

Understanding the family member of a child affected by Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome, from the perspective of complexity*

Compreendendo o ser familiar de criança com Vírus da Imunodeficiência Humana/ Síndrome da Imunodeficiência Adquirida pelo olhar da complexidade

Comprendiendo al familiar de un niño afectado por el Virus de la Inmunodeficiencia Humana/ Síndrome de la Inmunodeficiencia Adquirida, bajo la perspectiva de la complejidad

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ABSTRACT

Objective: To understand the significance of a family member of a child with the Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome from the perspective of complexity. **Methods:** This is a qualitative and exploratory study; data were collected between July and November 2008, through interviews with five family members of children with AIDS, who were sheltered in an institution of support. **Results:** The meaning of statements were coded and analyzed, resulting in three categories: experiencing the order, disorder and the organization of a family member of a child with AIDS; dialoguing with the assurance and doubt of disclosing the diagnosis to a child with AIDS; and, facing the limits of unknown, decadence, live and death. **Conclusion:** It was revealed that being a family member and caring for a child with AIDS, is a complex process that requires an understanding of multiple factors (such as: biological, psychological, social, spiritual, and the ones related to the disease and the patient) and the attitude of caring focused on the human being - a unique being, complex and multidimensional. **Keywords:** Child; AIDS serodiagnosis; Acquired immunodeficiency syndrome; Family relations; Nursing research

RESUMO

Objetivo: Compreender o significado do ser familiar de uma criança com Vírus da Imunodeficiência Humana/ Síndrome da Imunodeficiência Adquirida na perspectiva do pensamento complexo. **Métodos:** Estudo qualitativo, exploratório; os dados foram coletados, entre julho e novembro de 2008, por meio de uma entrevista com cinco familiares de crianças com AIDS, abrigadas em uma instituição de apoio. **Resultados:** O significado das falas codificadas e analisadas resultou em três categorias: Vivenciando a ordem, desordem e organização do ser familiar de uma criança com AIDS; Dialogando com as certezas e incertezas do revelar ou não o diagnóstico à criança com AIDS; e Confrontando-se com os limites do acaso, o caso, viver e morrer. **Conclusão:** Evidenciou-se que ser familiar e cuidar de uma criança com AIDS, constitui-se em um processo complexo que requer, além de uma compreensão biopsicossócio-espiritual dos fatores que envolvem a doença e o ser doente, uma atitude de cuidado focada no ser humano como um ser único, complexo e multidimensional. **Descritores:** Criança; Sorodiagnóstico da AIDS; Síndrome da imunodeficiência adquirida; Relações familiares; Pesquisa em enfermagem

RESUMEN

Objetivo: Comprender el significado del familiar de un niño portador del Virus de la Inmunodeficiencia Humana/Síndrome de la Inmunodeficiencia Adquirida bajo la perspectiva del pensamiento complejo. **Métodos:** Se trata de estudio cualitativo y exploratorio; los datos fueron recolectados entre julio y noviembre de 2008, por medio de entrevistas con cinco familiares de niños con SIDA, que estaban acogidos en una institución de apoyo. **Resultados:** El significado de las declaraciones codificadas y analizadas resultó en tres categorías: experimentando el orden, desorden y la organización del familiar de un niño con SIDA; dialogando con la seguridad y la duda de revelar el diagnóstico al niño con SIDA; y, enfrentando los límites del acaso, o caso, vivir y morir. **Conclusión:** Se evidenció que ser familiar y cuidar de un niño con SIDA, constituye un proceso complejo que requiere, además de una comprensión que abarca varios factores (biológicos, psicológicos, sociales, espirituales, relacionados con la enfermedad y con el enfermo) de una actitud sobre el cuidado que debe ser enfocada en el ser humano - un ser único, complejo y multidimensional. **Descriptores:** Niño; serodiagnóstico del SIDA; Síndrome de inmunodeficiencia adquirida; Relaciones familiares; Investigación en enfermería

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INTRODUCTION

The Acquired Immunodeficiency Syndrome (AIDS) is a disease that manifests after the infection by the Human Immunodeficiency Virus (HIV). The HIV destroys CD4+ lymphocytes responsible for defending the body, leaving individuals vulnerable to other infections and opportunistic diseases that appear in situations when the immune system is vulnerable and more susceptible to new diseases⁽¹⁻²⁾.

The HIV/AIDS epidemic constitutes a challenge to global public health because it brings new questions and implications for the process of healthy living, especially in the case of children and their families. It is important to be concerned with: outpatient treatment, performing of various examinations, use of antiretroviral treatment, complexity of adherence to treatment and, situations of prejudice and discrimination, among others⁽³⁾.

