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FAMILY DYNAMICS OF WOMEN WITH HUMAN T-LYMPHOTROPIC VIRUS

DINÂMICA FAMILIAR DE MULHERES COM VÍRUS LINFOTRÓPICO T HUMANO

LA DINÁMICA FAMILIAR DE LAS MUJERES CON EL VIRUS LINFOTRÓPICO T HUMANO

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Objective: to describe the family dynamics of women seropositive for the Human T-Lymphotropic Virus. Method: case study with consultation of medical records and interviews during home visits, between October and December of 2017, in Recôncavo Baiano, Brazil. The analysis of the data subsidized the construction of the genogram and ecomap. Results: the family composition is depicted in the genogram and the ecomap represented the different relations; the bonds of affection were identified. The data analyzed converge on the discovery of their seropositivity during prenatal care; the establishment of superficial relations with the Testing and Counseling Center; the contagion of a sexually transmitted disease; questions of interpersonal relations with the family; the denial of seropositivity and the omission regarding care actions. Conclusion: the study on the family dynamics of women seropositive for the Human T-Lymphotropic Virus showed that their care potential requires renovation.

Descriptors: Human T-Lymphotropic Virus 1. Human T-Lymphotropic Virus 2. Family Relations. Nursing care. HTLV Virus.

Objetivo: descrever a dinâmica familiar de mulheres soropositivas para o Vírus Linfotrópico T Humano. Método: estudo de caso com consulta de prontuários e entrevista semiestruturada domiciliar, entre outubro e dezembro de 2017, no Recôncavo baiano, Brasil. A análise dos dados subsidiou a construção do genograma e ecomapa. Resultados: a composição familiar está retratada no genograma e o ecomapa representou as diferentes relações; identificados os laços de afetividade. Os dados analisados convergem sobre a descoberta da soropositividade durante o pré-natal; o estabelecimento de relações superficiais com o Centro de Testagem e Aconselhamento; o contágio de uma patologia sexualmente transmissível; questões de relações interpessoais com a família; a negação da soropositividade e a

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omissão quanto às ações de cuidado. Conclusão: o estudo sobre a dinâmica familiar de mulheres soropositivas para o Vírus Linfotrópico T Humano mostrou que seus potenciais de cuidado precisam ser renovados.

Descritores: Vírus 1 Linfotrópico T Humano. Vírus 2 Linfotrópico T Humano. Relações Familiares. Cuidado de Enfermagem. Vírus HTLV.

Objetivo: describir la dinámica de la familia de las mujeres seropositivas para el Virus Linfotrópico T Humano. Método: un estudio de caso con la consulta de los registros médicos y entrevistas durante las visitas domiciliarias, entre octubre y diciembre de 2017, en el Recôncavo Baiano, Brasil. El análisis de los datos subsidió la construcción del genograma y ecomapa. Resultados: la composición familiar está representada en el genograma y el ecomapa representó las distintas relaciones; identificados los lazos de afecto. Los datos analizados convergen en el descubrimiento de su seropositividad durante el control prenatal; el establecimiento de relaciones superficiales con el Centro de Asesoría y Pruebas; el contagio de una enfermedad de transmisión sexual; las cuestiones de relaciones interpersonales con la familia; la negación de la seropositividad y la omisión en relación con acciones de cuidado. Conclusión: el estudio de la dinámica de la familia de las mujeres seropositivas para el Virus Linfotrópico T Humano demostró que su potencial de atención necesita ser renovado.

Descriptores: Virus Linfotrópico T Tipo 1 Humano. Virus Linfotrópico T Tipo 2 Humano. Relaciones Familiares. Atención de Enfermería. Virus HTLV.

Introduction

The infection by Human T-Lymphotropic Virus (HTLV) is present in all Brazilian regions, but is little discussed, which leads to the unawareness of health professionals and of a large part of the population. There is need to understand the way in which the HTLV modifies the life of its seropositive, to enable the access to the trajectory of demand, production and administration of the care with these people and their families and, consequently, provide data for the elaboration of public policies.

The estimates reveal that 15 through 20 million people in the world are infected by the most prevalent subtypes, HTLV-I and/or HTLV-II, but most of these people are asymptomatic. The genetic and immunological factors are the main responsible for the development of associated diseases. In Brazil, the infection by HTLV constitutes a public health problem, without the implementation of appropriate coping strategies. Studies of prevalence in specific groups confirm the presence of the HTLV throughout the country, with lower prevalence in the North and South extremes and higher in the Southeast and Northeast, pointing to higher rates for the state of Bahia[1], with a problem/disease of compulsory notification, given the growing number of cases.

