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Article

Conditioning Factors in the Transition Process to the Self-Care of Women with AIDS

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Abstract: This study aimed to know the conditioning factors of the transition process to the self-care of women diagnosed with HIV/AIDS. This qualitative study was carried out from June to September 2015 with seven seropositive women, users of a specialized service in sexually transmitted diseases in the municipality of Imperatriz, Maranhão State, Brazil. For the data collection, an individual interview was used, and data analysis was performed by content analysis delineated by Hsieh and Shannon (2005). The resources that influence the self-care in the transition process of women with HIV/AIDS are represented by personal conditioning factors, such as the meaning they attribute to the living with the disease, personal attitudes and cultural beliefs, socioeconomic status, preparation and knowledge about the disease, and by conditioning factors found in the community and society. The transition theory can provide important insights about the resources present in the adaptation process of women diagnosed with HIV so that they can perform their self-care satisfactorily.

Keywords: nursing theory; self-care women; HIV

1. Introduction

The acquired immunodeficiency syndrome (AIDS) is a disease that represents one of the biggest problems of public health in the present time, due to its pandemic character and severity [1]. People infected with the human immunodeficiency virus (HIV) develop a severe immune system dysfunction as CD4+ T lymphocytes, the main target cell of the virus, are destroyed [2]. However, the fact of being HIV-positive is not the same as having AIDS, since there are many HIV-positive people who live years with no symptoms and without developing the disease, but they can transmit the virus to others [1].

According to epidemiological data, from the beginning of the AIDS epidemic in BRASIL to June 2015, 798,366 cases of this disease were recorded in this country [3]. According to the surveys carried out by the Ministry of Health (MH) [3] and the State Department of Health (SDH) of the state of Maranhão, from the 1980s to 2015, 13.331 cases of people with HIV infection were identified in the state of Maranhão. In the municipality of Imperatriz, in this same period, 1.351 cases were recorded, and 46 cases in total were identified in the year 2015 (24 men and 22 women) [3].

Taking into account the epidemiological and clinical aspects already mentioned, study [4] analyzing the condition of women with HIV/AIDS, emphasize that their adaptation in the face of the diagnosis of HIV starts from the discovery of their seropositivity, which imposes on them a transformation of the consciousness about themselves and their life, leading them to a new way of thinking and facing this current and permanent condition.

Changes in the daily life of women after HIV infection can be evidenced from the fragility of marital relationships, in the decision for the prevention, as a reflection of HIV infection, and cases of abandonment by the partner, family avoidance, difficulties of acceptance in the work, and uncertainty of gestation due to the fear of infecting their child, which are identified as significant changes that effectively interfere with the response of the women to the infection. Thus, it is possible to notice a social isolation, with the stagnation of leisure and productivity activities caused by the social stigma of the infection [5].

The manifestation of HIV imposes on women episodes of high vulnerability, stress, anxiety, fear and denial. This transition period involves a process of inner reorganization as the person learns to adapt and incorporate new circumstances into his or her life [6].

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In [4] state that the diagnosis of HIV infection is perceived as a transition moment which can disorganize relationships and make difficult the attempts of adjustment to life in society.

According to the study [5] care related to women diagnosed with HIV/AIDS requires from nursing a better implementation and guidance for individualized care, guidance to face the disease, education and daily activities to rehabilitate women so that they may rethink possible forms of leisure without treatment-related impairment.

The discovery of the diagnosis of HIV/AIDS by the infected people is a time of transition in their life since in some aspects it brings changes to them, their relationships and life in society, especially among those close to them, such as their family and friends. This moment is also followed by uncertainties, anxiety, insecurity, and fear of the unknown and frightening situation. Therefore, to assist the woman in adapting to the new experience, it is necessary to know the factors that facilitate or interfere with her well-being to potentiate what is favorable for her quality of life in coping with the disease [5].

Regarding these changes caused in women's life by the diagnosis of a disease such as HIV/AIDS, the [7] Transition Theory provides theoretical elements so that the practitioners can facilitate healthy transition processes for the individual [7]. In this sense, [6] proposes that nursing interventions aim to facilitate healthy transition processes, making the return to daily life with the lowest number of limitations and implications.

