



## Repercussions of spirituality in the lives of women living with HIV

## Repercusiones de espiritualidad en la vida de las mujeres que viven con el VIH

## Repercussões da espiritualidade na vida de mulheres vivendo com HIV

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### Histórico

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### Abstract

**Introduction:** Spirituality in patients living with HIV helps to cope with the negative thoughts brought about by the illness. The purpose of the study was to understand the impact of spirituality on the lives of women living with HIV. **Materials and Methods:** This is a qualitative research on thematic life histories. The sample composed of seven women diagnosed with HIV/Aids for over a year. For the data collection, a semi-structured interview was used, with questions about the social context, sociodemographic and clinical situation, religion and spirituality. The content analysis technique was used for data analysis. The results were organized into two categories: seeking strength in spirituality and hope for healing. **Results:** In times of distress imposed by HIV/Aids, all the interviewees sought spirituality through prayer and even by materializing the presence of God as strategies to confront the disease. The yearning for healing by divine revelations is expressed in the interviewees' speeches. **Discussion:** According to the interviewees' life stories, the divine figure strengthened them in the face of challenges posed by HIV/Aids. **Conclusions:** Through this research, it was possible to verify that spirituality is present in the lives of women who live with HIV, and that it softens the adversities brought on by the disease.

**Key words:** Acquired Immunodeficiency Syndrome; Women's Health; Religion and Medicine; Sexually Transmitted Diseases; Adaptation, Psychological.

### Resumo

**Introdução:** A espiritualidade em pacientes que vivem com HIV ajuda a enfrentar os pensamentos negativos causados pela doença. O estudo objetiva conhecer o impacto da espiritualidade na vida das mulheres que vivem com HIV. **Materiais e Métodos:** Pesquisa qualitativa sobre histórias de vida temáticas. A amostra está composta por sete mulheres que foram diagnosticadas com HIV/AIDS há mais de um ano. Para a compilação dos dados, foi utilizada uma entrevista semiestruturada com perguntas sobre o contexto social, a situação sociodemográfica e clínica, a religião e a espiritualidade. Para a análise dos dados, aplicou-se a técnica de análise de conteúdos. Os resultados se organizaram em duas categorias: a busca da força na espiritualidade e a esperança de cura. **Resultados:** Em momentos de angústia causados pelo HIV/AIDS, todas as entrevistas recorreram à espiritualidade através da oração e mesmo à materialização da presença de Deus como estratégias para fazer face à doença. O anseio de cura mediante revelações divinas se expressa nos discursos dos entrevistados. **Discussão:** Segundo as histórias de vida das entrevistadas, a figura divina deu-lhes fortaleza para enfrentar os desafios gerados pelo HIV/AIDS. **Conclusões:** Esta pesquisa permitiu comprovar que a espiritualidade está presente nas vidas das mulheres portadoras de HIV e que mitiga as adversidades causadas pela doença.

**Palavras chave:** Síndrome de Imunodeficiência Adquirida; Saúde da Mulher; Religião e Medicina; Doenças Sexualmente Transmissíveis; Adaptação Psicológica.

### Resumen

**Introducción:** La espiritualidad en pacientes que viven con el VIH ayuda a afrontar los pensamientos negativos provocados por la enfermedad. El objetivo del estudio fue conocer el impacto de la espiritualidad en la vida de las mujeres que viven con el VIH. **Materiales y Métodos:** Investigación cualitativa sobre historias de vida temáticas. La muestra está compuesta por siete mujeres que fueron diagnosticadas con VIH/SIDA hace más de un año. Para la recolección de datos se utilizó una entrevista semiestructurada con preguntas sobre el contexto social, situación sociodemográfica y clínica, religión y espiritualidad. Para el análisis de datos se empleó la técnica de análisis de contenidos. Los resultados se organizaron en dos categorías: la búsqueda de la fuerza en la espiritualidad y la esperanza de curación. **Resultados:** En momentos de angustia causados por el VIH/SIDA, todas las entrevistadas recurrieron a la espiritualidad a través de la oración e incluso a la materialización de la presencia de Dios como estrategias para afrontar la enfermedad. El anhelo de sanación mediante revelaciones divinas se expresa en los discursos de los entrevistados. **Discusión:** Según las historias de vida de las entrevistadas, la figura divina las ha fortalecido para hacer frente a los retos generados por el VIH/SIDA. **Conclusiones:** A través de esta investigación se pudo comprobar que la espiritualidad está presente en las vidas de las mujeres que viven con el VIH y que mitiga las adversidades producidas por la enfermedad.