The HTLV is classified as a sexually transmitted disease. Consequently, its forms of transmission are similar to other diseases in this group, including the human immunodeficiency virus (HIV)[2]. People with positive serology maintains a silent network of transmission through blood, sexual and vertical routes. Serological methods for diagnosis of the infection can be classified into two categories: screening tests (immunoenzymatic tests - ELISA) and the confirmation tests (Westenblot or immunoblot)[3].

The problem of living with the HTLV is vast and complex, because it interferes with the daily life of people seropositive for the virus, causing profound changes[2]. This problem is based on the evidence that people find different ways to solve health problems, with the choice for certain treatment influenced by the sociocultural context.

The concept of vulnerability, in addition to including individual and social causes, also encompasses the biological aspects due to the peculiarity of the female genital organ, different from the male one. The vaginal mucosa presents a larger area of exposure to semen than the penis to vaginal fluid, that is, the amount of viruses that can be transmitted from men to women is higher than in the opposite way.

This biological factor, added to unprotected relations due to the difficult negotiation with the partner and his promiscuous behavior, further

increases the chances of this woman be infected by HTLV.

The importance of discussing the context of vulnerability, when related to gender relations, is crucial to understand that the decision about reproduction and contraception is shared responsibility between a man and a woman, that is, both must maintain a dialog in which there is a joint decision on the prevention[4].

The use of the tools in health enables the identification of weaknesses, vulnerabilities, prevalent pathologies, features of the monitored family, in addition to exposing, in particular, the identification of the causes of the distance of the care offered by the health service. This detection is important to restore the confidence of the user and reestablish the bond[5].

The family weaves networks involving people and close relations that will ensure sustainability and support to accomplish the own care, as well as the range of conditions and inputs necessary to accomplish it. The employment of the genogram and ecomap, as explaining and analyzing tools of this experience, makes the family organization visible and intelligible for the care, as well as the search undertaken by the services and health professionals, the answers obtained and their effectiveness[6].

Within this perspective, this study aims to describe the family dynamics of women seropositive for HTLV.

Method

Exploratory, descriptive case study, with qualitative nature, carried out with three women seropositive for HTLV registered at the Testing and Counseling Center (CTA) in a municipality in the state of Bahia in the year 2017.

This study emphasizes the way women seropositive for HTLV seek care and treatment, considering the influence of sociocultural and individual factors, which pervade and determine these choices. To understand the events outlined for such search, two tools that subsidize health care were used: the genogram and the ecomap.

The inclusion criteria were: female patients; diagnosis confirmation of positive serology for HTLV I and/or II; aged 18 years or more; registered at the Testing and Counseling Center-Specialized Care Service in Recôncavo Baiano, Brazil. The exclusion criterion was those women enrolled in the CTA not residing in the city locus of the study, due to the unavailability to perform the interview in the residence of the user.

The data collection was performed through consultation of 21 records of seropositive women monitored by the CTA, and implementation of household interviews. The data collected subsidized the construction of the Genogram and Ecomap. The records provided information regarding registration, clinical history, address and clinical evolution of the user. The survey of the Family Health Unit (FHU) was then performed. Subsequently, there were the contact and the presentation of the research to FHU nurses, followed by the schedule and home visit accompanied by Community Health Agents (CHA) of each participant and the household interview, maintaining the principle of privacy and anonymity.

After the interviews in the residence of these women, the genogram and the ecomap were built, with the participation of three women who, after contact, met the criteria and agreed to participate in the research. The families were designated by names of flowers (Violet, Daisy and Jasmin), once they are associated with beauty, virtue, hope and delicacy. Women and their families were identified in this text with the initials of their names.

The genogram is a diagram that outlines the structure and the family history and provides information about the various roles of its members and the different generations. It offers a basis for discussion and analysis of family interactions. The ecomap is the diagram of the relations between the family and the community to assist in the evaluation of the available support and its use by the family[7].

During the construction of the genogram and the family ecomap, the participants reported, by means of pre-structured conversation, information on their origin, particularities of their family members, significant events of their life and family health conditions.

