THE DAILY LIFE OF WOMEN AFTER HIV/AIDS INFECTION: GUIDELINES FOR NURSING CARE

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ABSTRACT: This research aims to understand the daily life of women after HIV/Aids infection as guiding principles for nursing care. Qualitative research, with the participation of 39 women who were receiving outpatient care for HIV in Fortaleza, in the state of Ceará. The data were collected through interviews and analyzed using Content Analysis. From the results, one category emerged: changes in the daily life of women after HIV infection, with three subcategories: changes in the emotional and family scopes; changes in the social, professional and leisure contexts; new daily habits aimed at quality of life. At the end of the study, it could be noted that the seropositive women experience situations of family abandonment, social isolation, stagnation of professional and leisure activities, due to the stigma caused by the disease. The statements showed that they reduced or stopped drinking, smoking and having unprotected sex. The results indicate the need for nursing care actions that address bio-psychosocial-spiritual issues.

DESCRIPTORS: Nursing care. Women. HIV.
INTRODUCTION

The current woman’s health policy proposes to contemplate, through principles and guidelines, the factors related to the promotion and humanization of health. It detaches from the biological and medical focus and adopts the holistic concept of health, proposing to assist women in all stages of their lives and covering aspects which were, until then, beyond the scope of healthcare services.1

In Brazil, the reduction of deaths caused by HIV infection and aids has been evident in the last few years, mainly due to the incentive provided by the health policies adopted by the Unified Health System (SUS) and by schemes with this purpose. It can be noted, however, that there is still a pressing need for change in the epidemiological profile of the infection, which moves from the cities to the countryside, in particular from younger to older people, richer to poorer, homosexual to heterosexual. Concerning women’s reality, there is greater vulnerability in relation to social and gender contexts.2

However, in relation to the scope of care provided to women with HIV/aids, there is a valorization of the disease and of the clinical diagnosis support. Moreover, there are consistent concerns about ethical dimensions, reproductive health and human rights. This results from the fact that the scientific paradigm based on biological approaches which only considers the physical body, is not able to cover the complexity of the social aspect of aids in women.3-8

The HIV/aids epidemic in the daily lives of women includes biological, social, psychological and religious issues. Among them, in the psychological scope, the fears that take control in the daily lives of women from the time of the HIV diagnosis, among these the fear of themselves, of discrimination, of preconception, of physical pain and finitude, should be highlighted. In can be added that fear originates from a lack of information about the disease or from inappropriate information, combined with the impact of contagion within the family, with discrimination and prejudice at work. This reality is an alert for nursing care in this field, which has to develop actions that contribute to the improvement in the quality of life of these women.5

Given this context, this study was intended at answering the following question: what are the changes in the daily lives of women after HIV infection? Women, due to not knowing the meaning of basic terms used within the aids epidemic context, for example, considering the sick person and the person infected by HIV as similar, may have their perception affected in relation to the severity of aids and having a distorted view about the individual progression of the disease, thus considering it with greater or lesser severity, which may impact their daily lives.9

In this sense, the questions related to the specific issues of HIV/aids contamination in women are included in the Brazilian public policies as an extended discussion, involving broader issues, such as gender equality and strengthening of citizenship, so that they can change the history and face the seropositive situation with dignity.

Based on the above, this research was aimed at understanding the daily lives of women after HIV/aids infection as a support to guide nursing care in relation to women’s health care.

METHODS

This is a qualitative and descriptive research, analyzed with theoretical support from phenomenological studies and social representations about the topic. The scenario was a public healthcare that offers inpatient and outpatient care, located in the city of Fortaleza, in the state of Ceara, Brazil, which is considered a benchmark in the treatment of infectious diseases.

Thirty-nine women participated in the research. In order to ensure anonymity, the identification of the participants was carried out using flower names. The participants were recruited based on the following inclusion criteria: being over 18 years of age, having had a confirmed HIV/aids diagnosis, having been assisted in the institution for at least six months. Also, a qualitative research script was used, keeping in mind the theoretical saturation of data.

Data collection was carried out from August to December 2010, through individual interviews based on a script with semi-structured questions. The interviews took place in a private place. The interview script contained questions related to the participants’ socio-demographic data, such as age, level of education, marital status, income, professional occupation, cause of exposure, origin, in addition to the following open questions: what was the main reason that exposed you to HIV infection? What has changed in your daily routine after HIV infection? Those were recorded to an MP4 player with the agreement of the participants, and will be stored for a period of five years. After this period,
the information will be deleted. The recruitment of
the women was undertaken by convenience and
while awaiting their appointment in the outpatient
care center. The women were approached and
invited to a private place in order to participate
in the interview.