**Palabras clave:** Síndrome de Inmunodeficiencia Adquirida; Salud de la Mujer; Religión y Medicina; Enfermedades de Transmisión Sexual; Adaptación Psicológica.

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## INTRODUCTION

Currently, the number of HIV/Aids cases among women is on the increase, as compared to the number of cases diagnosed among heterosexual men<sup>1</sup>. This growth has been termed the feminization of the Aids epidemic<sup>2</sup>. In no other part of the world has the HIV/Aids epidemic undergone such an epic transformation as it has in Brazil. A large number of women in world living with HIV/Aids today are married women who live with their families, and the source of infection is largely of extramarital origin<sup>3</sup>.

The moment that a patient receives a positive diagnosis for HIV/Aids, he/she experiences fear—not only the fear of death as a result of the disease, but also fear of prejudice, fear of not receiving social support, and fear of other people knowing about their condition. The patient then begins to re-evaluate his/her life and re-plan his/her goals<sup>4</sup>.

The family, relationships with small groups, friends, religious groups and spirituality, are the means by which patients cope with the disease<sup>5</sup>. Moreover, many women living with HIV use spirituality as a fundamental resource for overcoming the stress and demands associated with the disease<sup>6</sup>. Through spirituality, a strong trust is established in a higher being, with whom the patient communicates with every day and who becomes the centre of all hope of healing for the patient. The spirituality is a set of beliefs that bring vitality and meaning to the events of life; it reflects the human propensity for self-interest and for oneself and also the human need to find

reason, hope and a will to live<sup>7</sup>. Spirituality involves belief in a higher power, transcendence, connection and interconnection. Spirituality can intensify the life of women living with HIV; in the majority of cases, women seek spirituality as the cure for their illness, entrusting God with all their chances for cure<sup>8</sup>.

Spirituality in patients living with HIV helps to cope with the negative thoughts brought about by the illness, such as that illness is a punishment, but it also increases a person's ability to cope with the stressful situation while maintaining calmness even in the face of adversity; results still point to patients longevity<sup>9</sup>.

Studies relate spirituality to positive self-care, related from the thoughts to the behaviors. Among the spiritual practices patients develop a system of adoption of doctrines, affiliations to religious institutions, praying throughout the day and expressing gratitude to God<sup>10</sup>; which leads to physical and mental well-being mainly of women living with HIV<sup>11</sup>.

Researchers are now recognizing the significance of spirituality in health research. However, few studies have explored the representation of spirituality in the lives of women living with HIV. The present study becomes different from the others, as it intends to verify how women seek the strengths to confront HIV/Aids through spirituality and how they place hope in divine healing. With the aim of filling in this research gap, the present study sought to understand spirituality in the lives of women living with HIV.

## MATERIALS AND METHODS

### Type of study

To achieve the proposed goal, a qualitative approach to thematic life histories was used. The study was conducted from June to September 2015 at the Specialized Assistance Service for the care of person living with HIV, in the city of Imperatriz, Maranhão, Brazil.

### Selection criteria

Women above the age of 18 years who were diagnosed with HIV/Aids more than one year ago, who used antiretrovirals, and had no neurological conditions were included in the sample.

### Population and sample

Of a universe of 325 women enrolled in the health unit, 200 were diagnosed more than one year; 105 follow the treatment regularly; 73 have a fixed residence in Imperatriz, Maranhão, Brazil; and 70 were of age. It was adopted as an on-demand inclusion criteria according to the women present on the day of the interviews. For the study seven women were selected for convenience during the adherence group meetings, medical and nursing consultations, after applying the inclusion criteria.