Women living with HIV/AIDS should be encouraged to promote their self-care and seek appropriate support for the implementation of such care. Orem's nursing self-care deficit theory contributed to the construction of a specific disciplinary language, assisting in the empowerment of these women [8].

In nursing, the Orem's theory is the main theoretical reference in work with concepts for self-care and can facilitate the planning of care for nurses who care for women diagnosed with HIV/AIDS. According to this theory, nurses play an important role in facilitating undifferentiated transitions; this role has its significance increased when it is related to a process of health-disease transition, and it is necessary to assume an attitude of listening and acceptance of the other one, education and guidance, promotion of self-care and comfort [9].

With these arguments, it is possible to notice the real need of understanding the experiences of women diagnosed with HIV/AIDS and the meaning that each one attributes to health-disease conditions, according to the values, beliefs and other personal conditions of the community and society, which characterize the uniqueness throughout the transition of women to self-care [10].

With the purpose of generating pieces of evidence that contribute to the clinical practice of health professionals in the care of women with HIV/AIDS, this study aimed to identify the conditioning factors of the transition process to the self-care of women diagnosed with HIV/AIDS.

2. Materials and Methods

This is a descriptive qualitative study carried out with eight HIV-seropositive women, who were being monitored by the Specialized Attention Service (SAS) of the IST/AIDS programs in the municipality of Imperatriz, Maranhão State, Brazil.

The SAS, which is a municipal program of IST/HIV/AIDS, this study's scenario, was implemented in 1988 for specialized care of HIV/AIDS patients in the municipality of Imperatriz. At

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the beginning, the program's headquarters was located in the Health Center "Três Poderes", but nowadays it is in the Health Complex of the Anhanguera Park, and it monitors approximately 966 outpatients with AIDS, from the municipality of Imperatriz, and from southern Maranhão, Pará, and Bico do Papagaio region (Tocantins State).

Participants were selected based on criteria such as diagnosis of HIV-seropositive during the collection period, register and involvement in the SAS, age equal to or over 21 years, and availability to participate in the meetings.

The present study was approved by the Research Ethics Committee of the Federal University of Tocantins - UFT (CEP/UFT), No. 105/2014, according to the precepts of Resolution 466/2012 of the National Health Council (NHC).

The data collection was carried out between June and September 2015, through planned individual meetings (managed) in which a pre-elaborated semi-structured instrument was applied, composed of two stages. The first one consisted of questions regarding age, gender, education, marital status, historical of diseases and medicines in use, and the second one addressed a guiding question on the factors that contribute and/or limit women in the face of the diagnosis of HIV.

All meetings were audio-recorded and transcribed in full. Statistical analysis was performed by systematizing the data. First, data pre-analysis was carried out, consisting of fluctuating readings of the data, involving comings and goings to the material. Afterward, data were organized in a registry unit that, in general, is a larger unit.

The content technique analysis delineated by study [11] was used for data analysis. This method is suitable when it is aimed to describe an existing phenomenon or when the research literature is limited.

Therefore, the analysis was performed inductively and followed the steps described [12] .The whole text was read and reread several times so that the its content could be understood. In the next step, the content was structured in units of meaning, which were condensed and labeled with codes according to the research questions and study objectives. The codes were condensed, and the relationship phases consisted of pre-categories and supported by the perspective of the theoretical reference of Afaf Meleis' Transitions Theory and Orem Self-Care Theory.

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3. Results

The resources that influence self-care in the transition process of women with HIV/AIDS participating in this study are represented by two categories: personal conditioning factors of women with HIV/AIDS, and conditioning factors of the community and society that influence in the self-care of women with HIV/AIDS.

Personal conditioning factors of women with HIV/AIDS

For the personal conditioning factors of women with HIV/AIDS, four subcategories were verified: meanings, attitudes and cultural beliefs, socioeconomic status, and preparation and knowledge.