The analysis of the results was performed
using the content analysis technique, which is a
set of communication analysis techniques, with
systematic and objective procedures that permit
inferences about knowledge production and reception. Attention is given to the linguistic
materiality through the empirical conditions of
the text, establishing categories for its interpretation. The intention is to understand the participants’
thoughts through the content expressed in the text,
in a clear conception of written language and in
the context of the proposed analysis.

The study received approval from the Re-
search Ethics Committee of the institution where
the research was undertaken, under registration
number 13/2010. Informed Consent Forms (ICF)
were used with information about the objectives,
the data collection procedure, the benefits and
assurance of confidentiality and respect for the
wish to participate or not in the research. This
document was presented to the participant women
and signed by the women and the researcher at the
beginning of the interview.

RESULTS AND DISCUSSIONS

Thirty-nine women were interviewed. The
most expressive age group was between 30 and
39 years of age (16 or 41.0%), followed by 40 to
49 (11 or 28.2%), 20 to 29 (08 or 20.5%) and 50 to
60 (04 or 10.3%). Their marital status varied, with
emphasis on single women with 12 (30.7%), fol-
lowed by 10 married ones (25.7%), nine in a de
facto relationship (23.0%), five widows (12.8%) and
three separated (7.8%). Most of them had children
(29 or 74.4%). Their professional occupation var-
died, being 15 unemployed (38.5%), 14 employed
(35.8%), eight housewives (20.6%) and two retired
(5.1%). The most reported occupations were maids
and dressmakers.

Concerning the level of education, most
women had a low level of education, with 12
(30.8%) and 11 (28.2%) not having completed
primary and secondary school, respectively,
eight having completed secondary education
(20.6%), four having completed primary education
(10.2%), two not having completed higher educa-
tion (5.1%) and two being illiterate (5.1%). Most
of these women – 20 (51.3%) had come from the
state’s countryside towns and 26 (66.7%) gained
an income of up to one minimum wage.

The analysis of the information provided
by the participants lead to one thematic category:
changes in the daily lives of women after HIV
infection, which was constituted by three sub-
categories: changes in the emotional and family
scopes, changes in the social, professional and
leisure contexts, and new daily habits aimed at
improving quality of life.

Changes in the daily lives of women after
HIV infection

This category was thereby denominated by
considering, in the women’s statements, the de-
scription of the changes occurred in the emotional,
family and social scopes, as well as the changes
to daily habits after HIV infection. The three sub-
categories that resulted from the statements are
presented below.

Changes in the emotional and family scopes

This subcategory showed the changes in
marital relations as a result of HIV infection in
women. The repercussions of the abandonment
by the partner were important and effectively af-
fected the response of the participant women to the
infection and to the available healthcare treatment.

The only people who know I have it are my
mother, my husband and my father, most of my fam-
ily does not know, because I fear, there are people who
discriminate and feel disgusted (Bromeliad).

There are no longer any men attracted to me, I
looked different […], when I am depressed, I keep telling
God that he has punished me. Less than one month ago,
I tried to commit suicide (Poppy).

[…] and, even my husband, started leaving me,
slowly (Anthurium).

At first, everything changed, it was horrible for
me to continue with my life. I do it this way, I have to
isolate myself to a certain extent, then I do not explain
anything to neighbors, they do not know I am sero-
positive, I live on a rental, then when people start to
get curious, I move to another place, then I ignore it,
pretend I am a normal person, who does not have any
health issues (Angelica).

For these situations, the limitations that
are a challenge to any healthcare intervention
are related to the male culture that oppresses
women and puts them in a weaker position. The stigma attached to HIV infection in society occurs because there is no perspective of cure and the infection is facilitated by affective relationships, which are essential to human beings. This shows that the nursing/healthcare professionals, when providing care, have to deal with lonely women who were abandoned by their partners and are socially rejected.