The family ecomap connected the circumstances of the environment, showing the bond between family members and other social systems. It also showed the relationship between family and community: community services (nursery, school, health care unit, etc.); social groups (churches, association of residents, groups of activities, etc.); significant relationships (neighbors, friends, family, etc.); work; others (forms of leisure).

After analysis of the content of empirical data collected in the semi-structured interviews, recorded and fully transcribed, the figures corresponding to the genogram and ecomap were elaborated.

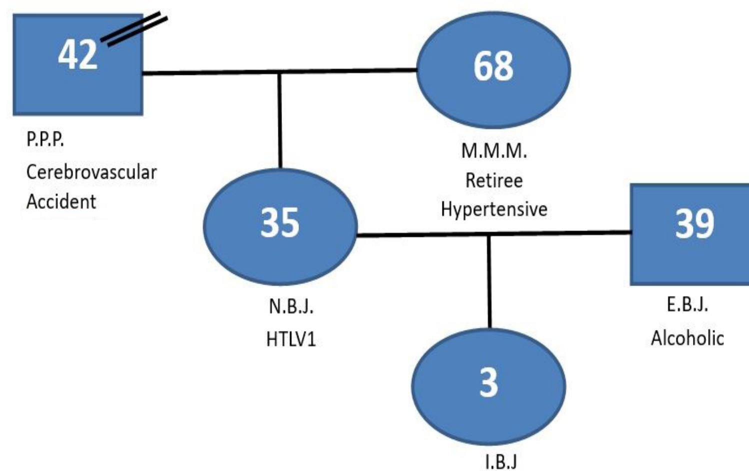
In the figure built for the family ecomap, the genogram with family members and their ages is presented in the center of the circle and the outer circles show the contacts of the family with the community.

The study was approved by the Research Ethics Committee under Opinion n. 2.888.086 and complied with the ethical principles of research and adopted the recommendations of Resolution n. 510 of 7 April 2016, of the National Health Council.

Results

The family composition is depicted in the genogram. The male sex was represented by squares and females, by circles. Each family member was identified by the initials of the first name (below the geometric shapes), age (within the geometric shapes) and occupation (below the initials of the names). The two parallel lines placed at the upper right of a form indicate death and the cause of death is reported below the initials of the name.

Figure 1 – Genogram of Violet Family



Source: Created by the authors.

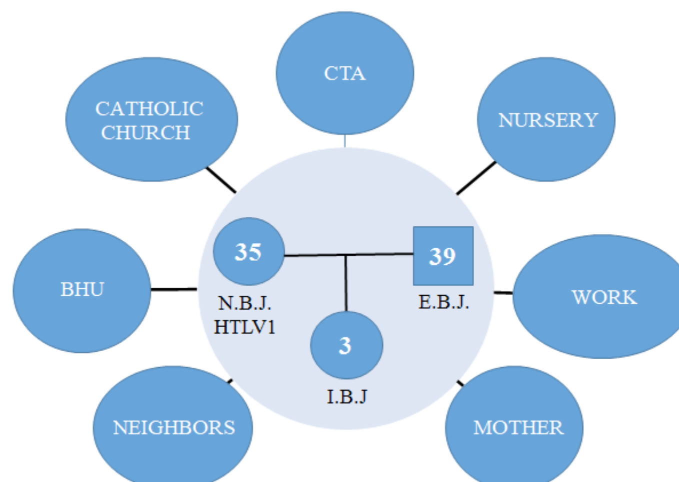
The Violet family is composed by N.B.J., 35 years old, self-reported *parda*, has been seropositive for HTLV for 3 years, works as general cleaner in a nursery, with employment of municipal government worker, family income of approximately three minimum wages, married since 2006 with E.B.J., 39 years, alcoholic, own-account driver. They had a daughter, I.B.J., with three years. N.B.J. received the diagnosis at the FHU, during low-risk pre-natal period. She lives in the peripheral neighborhood without sanitation. N.B.J. has no siblings and is only daughter. She misses the presence of her father, who died when she was a child. She reports that his death does not make her feel sad, because she was only a child. She considers herself the family's provider, with the aid of her husband, and also the family's caregiver. She considers her mother a heroin and herself the family's black sheep, due to her strong personality, which sometimes generate conflicts within the family core. She reports that most remarkable moment

in her life was the birth of her daughter. The family structure is complemented by patterns of interaction with the mother and the husband: by the couple (conjugal subsystem); between the couple and the mother, which refers to presence and confidentiality of all moments of her life, including the diagnosis; and with the daughter (fraternal subsystem).