In the subcategory meanings, it was possible to verify how women notice their new health condition after discovering the diagnosis of HIV/AIDS, as it was reported in some of the statements:

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> *"I took the test because I was forced to do it... because I had already suspected about it! That I could have it, but, I did not want to know... I suspected, but I wanted to live in a world of illusion, that it did not exist... I wanted to live like that, without knowing" (Rosana).*

In the attitudes and cultural beliefs subcategory, it was observed that faith and religiosity are allied in the transition process, as they comfort and make the people with AIDS more focused on their care process to promote their health, as evidenced in the following reports:

> *"I'm a Protestant and if I have... Jesus has already healed me because I gave myself to Him. Sincerely" (Cravo).*
> *"Oh, first, I have faith in God, and that one day, this problem can be solved; I hope for the cure" (Bianca).*

In this subcategory, the spiritual comfort acquired in the religious experience mitigates the biopsychosocial repercussions of the infection, which can be noticed in the following reports:

> *"Faith is a primordial factor for me too, I'm a person very close to God, I have this very close contact with God, it is a relationship between father and daughter, I don't see God there on the heavenly throne far from me pointing His finger to the first sin that I commit, I see God as a friend father who watches me, who embraces me, who puts me on His lap" (Lucia).*

In the socioeconomic status subcategory, it was verified the importance of the practices of labor activities carried out by women and their autonomy to manage their self-care through the work, as well as the possession of financial resources for their leisure and health care.

> *"I work with my sister she deals in a bar, and I always help her... I do the laundry for her... clean the house for her ... and she pays me. And with that money, I buy something for the house, and I receive the money from the "Bolsa Família" that helps me pay my rent" (Rosana).*
> *"I work to pay for my household expenses" (Lucia).*

The preparation and knowledge subcategory is related to the time the HIV diagnosis is discovered, and how was the women's perception of AIDS.

> *"I was too sad I cried, and cried, thinking that in three months I would die! It was like that... I thought that in three months I would be dead... I thought it was a disease that arrived and suddenly, and then the person died. Today, I think it's better than having cancer... than having other things... because until today I'm alive and well" (Rosana).*

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192 *"I thought about infected people; it was a very serious case, they died quickly, it had*
193 *no treatment, right? Doubt about people who didn't have knowledge, either...*
194 *only" (Bianca).*
195
196 **Conditioning factors of the community and society that influence the self-care of women with**
197 **HIV/AIDS**
198
199 From the conditioning factors of the community and society associated with the self-care of
200 the studied women, three subcategories were verified: family participation and affective and family
201 context, formal social support, and informal social support.
202 In the family participation and affective and family context subcategories, it was observed
203 that the family, supporting the woman with AIDS, becomes an emotional support facilitator in the
204 transition process since it allows her to feel confident that she will be assisted to get around all
205 difficult moments after the HIV diagnosis. Such situation can be noticed in the following reports:
206
207 *"I told my children... my children are the only ones who know" (Margarida).*
208 *"My husband knows, I shared with my two brothers and my mother, who also*
209 *gives me great support" (Bianca).*
210
211 The emotional support in the family context was also related to the acceptance of the
212 woman by her partner, after confirming the diagnosis of HIV infection. This moment of discovery
213 of the diagnosis and the support given by her partner can be seen as a facilitating process to face the
214 disease since it has a positive impact on the treatment of the woman who is supported in a difficult
215 time. The reports collected from the women who participated in the research showed the
216 importance of this affective dimension:
217
218 *"My husband knows since I took the test. At that time, he was twenty, and I was*
219 *seventeen years old. I took the test, and when he went to take me, I told him the*
220 *result at the same time. Then, I said that if he wanted to get a divorce, I would go*
221 *away (...) then he said no! He said that he didn't want me to go away and that we'd*
222 *be together!" (Rosana).*
223
224 On the other hand, prejudice and lack of information about HIV can generate
225 uncomfortable situations for the woman from the moment she suffers due to the discrimination by
226 her family. In these situations, living side by side with the family can be an inhibitory conditioning
227 in the health-disease transition process, as verified in the testimonies of some women.
228
229 *"My son was like that, he stayed a long time without stopped by my home, and he*
230 *neither ate at my home nor drank coffee, he doesn't drink coffee" (Maria).*
231 *"My mother-in-law is very prejudiced... She doesn't know that I'm infected, but*
232 *when she comments on people who have a seropositive problem... it hurts me*
233 *inside" (Bianca).*
234

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The formal social support was another conditioning factor in the process of transition to self-care, found in this study. This subcategory of analysis arises from the resources found in the community, from the perception of women, which can influence the way they face the problem and in their personal growth.