### Data collect

Initially, the women were extended a verbal invitation, and the interviews were only scheduled with those who accepted the invitation

to participate in the study. The procedures and objectives of the research were explained to the participants along with the invitation. Once they accepted the invitation, they were instructed to sign the Free and Informed Consent Term.

For the data collection, a semi-structured interview was used, which contained questions about the social context, sociodemographic and clinical situation, religion and spirituality. The interviews started with a warm-up session, which was an informal session in which the researcher tried to build a rapport with the interviewees. Subsequently, the questions were posed to the interviewees and their responses were audiotaped. The interview lasted an average of one hour, and were conducted in a reserved room. The real names have been replaced by P1, P2, P3, P4, P5, P6 and P7. The audio recording was played several times in order for the researchers to understand the material, and they were then transcribed and returned to the interviewees for approval and possible changes.

### Analysis and processing of data

For data analysis, the technique of content analysis<sup>12</sup> was used. Initially, pre-analysis of the data was carried out, this involved floating readings of the interviews, with changes made to the material as required ([Chart 1](#)). From then on the registration units appeared, described as: the search for the exam, signs of spirituality on receiving the diagnosis, spirituality as a protective factor, representation of spirituality in moments of sadness, spirituality and healing.

**Chart 1. Logging units from floating readings. Imperatriz, Maranhão, Brazil, 2016**

Registration units
The search for the exam
Signs of spirituality on receiving the diagnosis
Spirituality as a protective factor
Representation of spirituality in moments of sadness
Spirituality and healing

Source: Research Data, 2015.

With the help of the registration units, the data were searched for recurrences and singularities of the themes, in order to quantify the pertinence of the themes from which the units of context were derived, in three: Seeking God for strength to accept the diagnosis, Prayers and materialization of God to assist in coping with adversities arising from HIV/Aids, The hope and certainty of divine healing (Chart 2).

**Chart 2. Context units derived from the pertinence of the themes. Imperatriz, Maranhão, Brazil, 2016**

Registration units	Context units
<b>The search for the exam</b> <b>Signs of spirituality on receiving the diagnosis</b>	Seeking God for strength to accept the diagnosis
<b>Spirituality as a protective factor</b>	Prayers and materialization of God to assist in coping with adversities arising from HIV/Aids
<b>Representation of spirituality in moments of sadness</b> <b>Spirituality and healing</b>	The hope and certainty of divine healing

Source: Research Data, 2015.

Categorization is an operation for classifying constitutive elements of a set by differentiation and, then, by regrouping according to the genus (analogy), based on the previously defined criteria<sup>12</sup>. The two categories of analysis according to the context units: seeking strength in spirituality is the hope for healing (Chart 3).

**Chart 3. Categories of analysis. Imperatriz, Maranhão, Brazil, 2016**

Context units	Categories of analysis
Seeking God for strength to accept the diagnosis	
Prayer s and materialization of God to assist in coping with adversities arising from HIV/Aids	Seeking strength in spirituality
The hope and certainty of divine healing	The hope for healing

Source: Research Data, 2015.

### Ethical aspects

This study was approved by the Research Ethics Committee of the Federal University of Tocantins - UFT protocol n.105/2014, issued in the year 2015; in accordance with Resolution 466/2012 of the National Health Council.

### RESULTS

The age of the interviewees ranged from 37 to 62 years. All the women who participated in the present study reported that they had children; two reported that they were married (P1 and P6); three, that they were widows (P3, P4 and P7); two, that they had separated from their partners (P2 and P5); and two, that they were former sex workers (P6 and P7) (Chart 4).