The HIV has already caused about 25 million deaths since the epidemic began and had led to profound demographic, economic and social changes in most affected countries. It is estimated that each day approximately 6,800 people are infected by the HIV and 5,700 die as a consequence of the disease worldwide⁽⁴⁾.

Young people aged 15-24 represent 45% of new infections and the number of young people living with HIV increased globally from 1.6 million in 2001 to 2 million in 2007. It is believed that 370,000 children under 15 years became infected with HIV in 2007 and about 15 million have lost one or both parents due to AIDS⁽⁴⁾.

Thus, the HIV/AIDS significantly changed the healthy living of children and adolescents who, in most cases, experienced successive losses, besides being exposed to social and racial prejudice, among others, when they were not protected by the educational processes of personal and family self-organization. It is necessary that the child with HIV/AIDS be understood and recognized as having potentialities and limitations, as any other child. That is to say, he must be supported way beyond the disease. Within this context, the care for this child needs to go beyond the apparent limitations, and must consider the uniqueness of each child⁽⁵⁾.

Parents are primarily responsible for the emotional structure of the child, since they play a role as facilitators in the process of growth and development. Thus, the environmental conditions of micro and macro systems, in which the child lives, are fundamental to obtain a satisfactory performance of different dimensions and assimilation of adverse advents, as is the case of the disease⁽²⁾.

We must consider that the experience of HIV/AIDS is not confined only to the child with the disease. This reality, therefore, affects and jeopardizes lives of all those men and women who are part of daily contact with the disease, represented in this case by family members and caregivers who are closer in network of relationships and interactions.

Being family member of a child with HIV/AIDS from the perspective of complexity

Being a significant caregiver family member of a child with HIV/AIDS makes arise feelings of doubt, revolt and disorder. Also they must face uncertainty and fear in order to facilitate and safeguard the live and welfare of the child⁽⁶⁻⁷⁾. Therefore, living with the child and the various coping strategies - used specially by parents who feel guilty for the child's disease - made family members utilize a wide variety of arguments to justify their pain, turmoil and loss⁽⁸⁻⁹⁾.

To understand this process, in most cases troubled, the approach of complexity enables to generate a thinking process that connects and integrates the certainties and uncertainties, the unknown and the decline, the order and the disorder of being a family member of a child with HIV/AIDS. Replaces causality and unidimensionality by a circular thinking that will address the multidimensional and unicity of interactive possibilities among all those involved in caring.

The complex thinking⁽¹⁰⁻¹¹⁾ portrays, therefore, a social process, professional, personal, dynamic and gradual that takes time, attitude, behavior and tireless effort in finding new forms of action and interaction, namely the pursuit of the new with basis in the reality. The complexity approach lets assume rationally the inseparability of contradictory notions, such as order, disorder and organization, to conceive a complex phenomenon as being a multidimensional one. That is to say, it unites two notions that tend to exclude mutually but are inseparable in the same reality.

Unlike traditional simplified thinking, complexity asks for thinking about concepts without taken them as completed, about breaking closed concepts, about reestablishing articulations between what was separated, in an attempt of understanding the multidimensionality, the uniqueness with the location and temporality, never forgetting the integrative wholes⁽¹²⁾.

Under this approach, the logic of the complexity means to transcend linear explanations and to develop a kind of moving explanation that should be circular. An explanation that goes from the parts to the whole and then from the whole to the parts, trying to understand (giving meaning) the phenomenon under study in a contextualized way.

To understand the human being, as a singular and multidimensional entity, it's necessary, in this perspective, to recognize the complex nature and process of living with cultural and social differences. It is necessary to consider the dialogue between different disciplines, in order to understand and embrace life's adversities as events that incentive the creation of a new organization.

Dealing with contradictions and uncertainties of HIV/AIDS represents, therefore, a challenge to family

members directly involved with the disease who need, besides living with social adversities, find strategies to alleviate physical pain and deal with the plurality of factors involving the prejudice of HIV/AIDS.

Living with the disease on the condition of family member, implies to accommodate the different feelings, implies to capacitate the human being, whether child or family member, to obtain a healthy living condition, regardless of where they are. It means caring and establishing a relationship of care based on the assigned meaning that each individual has about their existence.

Facing the disease that has been growing tremendously in many different social contexts, indiscriminately affecting adults, children and youngsters, especially in anticipation of possible new insights, more humanized and committed to the human being – entity unique and complex - bearer of a stigmatizing chronic illness, this study aimed to understand the meaning of being a family member of a child with HIV/AIDS under the perspective of the complex thought.

