

## ELDERLY WITH HUMAN IMMUNODEFICIENCY VIRUS: INFECTION, DIAGNOSIS AND LIVING WITH THE DISEASE

### PESSOAS IDOSAS COM O VÍRUS DA IMUNODEFICIÊNCIA HUMANA: INFECÇÃO, DIAGNÓSTICO E CONVIVÊNCIA

### ADULTOS MAYORES CON EL VIRUS DE LA INMUNODEFICIENCIA HUMANA: INFECCIÓN, DIAGNÓSTICO Y CONVIVENCIA

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## ABSTRACT

The study aimed to understand how older people with the human immunodeficiency virus (HIV) were infected, how they found out the diagnosis and started to live with HIV. Exploratory, descriptive and qualitative study conducted between November and December 2012 where nine HIV-positive elderly assisted in a reference unit of a university hospital in southern Brazil were interviewed. Data were submitted to content analysis, resulting in six categories: (lack of) knowledge about HIV/AIDS before infection; HIV infection; discovery of the diagnosis; reaction of the elderly before the diagnosis; seropositivity and daily life of the elderly; sexual life and prevention after the discovery of HIV infection. The study led to the conclusion that older people had limited knowledge about HIV before they discovered they were HIV-positive, demonstrating the importance of carrying out educational activities aimed at prevention.

**Keywords:** Aged; Acquired Immunodeficiency Syndrome; Nursing.

## RESUMO

*O estudo teve como objetivo conhecer como pessoas idosas com o vírus da imunodeficiência humana (HIV) se infectaram, descobriram o diagnóstico e passaram a conviver com o HIV. Pesquisa qualitativa exploratório-descritiva realizada entre novembro e dezembro de 2012 entrevistou nove pessoas idosas soropositivas atendidas em uma unidade de referência de um hospital universitário do sul do Brasil. Os dados foram submetidos à análise de conteúdo, resultando em seis categorias: (des)conhecimento sobre o HIV/AIDS antes do contágio; infecção pelo HIV; descoberta do diagnóstico; reação da pessoa idosa diante do diagnóstico; soropositividade e o cotidiano da pessoa idosa; vida sexual e prevenção após a descoberta da infecção por HIV. Pode-se concluir que as pessoas idosas possuíam conhecimento restrito em relação ao HIV antes de descobrirem que eram soropositivas, demonstrando a importância da realização de ações educativas com vistas à prevenção.*

**Palavras-chave:** Idoso; Síndrome de Imunodeficiência Adquirida; Enfermagem.

## RESUMEN

*El presente estudio tiene como objetivo entender cómo adultos mayores se infectaron con el VIH, descubrieron el diagnóstico y conviven con el virus. Estudio cualitativo exploratorio-descriptivo realizado entre noviembre y diciembre de 2012. Nueve adultos mayores con VIH fueron entrevistados en una unidad de referencia de un hospital universitario del sur de Brasil. El análisis de contenido resultó en seis categorías: (des)conocimiento sobre el VIH/SIDA antes del contagio; infección por VIH; descubrimiento del diagnóstico; reacción del adulto mayor ante el diagnóstico; seropositividad y vida cotidiana del adulto mayor; vida sexual y prevención después del descubrimiento de la infección por el VIH. Se concluye que dichos adultos tenían poco conocimiento sobre el VIH antes de recibir el diagnóstico, lo cual demuestra la importancia de llevar a cabo actividades educativas con miras a su prevención.*

**Palabras clave:** Anciano; Síndrome de Inmunodeficiencia Adquirida; Enfermería.

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## INTRODUCTION

The population of people over 60 years of age in Brazilian society is constantly growing. Rapid advances in medicine and technology have encouraged people to grow old in a healthier way and with better quality of life.<sup>1</sup> Due to the extension of healthy life, the elderly population continues developing their usual activities, including the exercise of sexuality and the sexual act itself.<sup>2</sup>

The sexual affective relationship is not restricted to young people. Elderly can also remain sexually active. However, these elderly had restricted access, while in the youth, to information about sexually transmitted diseases (STDs). This may make them vulnerable to acquiring infectious diseases such as the acquired immunodeficiency syndrome (AIDS), that has the human immunodeficiency virus (HIV) as causative agent.<sup>3</sup> The HIV and AIDS epidemic among elderly in Brazil has been characterized as a public health problem due to the increasing number of reported cases.<sup>4</sup>