Chart 4. Characteristics of the participants

Interviewee	Information
P1	P1 is a public employee aged 47 years. She is married and has two children. The daughter is evangelical, and at the time of the study, the eldest son was arrested for drug trafficking and robbery. The son has a son whom P1 takes care of. She has lived with HIV for 1 year.
P2	P2 is a pensioner aged 61 years. She is evangelical and has lived with HIV for 2 years. She had separated from her partner when she was young, and her partner was the owner of a bar in the neighbourhood where they resided. At the moment, she only takes care of the house and lives alone.
P3	P3 is retired and 61 years old. She has been living with HIV for 1 year. She is evangelical and lives with her children. She is a widow, and she believes that she was infected by her husband.
P4	P4 is a pensioner aged 58 years, and she has been living with HIV for 8 years. She was monogamous during the duration of her marriage, but she is a widow (her husband died of HIV/ Aids ) now and currently lives alone.
P5	P6 is retired and 62 years old. She has been living with HIV for 10 years, and she reports that she suffered a lot because she was not accepted by her parents. She got married and also suffered during the marriage. At the time of the research, she was caring for her mother who had Alzheimer's.
P6	P6 is unemployed and a former sex worker. She is 37 years old and is in her fifth marriage. She has a two-year-old daughter who is also living with HIV/Aids and is under treatment. She has been living with HIV for 2 years.
P7	P7 is a 37-year-old currently unemployed former sex worker, who left the profession after marriage. She is now a widow and mother of four and lives with the two younger children. The other two children live in another state with the first husband. She has been living with HIV for 1 year.

Source: Research Data, 2015.

Two of the participants in this study were found to be seropositive for HIV through routine exams (P1 and P7). Even though there was a suspicion of infection, P1 did not voluntarily get tested, and as stated before, the disease was discovered only in the course of a routine exam. One of the interviewees was tested when she presented with

marked loss of weight, and another was tested in the course of some pre-surgical exams.

P2 refers to HIV/Aids as a punishment—something that she deserved for having done wrong before God. She says that among the other tests carried out, “(...) she also gave this curse

(...)”, referring to HIV/Aids as a punishment, for disrespecting the morals and good manners that she said was working in a bar.

The representation of God is one of the themes of this study. This theme finds its roots in the beginning of the HIV/Aids epidemic, when a large part of the world population referred to the disease as a punishment from God, since the first diagnoses were in homosexuals, drug users and sex workers as a result of the conservative impositions of the time. It was believed that these individuals were not worthy of divine grace, and they were thus punished with a disease that led to death.

To ease the pain and suffering that a positive HIV diagnosis brings, women in this study reported that they sought spirituality to help them confront this disease, even in the hope of healing in some cases. Nowadays, the health sciences and

religious sciences are no longer considered as distinct fields, and they are believed to be interconnected in the health–disease process, as can be observed in the categories of analysis below.

### Seeking strength in spirituality

Most women living with HIV seek spirituality as a means of easing the tension arising from a positive diagnosis and assisting them in coping with the disease. The divine figure gives strength to women in the face of problems, as mentioned in the interviewees’ statements. Religion has a strong presence in the lives of the interviewees and assumes different forms—from the materialization of God in the form of an image to the act of praying. P1 reports that when she is in some trouble, she evokes God so that she can “(...) sit on his lap and talk to him about her problems (...)”. This is an excerpt from her interview:

*“I have been evangelical. Today, I am outside the church, but I have this very close contact with God. It is a relationship of father and daughter. I see God as a father friend who looks at me, who embraces me and puts me on his lap. When I am very distressed with something, this is how I do: ‘God sit here, I want to sit on your lap’. Mentally, I sit on his lap, and there I cry. I tell my problems and, from there, I go quiet” - P1*

P4 has a similar perception of God: according to her, “My best friend is God. When I get sad, I pray.”

P1 and P4 therefore perceive God as a friend. P4 deals with her episodes of sadness by establishing a connection with God through prayer.

P5 stated in her interview that, “All my life I had faith in God (...) God who gives me strength”. Similarly, P7 also stated that, “My strength even comes from God”. Thus, P5 and P7 affirm that their strength comes from God.