Finding out about an HIV/aids diagnosis is a moment of transition in people’s lives. It changes people, the relations and life in society, mainly in relation to the closest people, such as family and friends. This period is also followed by uncertainties, anxiety, insecurity, fear of the unknown and scary situation. Therefore, when facing the new reality, people experience moments of pain.\(^{11}\)

The impact of HIV infection concerning reproductive decisions can also be highlighted. Seropositive women should be assisted during the reproductive stage depending on criteria, such as stage and progression of the disease, viral load level and other indicators, which are important to direct them about the most appropriate period for conception, in order to reduce the risks of infection to the baby.\(^{12}\)

Family-related and affective repercussions resulting from being seropositive are relevant and should be considered in nursing care planning. It requires continuous monitoring of these women. Professionals should be aware of the effects these repercussions cause on women’s responses concerning treatment adherence. Nursing care should meet the bio-psychosocial needs and consider the factors involved in being HIV positive, among them the fear of contamination to other family members, isolation, guilt, psychological conflict and reproductive issues, in order to ensure quality care.

Among the care possibilities for professional nursing in this area, the therapeutic group composed of HIV positive women and professionals can be mentioned. The group should be seen as a space for expressions and thoughts, feelings and changes. For this, there must be a supportive and sympathetic posture among members, aimed at developing individual and collective potentialities. It is imperative, however, that professionals select a group methodology approach, with the understanding that there is a common goal: to support the development and education of members based on their real experiences. This work method is a form of healthcare in which nurses become independent professionals.\(^{13}\)

### Changes in the social context of work and leisure

The issues of being HIV positive in the social scope were highlighted in this subcategory, with a focus on productive and leisure activities. Women reported having difficulties in being accepted in the workplace. In addition, the infection itself, depending on the stage it is at, can also directly affect the physical and psychological strength of women to perform tasks.

What I no longer do is work at other people’s house, only at my own… And I do not cook lunch, my neighbor does that because I have no motivation (Iris).

[...] I do not work because if we go after a job around and tell them, take a test to know… then, they do not let you! (Astromelia).

In relation to work […], I have been leaving my resumes for a long time, I believe the last job I had, the manager saw my documents in the drawer and, since this day, she has been treating me differently, I think they found out I was this way and have pushed me out over time (Dahlia).

The fear of prejudice and discrimination after HIV infection in women goes beyond the family, and may be seen at work, leading to a real or imaginary risk in view of the fear of losing their jobs. For those women who achieved their space in the workplace, it means feeling like a citizen, whether it relates to a formal or informal job, since the importance lies in the possibility of economic independence, in the contribution to the family income and satisfaction of basic family needs. The threat of unemployment, due to prejudice, empties the achievement.\(^{5}\)

Through the statements of the participant women, the effects of being HIV positive on productive activities could be noted and, despite the advances in the treatment of the disease, which ensure a longer life span, it has not been possible to extinguish the social prejudice and discrimination existing in society. On the other hand, the resistance of the interviewed women in facing this situation could be noted, thus reinforcing their isolation and withdrawal from the workplace. This situation is aggravated when women are the sole family provider, which was the situation experienced by some of the research participants, since the income was often decisive in ensuring appropriate economic support to suit the new needs.

The proportion of women living with HIV/aids who do not work can also be related to their health condition, which is compromised by the infection and the onset of opportunistic diseases.
Therefore, the care delivered to HIV infected women requires the implementation of individualized care, which also covers the family on the part of professional nurses. In the biological field, it is necessary to monitor the infection progress and implement, in conjunction with the women, preventive measures to avoid reinfections, onset of opportunistic diseases, as well as to encourage adherence to drug therapy. An important instrument should be considered for this purpose, which is the use of systematic nursing care that enables the collection of information, development of nursing diagnosis, care planning, prescription and regular progress of the women’s health condition.

A research undertaken with a group of HIV positive people, aged 50 or over, concluded that their statement in relation to the workplace was full of the prejudice experienced and the fear of experiencing it. Furthermore, the participants saw the infection as one more hurdle for work due to the fact of being discriminated. In their statements, however, the participants wished to feel useful, productive and capable of supporting themselves, but many of them were people without formal education, making their difficulties worse.14

Leisure was another important point that emerged from the statements of the participants, in which it was verified that many of them abandoned leisure, not realizing its importance for personal and family quality of life. The fact is that, when asking the women about their form of leisure, not realizing its importance for doned leisure, not realizing its importance for personal and family quality of life. The fact is that, when asking the women about their form of leisure, not realizing its importance for

To me, life ended, because I no longer enjoy going out… I stay more at home (Gardenia).

I used to enjoy dancing a lot […] spent the week working and, on Saturdays, there was no lack of friends to take me to forro, night clubs, sometimes I went out with men, it was not prostitution, it was loneliness, then after […] just went to two parties, a disappointment, nobody looked at me anymore, it seemed it was written in my forehead that I was this, I was that (Poppy).