Adhesion groups proved to be a formal social support facilitating the process of health/disease transition since they work as mutual support groups, in which the individual lives and discusses with their peers, as it can be seen in the following statements:

> *"The people from the area we live side by side with, once a month" (Bianca).*

Regarding the qualification to perform some activities, we can notice an empowerment of the women, when they feel useful and able to carry out activities of their daily life, as it was observed in the participants' reports:

> *"I look at a little baby in my house; I play with him a lot... I have a lot of fun. I wash the dishes, sweep the house, do the laundry. I keep doing everything normally. My daughter didn't want to let me do that. I frequently came here to the hospital (CTA), and the doctor told me I should busy myself doing something so I wouldn't be so worried about the problem" (Margarida).*

The use of medicines can be described as another facilitator in the self-care process. There was a health improvement in women who use medicines, as it can be seen in the following reports:

> *"I don't have much problem regarding it (AIDS) because I take medicine all the time" (Margarida).*
>
> *"I take my remedies correctly, I already take the CD4 which is normal, there is no danger, but I can't stop taking" (Maria).*

In the informal social support subcategory, leisure was another important point that arose from the expressions of the interviewed women, and it was observed that many of them abandoned leisure activities, not realizing the importance of these activities for the personal and family quality of life. This subcategory may be associated with the situation of inhibition of the woman in seeking the improvement of her well-being, which is summarily reported in the following fragments:

> *"One difficulty I feel is that I like to walk, so far, but I can't walk alone. I can't travel by bus for many hours. So, what I keep thinking today is that I want to travel, but I can't walk alone. That's the difficulty I have" (Margarida).*

4. Discussion

From the interviewees, it was possible to evidence the women's perception of their new health condition, since the discovery of the diagnosis of HIV/AIDS when some of them were upset

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due to confirmation of the disease. The personal meaning of HIV/AIDS and the non-acceptance of the diagnosis were reported by Von Zuben et al. [13] who evidenced that the participants did not accept their new reality, considering the positivity for HIV/AIDS as impossible. On the reaction of the participants in their studies, stating that some of them, when knew the diagnosis, did not were astonished, denied, affirming that they had always been healthy, that it was not possible to be sick [14].

Another situation was observed from the statements given by the participants in the present study, in which the understanding, acceptance of the transition process and self-care are related to the treatment and attribution to the improvement of the disease condition.

In this subcategory of the study, it was possible to verify that religiosity and spiritual comfort are used as a tool for individual strengthening to face fragilities that HIV imposes on women. In this context, the testimonies revealed a positive content related to faith in better days. Nursing care should recognize the religiosity as an ally in the process of treating women and consider it in the planning care to improve the conditions and quality of life of these women. That many participants have a hope of being cured, both by God and by supernatural power [15]. Because it is an incurable disease, they believe that only the divine can heal them. Thus, practices such as making vows to receive divine healing are developed.

Women believe that cultural beliefs through religion can help them overcome the barriers imposed by the disease, by developing their will to live; the redefinition of personal relationships, perception of the new meaning of life, and the reevaluation of the judgment on death minimize the biopsychosocial repercussions of HIV infection [16,17]; also reinforce the findings of the current research.

In the present study, the work performed by the women appeared as a facilitator in the process of transition to the self-care of women with HIV/AIDS. From the fragments of the participants' reports, it was found that the work is a facilitator because it develops the empowerment of women, arousing the productivity and a set of evocations of their conception of work, by seeing an opportunity in the market as some of their possible psychosocial repercussions.