The incidence of HIV/AIDS in this portion of the population was 9.5% in 2013, and the sexual act was the main form of contagion. According to the AIDS and STD Epidemiological Bulletin, 458 new cases among male elderly and 300 among female elderly were reported in Brazil until June 2014.<sup>5</sup> Although there is an increase in the number of notifications, sometimes HIV in older people is not diagnosed earlier due to the fact that there is no approach to their sex life.<sup>6</sup> The prevailing belief that HIV/AIDS is linked to certain risk groups, such as young people, represents an obstacle to the detection and prevention of this disease in the elderly.<sup>7</sup>

Research carried out in an outpatient unit of a university hospital in Rio de Janeiro proved that ignorance about the infection, ways of transmission and prevention is present among people over 50 years of age.<sup>8</sup> Considering the increase of elderly people and the growing number of cases of AIDS recorded in this portion of the population, studies addressing this issue become relevant. By knowing how HIV-positive elderly people were infected and how they found out the diagnosis, it is expected to provide information that may support the nurses' action with a view to developing preventive strategies for other older people not to get infected and for those already infected to adopt measures of preventing transmission of the virus, which justifies the development of the present study.

The research is justified also by the awareness that the issues related to the health of the elderly and on STD/AIDS in this population are of great importance in the context of public policy, as these are highlighted by the Ministry of Health as a priority for research in Brazil.<sup>9</sup> Based on these, the question raised is: how HIV-positive elderly people were infected, how they discovered that were infected and how they started to live with this diagnosis?

## METHODOLOGY

This is an exploratory and descriptive study with qualitative approach, conducted in a midsize university hospital located in the state of Rio Grande do Sul, Brazil. The institution has 187 beds, with exclusive service to users of the Unified Health System (SUS). It has a unit called Adult AIDS Day-Hospital, considered a reference in care of people with HIV/AIDS. For this reason, this unit was chosen for the collection of data in the present study.

The established inclusion criteria were: be an elderly person according to the Statute of the Elderly,<sup>10</sup> be able to read and keep under outpatient treatment at the day-hospital referral center. Established exclusion criteria were: cognitive impairment that prevented the elderly person to fully exercise autonomy. For this, the version of the Mini Mental State Examination (MMSE) validated in Brazil was applied. The cutoff point used to indicate cognitive impairment was 18 points for illiterate people, and 23 points for those with more than one year of schooling.<sup>11</sup>

During the period of data collection, nine elderly were received at the Adult AIDS Day-Hospital; all met the inclusion criteria and composed the *corpus* of the study.

Data collection took place between November and December 2012, with semi-structured interviews that were recorded using digital devices (MP4) and were later transcribed. The script used for the interview consisted of two parts: the first addressed the identification of participants: age, sex, education, marital status, religion, income, occupation; the second part had open questions about HIV/AIDS and about perceptions of the elderly, as well as the changes in personal life and sexual practices after diagnosis, questions about the living with the disease and about methods of prevention adopted.

Data were evaluated based on content analysis, which consists of discovering the core meanings that compose a communication, whose presence or frequency add significant perspectives to the study of the object in question.<sup>12</sup> Thus, the implementation of the process of review followed the three steps of the method. Initially, there was a thorough reading of the data, then the organization of the material and formulation of hypotheses. Following, the exploration of the material was made, distributing excerpts or phrases of each text in units, allowing the exact description of the relevant characteristics of the content expressed in the text. In the third phase, the frequency of the information provided was verified, connecting them according to the theme.<sup>12</sup>

Ethical and legal principles involving research with human beings were respected, according to the Resolution 466/2012 of the Ministry of Health.<sup>13</sup> Participants signed two copies of the Informed Consent (IC), of which one was kept by the participant and the other was given to researchers. Anonymity of participants was assured by identifying them by the word "elderly" followed by a numerical digit that corresponded to the

order of interview (Elderly 1, Elderly 2 ...Elderly 9). The research project had favorable opinion from the ethics committee in research under number 95/2012.