In the narrative, during the interview, N.B.J. expressed doubts and fears about the seropositivity, especially when she received the diagnosis. She talks about the expectation for the arrival of the daughter, about the transformations that went through pregnancy, positive expectations, frustrated by the discovery of a sexually transmitted disease, incurable, with repercussions in interpersonal relations with the spouse/partner and with the child. The process of not breastfeeding affected negatively her life as a mother, and she mentions she missed such bond.

In the Violet Family's Ecomap (Figure 2), the absence of interaction with other members of the family is justified especially by geographic remoteness and lack of connection with the nuclear family. Nevertheless, it does not represent a poor family relation to N.B.J., since she characterizes her family bonds with definitions of non-confrontational union. She considers having strong bonds with the Catholic Church, with the FHU, where she received the diagnosis of seropositivity, with neighbors, her mother, the child-educating school where she works and the nursery where her daughter studies. She considers the CTA a health-seeking and maintenance space, but does not feel dependent on the referred health service, because she does not consider the diagnosis of seropositivity for HTLV as something that interferes in her life. She assures not having health limitations that may be associated with the diagnosis. In the Ecomap, the lines represent the different relations and seek to give prominence to the quality of the bonds between the patient and the family members, with a focus on those who experience the chronic condition of the HTLV.

Figure 2 – Ecomap of Violet Family



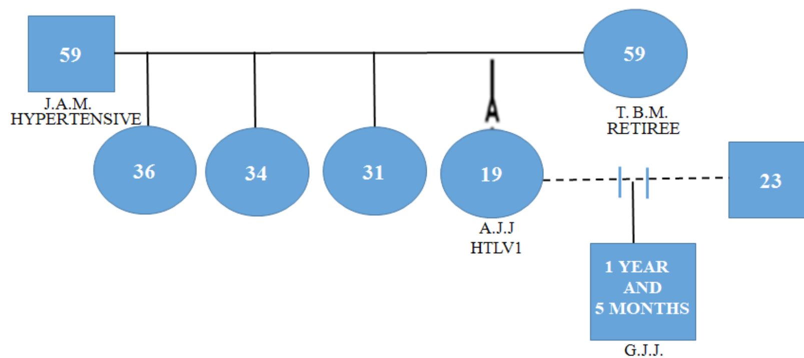
Source: Created by the authors.

The Daisy Family is composed of A.J.J., 19 years old, self-reported black, and her son G.J.J. of 1 year and 3 months, result of a fleeting dating with a 23-year-old man. A.J.J. sees her son as a positive moment, as well as having discovered the seropositivity one year before, while attending the prenatal care in the basic healthcare network. She has no income, lives in a peripheral neighborhood, without sanitation, with the son and her adoptive parents - J.A.M., hypertensive,

government worker in a municipal institution, and T.B.M., retired by physical limitations - responsible for the financial maintenance of the house. She has three adopted sisters who do not reside in the family home. A.J.J., until two years of age, lived with her biological mother, being subsequently adopted. She has no contact with the biological family or relationship of affectivity. She reports approximation and affective and respectful interaction with the adoptive family, considered by her as a united and cozy family core. She considers her mother and her adopted little sister as heroines in her life, as well as considers herself the black sheep of the family, for having gotten pregnant young and discovered the seropositivity in this context. She has no bond with the child's father, defines the relationship as a dating whose the only good outcome was the child, her treasure. She cannot report whether her ex-partner underwent the test to confirm seropositivity for HTLV, but believes to have been infected by her biological mother during breastfeeding, of whom she also has no information whether she underwent the serologic testing. The family genogram was built until the first generation, because she was adopted, not enabling mechanisms for investigating the child-mother transmission.

Since it is a Sexually Transmitted Infection, A.J.J. showed, in the interview, fear, uncertainty, doubt and questions about how she acquired the HTLV and the form of treatment to maintain her quality of life. Since this virus is still unknown for a large part of the population, the anguish and uncertainty increase by the non-recognition of studies and investments that put the person diagnosed as a priority for the care.