[…] it changed, I used to enjoy going out, going around, and I do not do any of this any longer (Pink Alpinia).

[…] like, going around, having my friendships, I still have them, but not many, because many people talk about it, there are people who ask me and I deny it, because if I say that, you know! (Chrysanthemum).

Most HIV positive women isolate themselves from social situations and avoid situations where they may expose their health condition. The statements showed a feeling of guilt for having caught a disease with sexual connotation and which required reorientation of healthier practices of leisure. The lack of acceptance of the new condition was evidenced, which limits behaviors and actions, besides requiring continuous self-care.

The religious beliefs that interpose in the experiences of sexuality and HIV/AIDS, showing the need to hide their sexual orientation, the guilt in the face of the disease, often associated to the concept of sin, cause intense pain to people suffering from the disease.11

The limitations for nursing interventions are related to professionals’ little time availability to intervene in these situations with the women. It is necessary to perform a daily work of readapting the women, so as to enable them to rethink possible ways of leisure, without compromising treatment and understanding this as a basic health need of human beings.

Women consider aids as a disease permeated by prejudice, and this explains their attachment to religion as a way of support to face it. Furthermore, the disease is also seen as a new start. After the impact of the diagnosis, there is a need for restructuring and maintaining life in its various roles.15

The spiritual comfort acquired through religion eases the bio-psychosocial repercussions of the infection. Nursing care should recognize the religious dimension as an ally in the treatment process of women and consider it in the care planning, in order to improve these women’s conditions and quality of life.

When dealing with spirituality, nursing professionals may be closer to self-knowledge. This situation provides access to the symbolic language of the unconscious and permits dealing with images and small stories full of symbolism, expressing fears, anxieties and dilemmas, among others, which are present in the psyche. Thus, it can be possible to establish a dialogue with the patients and groups involved with important health issues, such as HIV positive cases.16

From these images, healthcare professionals can voluntarily participate in the process of elaborating meanings and of internal mobilization, central factors in the dynamics facing the crisis of living. The skillful eye, however, imposed by the biomedical model in a view that separates material from subjective dimensions, is a hurdle in getting
involved with human drama\textsuperscript{16}. It is necessary that nursing professionals develop and integrate  
\textit{racial, sensitive, affective and intuitive dimensions in order to assist human beings. Without these skills, the assistance provided to patients is compromised.}

Nurses are in key positions to actively listen, assess spiritual needs and make necessary referrals to HIV positive women. The effects of spirituality are positive in the bio-psychosocial functioning in relation to HIV and other chronic diseases. Nursing professionals are encouraged to study and approach the spiritual demands of this population.\textsuperscript{17}

Women with HIV/aids should be included in society, perform productive activities and enjoy a routine that involves leisure. The incentive towards social and economic inclusion of women is aimed at avoiding “civil death”. It is necessary to keep them active, caring for their children and family. This way, these women can deal better with being HIV positive.\textsuperscript{18}

The social isolation expressed in their statements indicates to professional nursing the need for actions to convince women to return to social life, to plan options for leisure that are compatible with their new reality, without reasons to avoid previously pleasing situations. Nursing professionals should provide care that is consistent with the different needs presented by the individual, the family and the different community groups.

In the process of assisting HIV positive women, nursing professionals should have a theoretical reference framework and a care method. The use of these work process elements provides a technical-scientific standard for care delivery in this field and can cover important psychosocial-spiritual issues for the implementation of care to women.

\textbf{New daily habits to ensure quality of life}

In this subcategory, changes in the daily lives of the interviewed women were reported, and related to self-care after the diagnosis. This shows their wish to live, despite the misfortune of the infection.

\textit{What has changed is that I started being more careful in relation to prevention of diseases and taking better care of my diet, even after I started taking the anti-retroviral medications because, when they cause you to put on weight, you have a lot of lypodystrophy [changes affecting the arms, legs and face, due to the fat loss] and I am terrified and I take better care} (Sunflower).

\textit{I think a lot has changed […] I used to enjoy a lot before, I drank a lot, I took a lot of drugs, but now… I think it was about four years ago that I completely quitted drugs and alcohol} (Astromelia).

\textit{I would not say that I stopped doing anything, I just added to it. I added the quality of life issue, to consider myself more. Greater attention was given to me and the world I live in; then, there was a growth afterwards, of course with a huge and painful overcoming period, then there comes the person’s strength issue} (Eremurus).