*“When I come across some difficulty, or I am sad, I pray because I am a believer. I pray and leave. I’m walking and when I come back, I’m fine”-P2*

Prayer is seen as a means of direct communication with God. It helps them deal with their sadness, and they feel well and have renewed strength to continue living with the disease. Thus, prayer helps alleviate the emotional problems associated with HIV/Aids.

*“I am neither Catholic nor a believer (...) I believe in that all-powerful father, who is only one, who is our saviour...For me he is everything, because if it were not for him, today I would not be here”-P6*

P6 affirms that she does not have a definite religion, but believes in God. She believes that she owes her life to an almighty father, because of whom she is alive today. This response shows that spirituality is not correlated with religion, as believing in a powerful being seems to soften P6 suffering and help her accept of her state of health.

### **The hope for healing**

*“My vision is to heal and I get well: of God heal me and I finish being good, that I heal and prove in my documents that I have nothing”-P4*

The interviewees were aware of Aids being an incurable disease, so they felt that their only option was to wait and seek healing from a superior being. As depicted by the statement above, P4 hopes that God will cure her and that she will be seronegative in the future. P3 also stated that, *“My plans are for Jesus to heal me”*. P3 claims that she is Protestant, and she believes that she receives blessings from TV programs in which they appear to sprinkle holy water on the viewers. She says that, *“When I drink that water it seems that it washes me inside”*. She seems to believe that ingestion of the blessed water will rid her body of the HIV virus. Such an attitude can be a worrying factor. If a patient is convinced of total cure through these blessings, they may

not adhere to the treatment protocol, which could lead to aggravation of their condition. However, in the present research, the participants did not discontinue the treatment because of the belief that they would be healed by a superior force. It is probably these two factors—adherence to treatment and belief in a superior being—that were responsible for the good state of health of the interviewees.

P2 stated in the interview that, *“I am a believer (...) If I have, Jesus has already healed me, because I gave myself to him”*. These words reflect her belief in a religion as well as spirituality in the form of belief in God.



P6 waits for God to solve her problem, by awaiting healing through divine grace: *“I have faith that God may one day solve my problem”*. According to her, a supreme being armed with all the powers will save everyone, as expressed in her statement, *“I believe in that all-powerful father, who is only one who is our saviour”*. The relevance of spirituality in the lives of these women is emphasized in their faith and in the desire and certainty of healing.

*“My children were very afraid of losing me (dying). One of them drank too much. After he discovered I had this problem, he made a vow to God that if God would not let me relapse from this disease, he would never put alcohol in his mouth again”-P3*

Spirituality provides a woman who lives with HIV a means of even social interaction—a factor that is evident from P3 statement: *“When I go to church everyone embraces me, the bishop embraces me”*. However, she is the only one who talks about social participation through spirituality and religion; the other interviews seem to indicate that it is possible to live a solitary life with spirituality.

## DISCUSSION

One of the former sex workers learned of the prenatal infection only because the hospital required that she be tested. As well as many women that are diagnosed at the time of the obligatory prenatal test<sup>13</sup>.

All women living with HIV only have decided to do the test after their partners have discovered HIV test results. In the sample, two widows had witnessed the death of the spouse as a result of

The representation of spirituality in the yearning for healing was not restricted only to the patients, but it was also reflected in their families. The son of one of the interviewees seems to make a bargain with God for healing his mother. The attitude of P3 son may seem to many people as an act of desperation, but it gave her strength to continue with the treatment:

HIV/Aids<sup>3</sup>. Despite this, they did not search for any health service, and the diagnosis was made only months later in the course of routine examinations. In the general population, the fear of testing positive for HIV/Aids is an important limiting factor that prevents people from voluntarily getting tested. Even in cases where there is a strong likelihood of HIV infection, people often postpone the test and when it is subsequently discovered, the patient is in an advanced stage of the disease.