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The case of people living with HIV/AIDS, it should be considered that labor activity allows, in addition to the access to material conditions of existence, the deviation of thought, from the negative demands of the disease to productive action [18]

Concerning the HIV/AIDS diagnosis discovery, it was possible to verify in the participants' testimonies, a moment of apprehension and surprise by the participants' perception of the possibility of death caused by HIV/AIDS. The vulnerability of women to positive HIV/AIDS diagnosis as a life-and-death paradox that becomes part of the experience of women living with HIV, causing an enormous anguish for them [19].

Regarding the family dimension, some women pointed out that the family, supporting them, becomes an invigorating emotional support in the transition process since it promotes a feeling of security that they will be helped to get around all the difficult moments that may exist after the HIV diagnosis.

The support given by family members, friends and partners guarantees a facilitating condition to face the disease, and the family plays a fundamental role in the dimension of emotional support and assistance in care during drug treatment [20,16,9].

The support given by the partner/spouse related to the care of the seropositive woman can be seen as a facilitating process in the transition, helping to face the disease, since it positively affects the treatment of the woman who is emotionally supported during a hard moment [21].

On the other hand, some testimonies evidenced the prejudice from family as an inhibitor in the health-disease transition process, since it causes suffering, helplessness and lack of motivation for the treatment adhesion.

The revelation of positive HIV serology to family members is a challenge that many women cannot overcome and keep it in secret, justifying they make that decision to avoid concern to their elders or because they are afraid of discriminatory attitude from someone close to them [21].

Regarding social contact, some participants reported the importance of living with others who also have the disease, since this relationship can help in the health-disease process. The main strategy to face the stigma is the establishment of small groups of people who live with HIV. Being part of adhesion groups provides the sense of belonging to the same family and increases the chances of gaining much access to information relevant to face the disease [22].

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In the present study, the positive perceptions regarding the correct use of antiretrovirals were expressed in the women's speech, as they reported hope for better days by the fact they were taking the drug correctly. State that antiretroviral therapy gives hope to people with HIV/AIDS, and acts symbolically by unlinking the disease from a synonym for death [23].

Regarding leisure, the participants' reports emphasize this conditioning factor as deficient, since most of the health services do not provide such activities, such situation can be an inhibiting factor related to the treatment of the disease. However, Silva et al. [5] found that many women abandoned leisure, not realizing its importance for personal and family quality of life. Most seropositive women distance themselves from social contact and avoid situations that may expose their health status.

It is important to consider the theoretical and methodological limits of the present study. Methodologically, it is a qualitative study, making impossible to generalize the results found here, requiring comparison and mediations. The theoretical limit or analysis by theoretical references can overvalue certain aspects compared to others. Thus, further studies are needed to explore the applicability of this theory to the context of adaptation to this disease and self-care of women with HIV.

5. Conclusions

This section is mandatory. Please summarize the main achievements and/or results in this section.

This study aimed to know the conditioning factors of the transition process to the self-care of women diagnosed with HIV/AIDS. From the results, it was possible to understand the importance of understanding the meaning of the characteristics of personal, community and society conditions that can facilitate or make difficult the healthy transition for women with HIV. Health professionals who recognize these conditions can be facilitators in this process through interventions based on guidance, support to face the problem, and women's empowerment to strengthen self-care.

Regain autonomy in the face of a disease such as HIV infection represents a transition process. The way of dealing with the transition is determined by various process elements, time and the individual perception that each person develops with the experience.

From the proposed reports, it was possible to notice the real need to guide the women to find ways to face and adapt to the condition imposed by the disease. Emphasizing the importance of guiding on the self-care deficit, when entering the transition process, it is necessary to know elements that do not increase the self-care deficit. Care related to women diagnosed with HIV/AIDS requires health professionals to be more involved, guided for individualized care and to face this disease.

This study also contributed for women's perceptions about HIV/AIDS and to identify changes noticed from the discovery of seropositivity. Personal conditioning factors and community resources can help or make difficult the self-care process after HIV/AIDS diagnosis, as well as the process of living with the disease. The way to face the disease, preparation and knowledge about it, and the importance of guidance for self-care were fundamental for the elaboration of this study.

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