## RESULTS AND DISCUSSION

Regarding the profile of the elderly, the ages ranged between 60 and 77 years. There was a predominance of males, with six men and three women. These results are similar to those found in other studies, which indicate that most HIV-infected people aged at 50 years or older are male.<sup>4,14</sup> Regarding marital status, one elderly person was married, one was divorced, two lived with a partner, two were single and three were widows. Widows, single or separated persons are more at risk of becoming infected, as they have more propensity to sexual intercourse without a constant partner.<sup>15</sup>

Furthermore, studies indicate that there is a close correlation between unfavorable socioeconomic indicators and increased incidence of HIV/AIDS. People with little education, low income and residents of geographical areas with low human development index have been the most affected by the disease.<sup>4,16</sup> In the present study, all elderly people said they did not finished elementary school. Seven were retired and had a monthly income of one minimum wage, two were autonomous and had no fixed income.

Six categories emerged from the data analysis: a) (lack of) knowledge about HIV/AIDS before infection; b) HIV infection; c) discovery of the diagnosis; d) reaction of the elderly before the diagnosis; e) seropositivity and daily life of the elderly; f) sexual life and prevention after the discovery of HIV infection.

### (LACK OF) KNOWLEDGE ABOUT HIV/AIDS BEFORE INFECTION

It was evident in this category that the lack of knowledge about the infection may have contributed to the acquisition of HIV. Some elderly people said that their knowledge about the disease prior to infection was vague or non-existent:

*I had no knowledge, I used to hear about it only and it used to scare me [...] I did not imagine that it could get that (Elderly 3).*

*I knew, something like that, I would hear people talking on television, but I thought that wasn't for me (Elderly 8).*

The ignorance of the ways of contamination along with the lack of protection during sex predisposes the elderly, who are in a vulnerable position, to the acquisition and transmission of the virus.<sup>17</sup> In this category, the limited perception of the risk of contracting HIV and the consequent lack of prevention are

evident. Some participants pointed out that before they knew they had the disease, they used to consider contamination something far from their reality, impossible to happen to them, and for that reason they did not use any form of prevention.

In this sense, it is necessary to develop public health programs specifically for the elderly that may provide information related to HIV/AIDS and the existence of the risk of infection. This could contribute to the adoption of preventive measures.<sup>1</sup>

As educators, nurses should seek to guide the HIV-positive elderly on how to live with HIV/AIDS, sensitizing them for self-care and adherence to treatment regimen, promoting health and well-being of these patients.<sup>17</sup> Educational strategies can promote change in the behavior of this population with respect to more understanding about HIV/AIDS. For this to occur, activities to be developed must adapt their information and must use a language that is easily understood by the elderly.<sup>8</sup>

### HIV INFECTION

The results of this category showed that most of the interviewed elderly people got infected through sexual relationships, a fact that confirms the thinking of other authors<sup>14</sup>:

*Well, I used to have sex without condom, I never used [...] I made it with a woman there (Elderly 7).*

*I do not know who was the partner, I do not remember [...] but I think that was the last one (Elderly 8).*

Although there are increasing numbers of cases of HIV/AIDS among the elderly, these people rarely consider themselves to be at the risk of contracting the disease.<sup>17</sup> Studies have shown that elderly men do not believe to be vulnerable to infection because they link the disease to homosexuals and drug users. As for the female, they do not believe to be at risk of contamination because they have a fixed partner.<sup>7-8</sup>

The interviewed elders reported that because they have a stable relationship and trust their partners, they did not use condoms, thinking that they were not at risk of HIV infection:

*My husband was a person that, I was the first and the only for him, and he was also for me, so when the disease appeared I did not believe (Elderly 3).*

*I never used, I think only the first time of us really [...] because I trusted him. But he was very womanizer and that's why this happened (Elderly 4).*

*I had a partner and he had too, but I did not know [...] I never used condoms with him (Elderly 5).*

In this research, it became clear that using condom with her partner is not a habit among older women, and this represents a risky behavior. Some women reported never having used a condom, because they believe that the monogamous relationship was one of the most effective preventive methods. The limited perception of risk and the lack of condom use among older women are related to, among other factors, the sense of protection, because they have a fixed partner, a stable relationship and no longer have the possibility of becoming pregnant because they are in climacteric or post-menopausal phase.<sup>2</sup>