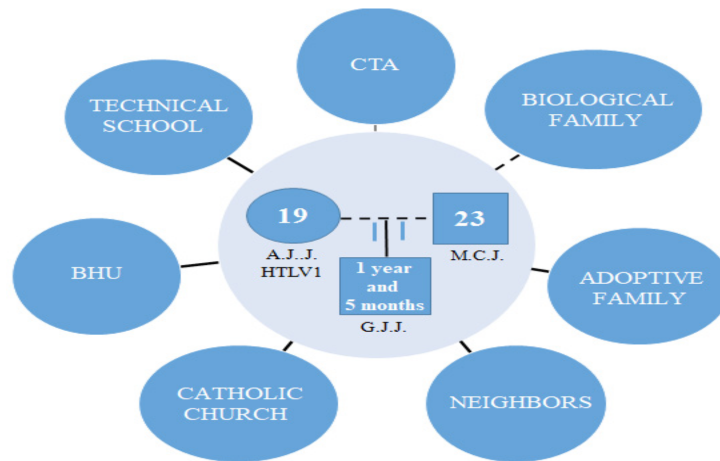
Figure 3 – Genogram of Daisy Family



Source: Created by the authors.

The the Daisy Family's Ecomap (Figure 4) shows that the discovery of positivity, associated with the undesired pregnancy, still young, directly interfered in the daily interaction with the adoptive family, who at first could not deal with the situation. She has weak bonds with the biological family and with the CTA, seen as the place where she managed to acquire the milk for her child, without recognizing it as a health space. She has a strong bond with the adoptive family, BHU, catholic church, technical school (where she attends a Nursing technician course), CTA and neighbors.

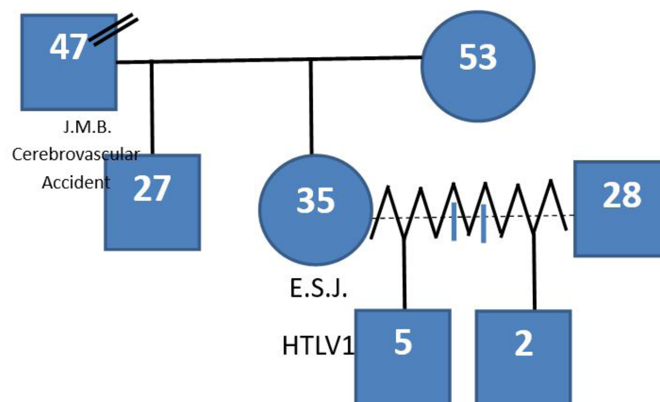
Figure 4 – Ecomap of Daisy Family



Source: Created by the authors.

Figure 5 describes the Jasmin Family, composed of E.S.J., her mother, a brother and two daughters. She self-reports black, with 35 years, two daughters (one with five and another with two years), own-account worker, resident in the peripheral neighborhood, without pavement and basic sanitation; her mother, 53 years old, is a housekeeper; her 27-year-old brother, a trader. She claims having a conflicting relationship with her daughters' father, who works as a waiter, is 28 years old, even if not living with him. E.S.J. has a strong bond with her brother and mother, with whom she lives. She considers her brother the family's provider and caregiver. She considers her mother as the heroine of her life. She calls herself as the black sheep of the family, since she is still partially dependent on her brother and mother, who assist in the care and raising her two daughters. The most important moment in her life was the birth of her daughters, who represent the strength to carve her way. The discovery of seropositivity happened about a year before, when performed the pre-natal of her second daughter at the BHU. In her speech, E.S.J. says that, when receiving the diagnosis from the BHU team, she was unaware of the repercussions that the virus would bring to her life and even confused the diagnosis with HIV, due to the similarity between the acronyms, receiving, in subsequent visits performed by the nursing team, guidelines about this diagnosis.

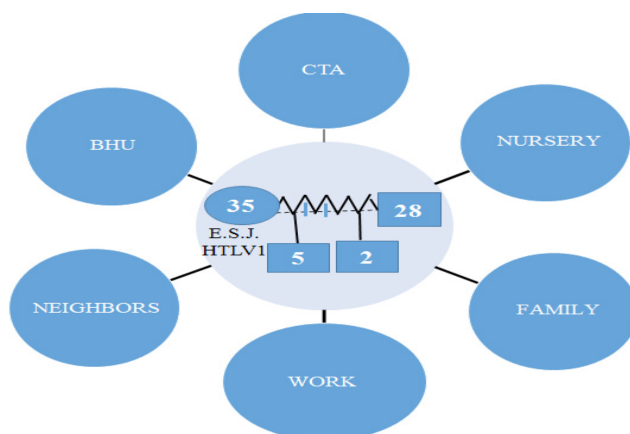
Figure 5 – Genogram of Jasmin Family



Source: Created by the authors.

