to place herself as responsible for her treatment, aiming at the protection of her

child. The desire for a planned and monitored pregnancy was addressed, expressing a concern with her own health and reinforcing the search for ways to avoid vertical transmission.

When observing the relationship between HIV and pregnancy, it's possible to see that it has some influence on the decision. While some participants put HIV as the main factor for not choosing pregnancy, others expressed not seeing the virus as an impediment. Although there is a certain weight of negative feelings that accompany the diagnosis and the whole context of pregnancy, many women still express the desire for pregnancy, listing other factors as reasons for postponing pregnancy.

Therefore, women living with HIV cannot have their experience reduced to this condition, and it is necessary to overcome the traditional and biologicistic model and seek a more sensitive and comprehensive look towards them. It is necessary to consider their specificities about gender and race issues, support network, source of income, among others, in order to respect their individuality.^{21,22} In this way, by paying attention to these aspects, the nursing professional promotes a strengthening of the woman's autonomy through information, encouragement, and other actions aimed at a safe pregnancy.

CONCLUSION

With this research, it was possible to understand some issues that motivate or discourage women living with HIV in the decision to become pregnant. The issues addressed by the women interviewed show that, even though some of them understand the theme, it is still relevant to review the therapeutic approach that is offered to this group. Many demands, doubts and fears end up being left aside for lack of preparation or willingness of the professional to address issues of sexuality and reproduction.

Therefore, it is necessary to be always seeking to offer guidance for all spheres involving women living with HIV, without interference from moral issues or prejudices coming from the professional himself. Thus, it is possible to promote a welcoming and safe environment, to stimulate these women to expose their issues, allowing a more sensitive and integral care.

Based on the findings of the present research, it is important to go deeper into the issues that permeate this theme, aiming at the formulation of a more concrete understanding of these issues.

The impossibility of reaching a large number of interviewees due to the Covid-19 pandemic and the limited time for data collection were presented as limitations of the research.

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