HIV emerged on the world scene in the 80s. Since then, more emphasis on the use of condoms as a way to prevent infection in the sexual intercourse has been given. Thus, older people may find it difficult to understand the need for using condoms, as when they began their sexual activities, this practice was not common. This makes specific guidance for this population necessary.<sup>17</sup> Aware of this need, the Ministry of Health launched educational campaigns aimed at encouraging condom use by the elderly. This shows that the government considers the elderly as human beings able to fully exercise their sexuality.<sup>3</sup>

Some older people demonstrated to have doubts about the forms of contagion and they did not know to inform exactly how they acquired HIV. Among the cases that have been reported, one in particular called attention because the elderly attributed the contagion to the application of a vaccine for the flu:

*[...] I'm sure I contracted HIV within the health center because I went there to take a vaccine for flu, I felt a lot of pain and I was with a little mark that never disappeared. The woman directly applied the vaccine and I suspect that it was there that I contracted it (Elderly 2).*

Think of other forms of transmission rather than the sexual via, or affirm not be sure about from who and when they acquired the disease appears to be a mechanism used to divert the importance of unprotected sex as a transmission mechanism.<sup>8</sup>

## DISCOVERY OF THE DIAGNOSIS

The discovery of HIV-positive status happened, for most of the elderly, due to the emergence of some signs and symptoms or a health problem:

*I began to dry out, change color, I was with boredom, so a doctor asked the exam, I did the exam and the result was that I had this. I went to the doctor and asked for the test for HIV, as it was the only one I had not yet made (Elderly 2).*

*I had been hospitalized because of thrombosis and I also had this thing of nosebleed, I did lots of tests, and it was then that the doctor asked this (Elderly 3).*

*I began to feel a pang, I went to the hospital and they said I had pneumonia [...] because of too many hospitalizations, then they ended up doing the test, that's when the doctor told me what I had (Elderly 8).*

The participants emphasized that the anti-HIV test is related, in some cases, to symptoms or prior exposure to vulnerabilities. In general, healthcare professionals tend not to require such test for the elderly because they do not take into account that the elderly has an active sex life.<sup>1</sup>

It was observed that one elderly person requested the examination. When a person tries to do the HIV test, he/she may be finding himself/herself under risk of acquiring or transmitting the virus, mainly because of having experienced a situation that represented a probable way of contamination.<sup>18</sup>

As a result, HIV infection is often diagnosed in the elderly only after extensive investigation and by exclusion of other diseases, what delays diagnosis and treatment.<sup>6</sup>

*After three months in hospital I was told that I had HIV, until then I did not know (Elderly 5).*

*Due to a lot of admissions, I ended up doing the test, then the doctor told me, I did not believe it... but it took about two years to find out HIV (Elderly 9).*

The reports show how much time consuming may be to find the diagnosis, taking months or even years to confirm HIV infection. Some health professionals still believe that AIDS is a disease that is far from the elderly population and they end up not considering the possibility of contamination. In this context, there is a high number of health professionals who do not have the habit of requesting the HIV test for older people because most of them often associate the symptoms to some disease typical of advanced age, delaying, thus, the identification of the infection.<sup>19</sup>

## REACTION OF THE ELDERLY BEFORE THE DIAGNOSIS

For the elderly, receiving HIV-positive diagnosis may cause, at first, great impact, awakening reactions and destabilizing feelings and defense mechanisms to cope with the fears and anxieties:

*Yes, I was very psychologically distressed [...] I started to feel things that even a day before the result of the ex-*

*amination I had not felt, all psychological, I think there's no one who can understand, it is difficult (Elderly 1).*

Initially, the reaction of the person who discovers to be infected can be shock, from which the person gradually recovers, slowly regaining the sense.<sup>8</sup> The impact of diagnosis and living with HIV are sometimes loaded with such intense feelings that the wish to die and desire to commit suicide are present:

*I was willing to kill myself [...] I thought I'd pick up a gun and shoot myself in the head, on the day I was on duty. Then I thought better, I regained sense and gave up (Elderly 6).*

The desire of suicide may be understood as an escape from a problem that is causing intense suffering, associated with frustration, hopelessness and abandonment. Such conflicts are ambivalent between survival and a situation of unbearable stress, a narrowing of perceived options and a need to escape that is usually associated with other feelings such as worthlessness and helplessness.<sup>20</sup>