The Jasmin Family's Ecomap represents the seropositivity as something that does not interfere in her life, once she has no impairment in her health condition associated with the virus. E.S.J. sees herself as a healthy person without limitations associated with seropositivity. Her family core includes her mother, brother and her two daughters as a basis, foundation and support to face the obstacles of life. She considers the CTA the space where she acquires the milk formula for her daughter and reports having no need to carry out health monitoring, once she is considers herself as healthy. She has strong bonds with the BHU, family, neighbors and the place where she works as a waitress and the nursery where her daughters study.

Figure 6 – Ecomap of Jasmin Family



Source: Created by the authors.

Discussion

The designation "chronic condition" covers persistent non-transmitted and transmitted health problems, long-term disorders, continuous physical and structural deficiencies. Its common characteristic is the persistence in time, and may persist for several years or decades, with the need for constant care[2].

The graphical representations of the genogram and ecomap have been very useful because they favor addressing the experience of the chronic condition, which requires continued management of people, family, services and health professionals.

The healthcare networks, made by individuals and their families, support the experience of illness and care. In the case of this study, this network was illustrated by the genogram and ecomap. The first represents the consanguineous family of kinship and/or affection, describing its composition, quality of its bonds and caregiving cores. The ecomap highlights the resources available and accessed by the family, the quality of its bonds and relationships.

> Such networks undergo changes over time and space, which gives them their own configurations and dynamism. However, it is not an easy task to give visibility to the changes suffered by families and their networks throughout the illness experience, given the limitation of the graphical representation in the flat drawing format, as it has been used until then, for showing only a "snapshot of the family moment"[7:657].

The analysis of the empirical material revealed strong points of convergence between the study participants: the discovery of seropositivity occurred in the pre-natal at the BHU; weak relations with the CTA, not seen as a health-seeking and maintenance space, only frequented in moments of serological testing, diagnostic confirmation and support for the distribution of milk formula; the self-definition of "black sheep", for having acquired a sexually transmitted disease and for issues of interpersonal relations with the family. Furthermore, since they were asymptomatic, the participants neglected their condition of seropositivity and omitted care actions, by believing they will not develop HTLV-associated pathologies.

The negligence of care arises from the fact of the HTLV be a virus with long latency

period, evolving asymptomatically for the largest number of the seropositive, and for not having high profile of morbidity and mortality[1]. Once HTLV is diagnosed, the first question is the need to make visible in which subjects the virus is present, because the whole range of consequences for their lives is not limited to the health problem itself, but also to their own life styles and projects, given the epidemiological characteristics of transmission of the virus and its possibilities for treatment and prevention of infection[8].

On the other hand, demonstrating the individual vulnerability, the seropositive women do not have accurate information about the diagnosis. The health professionals have reduced scientific information on the virus, because it is usually difficult to access. The insecurity and fear are feelings present when providing clarifications about the infection to the seropositive[2].

In relation to HTLV-I, the problem of identifying infected persons in the family network is crucial. In these cases, there is need to consider secondary prevention actions regarding the risk of vertical transmission of the virus (especially during breastfeeding). Such issues are challenges that public policies should carefully face[8].

The identification/screening of all pregnant women during the pre-natal is important, as well as the development of actions to prevent the vertical transmission, sich as guidelines on not breastfeeding and availability of infant formula to feed the child. However, there is still no specific policy for these mothers and children[2].

The healthcare networks are composed of genogram and ecomap drawings, which, in turn, were employed as tools for sorting and analysis, to discuss the experience of illness and family care. In this way, these drawings show how people weave care supporting networks, which can include services, through bonds established with their professionals. These can give some support to the care performed primarily by the family itself [9].

In this sense, the considerations about the current mode of assistance offered to people affected by the HTLV become relevant, aswell as the place of the patient as a subject, the implications related to life issues, among other aspects.

The knowledge of the trajectory while seeking health services allows for analyzing the facilities, difficulties and limitations of individuals and families in relation to access to each care level and what has been offered, as well as the answers provided by health services to the problems of these people[9].