\textit{I started staying more at home. I am more aware of what I can and cannot do. I started appreciating more my life, and according to the saying, I used to do whatever I wanted, but not anymore nowadays, I know it, I am aware of what I can and cannot do} (Dendron).

\textit{It has changed, after we find out we have such issue, then things change, you have to learn to live each day} (Carrot Flower).

The HIV positive serological diagnosis caused the women to change their habits, aiming to improve quality of life, so that they could live with and overcome the harm caused by the infection. Among important changes, such as avoiding drugs, alcohol, unprotected sex and others, however, there are those related to social isolation and leisure. The fear and guilt about the contamination make the social life of these women harder.

Aids is currently considered a chronic disease. Therefore, quality of life is an important target for those suffering from the disease or those who live with someone afflicted by the infection.

It is essential for people living with HIV to understand quality of life, considering the chronicity of the disease and the possibility of a longer life span. Moreover, living with a disgraceful, incurable disease, which brings many bio-psychosocial consequences can affect the healthy habits of life.\textsuperscript{19}

The identification of the factors that affect the quality of life of women living with HIV infection may contribute to a more humanized care delivered to these women by providing nursing care beyond the clinical aspects. Some of these factors are the physical, emotional, affective and spiritual aspects resulting from the disease, the continuous treatment, the use of anti-retroviral medications, the discrimination and prejudice.\textsuperscript{20}

A research involving people with HIV/aids to verify the factors related to quality of life revealed higher scores in relation to the sexual function, satisfaction with the healthcare professional and life satisfaction. It was also found that the higher quality of life scores resulted from
participants who were receiving anti-retroviral therapy, had health insurance and lower depression symptoms.\textsuperscript{21}

A study guided by the Beliefs in Health Model found that women in the post-reproductive period, with low income and education, retain information about the aids epidemic, recognize the severity of the disease, as well as the factors that make them susceptible to the disease, but do not overcome the difficulties to execute prevention actions.\textsuperscript{22}

Nursing care provided to women with HIV/aids involves guidance for the adoption of a healthier lifestyle and leisure habits. Prevention after infection relates to the reduction of the onset and progress of opportunistic diseases, preventive guidance concerning infection to other people and re-infection, introducing accountability for self-care and care to others. The treatment should reinforce preventive issues focused on adherence to drug therapy and monitoring of diseases. Furthermore, making use of intersectionality relates to the instruments that integrate women’s healthcare network or related fields, which can act on emergency matters arising from being HIV positive, such as psychological healthcare, obstetrical and gynecological care, invasive cervical cancer control, besides other degenerative diseases.

**FINAL CONSIDERATIONS**

The profile of the participant women in this study confirms Brazilian data concerning HIV/aids epidemic in women. The participants were young women of reproductive age, with children, low education and income, married or who lived in a de facto relationship, being most of them from the state’s countryside.

Changes in the daily life of these women after HIV infection showed their fragility concerning marital relations, concerning the decision for prevention as a reflection of HIV infection. The repercussions caused by being abandoned by their partners and their families were seen as effectively important and relevant in these women’s response to the infection. Besides, they reported social isolation with stagnation of productive and leisure activities, caused by the social stigma attached to the disease.

The considerable number of women who reported seeking comfort in religion for issues involving the subjectivity of being HIV positive should be highlighted though. This rests on the need for attention to psychosocial-spiritual issues, which are not currently a priority for care related to HIV/aids in the specialized outpatient care area.

The situations described above require nursing care that incorporates a care method that recognizes the needs of women with HIV/aids. Therefore, it is necessary to create parameters to measure the quality of nursing care provided in this field.

Other research to assess the quality of life of women living with HIV/aids is needed and can contribute to the development of professional healthcare interventions, as well as public policies that promote them.

Important changes in the daily habits of the participant women could also be noted, aimed at improving the quality of life and preventing other diseases caused by the infection, such as reduction or quitting of alcohol, smoking, drugs and unprotected sex practices. These evidences benefit the nursing care process, placing the professionals in the position of allies of these women, with a view to maintaining these changes.

The limitations of this study are related to the fact that the women’s statements analyzed resulted from one healthcare service and cannot be generalized; however, these data can be considered valid, due to the fact that, during the research period, the service provided assistance to 70\% of the population affected by HIV/aids infection in the state of Ceará. In addition, the women reported similar conditions to those seen in Brazilian research, carried out in other regions of the country. Therefore, this research may be useful to improve and implement nursing care actions concerning women with HIV/aids infection, considered as health policies.

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