The process of denial before the result was also present in this study. This process is characterized as a period experienced by several people who discover the diagnosis, whether in early stages of the disease or immediately after the detection of the infection:

*I came with my daughter and she said, mom, think that you won't have anything, because there is no chance, right? And I said, no chance, how I would have been contaminated? what way? When I saw the result I did not believe it, I asked them to do another one, because it could only be wrong (Elderly 3).*

*With six months to go to the reservation, I did that damn test and the doctor called me and said [...]: "look, you're with a disease there, huh ...". And I said [...] you can tell me, doctor, you do not have to hide anything from me. [...] Then when he told me what it was I freaked out and said: Excuse me, Doctor, what did you say? I am a person who go out of here straight to my house, married, well qualified, I always had the best functions, bonuses [...]. And he said, "Yeah, but the test is there" (Elderly 6).*

Rationalization was also present as an important mechanism of defense to assist in restructuring, enabling the elderly to process and re-organize their new condition of life.

*I have to accept it, right? What can we do? I will not lose my life because of this, I will face it (Elderly 4).*

This report is in line with what the authors characterize as a form of temporary protection which is soon replaced by a partial acceptance.<sup>8</sup>

## SEROPOSITIVITY AND THE DAILY LIFE OF THE ELDERLY

In this category are addressed questions regarding the participation of the family nucleus before the discovery of the diagnosis, the changes in the lives of older people and the difficulties that are met, with prejudice as one of the largest difficulties. According to reports, it was observed that some older people had more family support, featuring a facilitating factor that helped them in coping with the disease:

*With my family, all was ok, they have their lives and I have mine, but everyone accepts me and, in the beginning, they supported me very much (Elderly 2).*

*I called all the family and said "look, I'm with this". Everyone got shocked when I told the news, but they had to know I had the disease to be able to help me, and it has always been so, they never denied me anything (Elderly 7).*

It is worth noting that the family also suffers when finds out the diagnosis of a serious illness in his family, because they experience the consequences of that fact. The support of the family is extremely important for HIV-positive elderly, as it significantly contributes to face the reality, softening the suffering.<sup>20</sup>

Most of interviewed elders said to keep the results confidential, with only one confidant, one nuclear member of the family. The main reason to keep this information confidential is the fear of prejudice and discriminatory attitudes that may be openly, or indirectly, present:

*The way they treat the person, using this term, aid-etic (Elderly 2).*

*I avoid even go outside, afraid of people's reactions, since I found out in 2003, I only to go out when I go to the doctor really, because they speak, look, you know? (Elderly 5).*

*Only those who are the closest to me are the ones who know, those who are distant have prejudice (Elderly 3).*

*My son and I are the only ones who know, it is better to keep this with us (Elderly 7).*

The prejudice surrounding the disease causes HIV-positive older people to fear that their diagnosis may become pub-

lic, known by other people, leading them to hide the diagnosis. This fact predisposes the appearance of some feelings, such as anxiety, persecution and doubt, and may become the source of stress to the daily life of the elderly.<sup>8</sup> Another difficulty experienced by people with HIV has to do with exclusion from the labor market:

*Few are those who know, I do not comment on this because I work with refrigeration, then they may not want me to work in the refrigerator. Of course, if I have a bruise on my finger, I won't go to the refrigerator, you know? But it is complicated (Elderly 1).*

*I used to work, but now they sent me away, because the boss found out I had HIV [...] his son came and told me [...], "Look, it won't be possible to keep you, because my father found out that you have HIV". I was quiet, I was neutral, I did not say anything, until I put it in court because of that, I'm waiting the result now (Elderly 4).*

Some of the older people who had fixed employment said they maintain the positive result for HIV in secrecy, fearing that the disclosure of this subject would cause embarrassment and problems at work, and likely, the dismissal. One participant commented that she was fired because her condition was discovered by her boss. The loss of jobs caused by the diagnosis is presented as a decisive aspect in the life of an elderly person with HIV. The resume of participation in the labor market involves many difficulties. There is the fear that the same may happen again and that the next attempt end up to be frustrating, added to the fact that with advancing age, the chances of getting a job tend to decrease.<sup>21</sup>