At women living with HIV: they accept it as punishment for not meeting the moral standards imposed by society<sup>14</sup>. A woman is diagnosed with HIV/Aids, the diagnosis is similar to a death sentence<sup>4</sup>. However, even though most patients consider the illness to be a punishment from God, spirituality after a positive diagnosis helps in coping with HIV/Aids; and the spiritual support can help in coping with illness and social stigma experienced by patients<sup>15</sup>.

Is one of the spiritual resources that is most used by women living with HIV<sup>11</sup>. Seeking strength in God is a hallmark in the lives of most women living with HIV, and this contact with a superior force seems to have positive effects on the patient's health, such as improvement of their physical state and improvement in their quality of life<sup>16</sup>. Improvement of health through spirituality is only possible when women seek strength through faith and prayer, clinging to God, seizing a spiritual force, fundamental to continue their life. Spiritual and religious groups were considered as sources of strength for patients living with HIV<sup>17</sup>. According to the interviewees in the present study, prayer was the main way of communicating with God, and they resolutely took part in this act to help them solve the problems imposed by the disease.

The spirituality is a form of self-regulation of emotional problems, and that the evocation of a higher power is a form of gratitude for life<sup>18</sup> point out. In the present research, too, we identified feelings of gratitude to God, for health and for life, among the interviewees; as well as the results found in the present study in which the patients presented a process of transformation of themselves and/or their life and sought the spiritual growth, presenting a positive position before God<sup>19</sup>.

After the positive diagnosis, women with Aids appeared to be more spiritual than before<sup>11</sup>. This can also be noted in this statement by P7: *"I was a little distant even (from God), I confess. Now I got very close to him"*.

Women living with HIV believe that it is through God that their viral load has decreased and that they are being healed<sup>20</sup>. However, there is no concrete evidence linking spirituality with the reduction of viral load, and this reduction may be a result of the antiviral drugs administered. However, spirituality directly affects adherence to the treatment and use of medicines<sup>21,22</sup>.

Spirituality not only represented the search for healing from divine forces, but also aided in the process of coping with disease. The providing assistance to women with HIV should go as far as to understand the scope of spirituality<sup>23</sup>, since such assistance in combination with treatment can improve the condition and quality of life of women living with HIV. Moreover, the incorporation of religion and spirituality in HIV/Aids prevention and treatment programs is a means to reduce the psychological distress of HIV-positive individuals<sup>24</sup>.

According to the interviewees' life stories, the divine figure strengthened them in the face of challenges posed by HIV/Aids. With a superior force beside them, they experienced alleviation of their suffering. The spirituality in the life of women living with HIV, by reiterate the essential meaning of faith and confirming that spiritual strategies contribute significantly to the improvement of the patient's quality of life and serve as a form of social support<sup>25,26</sup>.

In addition to spirituality, religiosity is also a strong mark on the lives of women living with HIV<sup>27</sup>. The religiosity in the person living with HIV brings feelings of hope of healing and

comfort to ease the yearnings imposed by the disease<sup>28</sup>.

The establishment of the bond with God is a frequent action in the routine of women living with HIV, because through this established link they find the strength to reinvent themselves in the face of the difficulties brought by HIV/Aids, through this action they find even emotional comfort and confidence in the cure<sup>29</sup>, as well as the data found in the present study.

The present study presents methodological limitations, since the determinates of health and the social and cultural conditions of the women studied were not taken in consideration, suggesting that further studies be carried out detailing them.

## CONCLUSIONS

After a positive diagnosis of HIV/Aids, women became more spiritual, because the evocation of and attachment to spiritual forces help them accept their condition and improve their quality of life.

Through the interviews with the participants, it was also possible to verify that spirituality was an important feature in the lives of women living with HIV, and that it alleviated the adversities brought on by the disease. Attachment to spirituality, through prayer, God, Jesus, and TV programs, appears to be a strong factor that helps them cope with the disease.

Therefore, spirituality is a protective factor that assists women living with HIV in coping with their positive diagnosis, further assisting in adherence to treatment; thus, helping their process of care and acceptance of their health condition. Professionals, knowing how spirituality is present in women's lives, has the possibility of considering its elements and structure in the care process of women living with HIV.

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