Thus, it requires the development of practices, skills acquired over the processes of involvement of actors in their specific contexts. Therefore, the hesitations, uncertainties, the perplexity, the formations and dissolutions of interactive bonds are elements that should be duly taken into account[10].

The trajectories undertaken by individuals and their families represent the construction of the drawing that shows which services were accessed and the sequence of searches, which shows the number of institutions and their care levels to meet the health demands, giving an idea of the scope and integrality. The patient's perception about the symptom and its meaning is part of their experience of illness, and the therapeutic itinerary is the social construction of the disease; thus, the meaning of the disease emerges in this process[11].

Moreover, the specialized service needs a structural and care reorganization, which considers the possibility of welcoming, formation of educational groups and the participation of other professionals involved in monitoring[12] of women with HTLV, in order to offer a qualified attention.

In this study, the genogram and ecomap also allowed for better visualization of established exchanges, of the logic implemented by individuals and their families in health care, besides having facilitated the understanding of the multiple implications of illness for life, as evidenced in the care cores in the genogram. This allows for visualizing the household composition and, in it, the relations established between its members, the care cores. Nevertheless, it does not allow for highlighting the other participants

of this care at different times and with different ways to provide care. The ecomap is used as a way of giving visibility to such networks[6].

The study revealed that, when diagnoses of seropositivity for HTLV are confirmed, the visualization of family cores for possible identification of vertical transmission does not happen by the professional nurse who monitors the pregnant woman in the Family Health Strategy, hampering possible interventions from the multiprofessional team.

Due to the area of coverage, building a genogram and ecomap for all the families of the FHS coverage area would be difficult for health professionals. Nonetheless, the construction of a genogram and ecomap in FHS sees the patient as a unique being, connected to a family core, an environment and a community where they live. Very often, the relationships repeat over generations and are closely linked to the health-disease process[13].

In the case of this study, the application of the genogram allowed for visualizing the process of becoming ill, facilitating a better understanding of the meaning of the HTLV for the participating women. Carefully evaluating the genogram and the ecomap allowed for providing a historical look of how the family faces(ed) the critical events.

The increased number of cases of infected women results from factors ranging from problems of the health system, with poor access, lack of guidelines by the professionals from the area, up to the socioeconomic, political and cultural determinants, which influence education and knowledge of this part of the population regarding the programs and preventive methods of Sexually Transmitted Infections (STIS). The increasing process of women infected by the HTLV also brings problems to the health of their partners and their children. In the latter, by vertical transmission during pregnancy and breastfeeding.

There stands out the possibility of health professionals, in particular the nurse, employing the genogram and the ecomap, letting them know how families are organized for the care, resources and networks that support and sustain them in the experience of chronic illness. In this way, they can view when their care potential require renovation.

Some limitations in the research development are the difficult access to the women's residences, due to the number of participants included in the study, and the lack of previous researches on the topic.

Conclusion

The study revealed that the participants had strong points of convergence: discovery of seropositivity in prenatal care at the FHU; established weak relations with the CTA, not seen as a health-seeking and maintenance space; self-reported as "black sheep of the family", due to having acquired a sexually transmitted disease; questions of interpersonal relationships with the family; denial of the condition of seropositivity; and omission regarding care actions.

The construction and the description of the family dynamics based on the genogram and ecomap enabled the exposure on the way of life of women with HTLV. Theu also evidenced that health services and professionals should be sensitized about the chronic illness by HTLV. The nursing must be inserted in the production of knowledge on this theme, since it represents an area that includes, in its object, the care. The nurses' knowledge about this problem can redirect or renew the preventive actions focused on Public Health and assistance.

There stands out the possibility of health professionals, in particular the nurse, employing the genogram and the ecomap, letting them know how families are organized for the care, resources and networks that support and sustain them in the experience of chronic illness

Collaborations:

1 – conception, design, analysis and interpretation of data: Elaine de Araújo Dias and Maria da Conceição Costa Rivemales;

2 – writing of the article and relevant critical review of the intellectual content: Elaine de Araújo Dias, Maria da Conceição Costa Rivemales, Lavinya Lima Cordeiro Oliveira, Daniela Carneiro Sampaio, Claudia Feio de Maia Lima and George Mariane Soares;

3 – final approval of the version to be published: Elaine de Araújo Dias and Maria da Conceição Costa Rivemales.

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