## SEXUAL LIFE AND PREVENTION AFTER THE DISCOVERY OF HIV INFECTION

In this category, two types of behaviors of older people regarding sexual activity exist: maintain or abandon this practice. After the discovery of HIV, some people kept their active sexual life, but adopted preventive practices in order not to contaminate others and not contract other viruses:

*Yeah, now I'm more careful, right? I can't get another virus. But, it's all ok regarding this (Elderly 1).*

*My sex life is active, but always with a condom. Otherwise, women will go around saying [...] look, I got it from you [...] and I can say that's not true, because without a condom, nothing happens. Since I left my ex-wife, I never had sex again without condom. I have sex 20 times*

*a month, I get the condom in the health center, and that's it (Elderly 2).*

Sexual practice in old age is little discussed and sometimes even ignored by health professionals and society in general, as if the elderly did not have the capacity to enjoy sex. Health professionals do not have the habit, in their consultations, to ask about aspects related to sexuality and sexual practices of older people.<sup>22</sup> Knowledge of health professionals on attitudes and practices of elderly in relation to the experience of their sexuality is important, as this enables them to perform interventions in order to reduce the chance of this portion of the population to contract or transmit the HIV.<sup>17</sup>

It was observed in the statements that there was refusal by some elderly to continue their active sex life due to fear of disseminating the infection or because they believe that sex was no longer important in their lives, because of their age:

*Now I cannot get another virus, so it is better to stop (Elderly 1).*

*[...] besides this disease, we have to stop due to the age also (Elderly 3).*

*No, after that we never do it again, I never had anyone again, I don't even feel like it, it seems that I will pass on to others (Elderly 4).*

*It's been a long time since I last made it, since I was told that I had got it (Elderly 8).*

*Oh, when I was married we lived together, and at that time we did not use to have much sex, like this, penetration, this things, so I said to her, I'm tired of living with you this way, we'll get a divorce, but now that'm separated, I do not wanna know, don't anything, and more, I'm very old after all(Elderly 6).*

Studies have shown that it is common for people with positive serology for HIV in older age to present feelings of restriction in their affective-sexual relationship due to fear of transmitting the disease and also of getting infected by a new virus. With this, many end up suppressing sexual practice from their lives.<sup>28</sup>

Thus, it is evident that more effort should be made to change the situation of HIV/AIDS in the country, because the rates are increasing among the elderly portion of the population. Additionally to conducting educational programs for this audience, more interaction among health professionals is necessary, so that they may understand the process of HIV/AIDS expansion in this age group, recognizing the elderly as active

human beings and therefore, likely to be exposed to risk. By doing so, actions for development of preventive measures will be accomplished. In addition, professionals must provide assistance to older people with HIV according to their uniqueness.

It should be noted that this study had limitations, including the fact that it was developed into one unique reality. Furthermore, the information on the time that participants have been living with HIV was not included, and this may prevent the understanding if the participants acquired the virus while they were adults or after becoming elderly. However, the present findings are relevant to the health context. They present reports of a group of elderly people living with HIV and were discussed with a comprehensive literature, with studies performed in different contexts. Thus, it was possible to compare the data found here to data from literature. Similar conditions to those seen in more comprehensive researches, conducted in other settings and with higher number of participants, were observed. Thus, the study contributes to the expansion of knowledge about the theme, especially in the context of gerontology. Furthermore, the research can be useful for nurses who are working with elderly with HIV/AIDS, to prevent infection and aid the infected elderly to live virus and/or with the disease after the diagnosis.

## FINAL CONSIDERATIONS

It was possible to learn how the elderly with HIV were infected, how they found out the diagnosis and now they live with the virus. Most participants in this study became infected through unprotected sex and had limited knowledge about the virus and about the disease before they discovered they were HIV-positive. After learning the diagnosis, they acquired knowledge about ways of infection and prevention.

Regarding the positive diagnosis for HIV and related reactions to it, it was identified that older people felt an impact when they received the news. In this moment, a tangle of feelings happened, with emotional breakdown, leading them to despair, confusion and, initially, discontentment. The study also revealed that prejudice and discrimination remain present and make these people to meet a lot of barriers, thus hindering the process of restructuring and maintenance of life in their various roles.

The information from this study are relevant, as the population of elderly people has increased considerably, requiring that health professionals be alert to anything that might affect the health of these people, as is the case of HIV infection.

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