METHODS

This is a qualitative and exploratory research. Data were collected from individual interviews with five family members of children with HIV/AIDS, housed in a non-governmental support institution, which shelters children with HIV/AIDS (from zero to 12 years), being many of them orphaned of father and mother. The institution, located in the central region of the state *Rio Grande do Sul*, in addition to housing children with HIV/AIDS, maintains an educational program for families/caregivers involved in the process, in order to guide them about the disease and its social impact.

For being interviewed, were selected family members - who participated regularly in support workshops with different themes, which occur weekly on the institution premises - that accepted the invitation by signing the consent form. Among the family members, were three mothers, an uncle and a grandfather, who were responsible for the children. The questions that guided the interviews were: What it means for you to be a family member of a child with HIV/AIDS? Did you struggle to reveal the diagnosis to the child? What changed in your daily life? What were the doubts and uncertainties about the disease?

Data were collected between July and November 2008. The interviews were recorded and fully transcribed to facilitate the process of coding and analysis, as well as maintaining the reliability of the information. Further, the data were coded and organized based on the assumptions of content analysis⁽¹³⁾, which has three stages: 1) identification of main respondents' perceptions, 2) identification of categories based on analysis of participants' statement, and 3) interpretation of categories

based on the researchers' experiences on the subject.

Therefore, it was attempted to use the perspective of complexity, which requires from the researcher, besides flexibility and creativity, the sensitivity of understanding social phenomena in a broad and complex view. Also he has to consider specifically every one of the subjects.

The contributions of the participants were identified throughout the text with the initial letter "F" (family-member), followed by a number that corresponds to the statement, which was done to maintain the participants anonymity.

The research project was approved by the Ethics Research of the University *Centro Universitario Franciscano* – UNIFRA, under the number 247/08.

RESULTS

The meaning of the coded statements resulted in three categories: 1) living the order, disorder and organization of being a family member of a child with HIV/AIDS; 2) establishing a dialogue with certainties and uncertainties of revealing, whether or not, the diagnosis to children with HIV/AIDS; and 3) confrontation with the limits of unknown, decline, living and dying - categories that will be discussed in sequence by utilizing the perspective of complexity.

Experiencing the order, disorder and organization of being a family member of a child with HIV/Aids

The meaning or feeling of "being a family member of a child with HIV/AIDS", is experienced and lived in a unique and complex form by the members who take part in the process of "being sick" or are in touch with the disease itself.

Initially, the process is accompanied by a disorder, disorganization and uncertainty. The confrontation with the unknown, accompanied by feelings of guilt and helplessness, made more difficult the feeling of facing a phenomenon, apparently unacceptable and misunderstood by the family and society in general. We present now the statements that reflect the meaning of being and being part, at the same time, of a contradictory and self-organized process.

It is hard, right? Once I discovered I was full of doubts. I did not know how to deal ... no longer understood anything. (F1) it is quite difficult! And we have to live with this problem by making his life our life ... really, it's hard, sooner or later, she may become better or worse. No one knows what can happen. (F3) She could not have this disease, she could have treated the child, but not hide it, pretended to be a mother after she came into this world, there are many people who hide the disease, they should not hide it. (F4)

In the same way that the disorder, disorganization, chaos and uncertainty appear after they learned of the

disease, also a new organization or reorganization was processed gradually in the network of relationships and interactions, as is stated in the following statement:

At first, I did not accept it, there was a period of rejection of the treatment, but after talking with some friends and doctors, I thought ... What am I doing with my daughter? We will all die one day. But if we know how to care is better... Today, I am aware of that fact in my head ... I'm trying to organize myself again".(F2)

Dialoguing with certainties and uncertainties of revealing, whether or not, the diagnosis to children with HIV/AIDS

The disclosure of diagnosis to a child affected by the HIV/AIDS, is a process that in most cases occurs in secretive and indirect way – in an environment of certainties and uncertainties with the doubt of disclosing the illness to the child – of revealing the truth or omit the facts. In some cases, this process goes on for many years or until the moment when the child itself realizes that is entangled with medicines and medical care and that he is different or the disease made of him something special in the process of living with others. To ease the shock of revealing the HIV/AIDS diagnosis, some family members refer to other diseases or seek to mediate the situation with the help of qualified professionals.

To most family members, the diagnosis disclosure to the child it was a real drama. They used the most diverse arguments to avoid or prolong the confrontation with the very vulnerable situation, as shown on the following arguments:

I went to the doctor to know what to do. The first time she was hospitalized - was for not taking the medication. She said to the doctor that she did, but she didn't! If you force her, she starts to cry and then she doesn't do it in any way ... spits, vomits. Hence, I scold, scream, fight her and she starts bleeding from the nose and presents hysteric behavior. Then, the only solution was to explain the situation, how it happened ... I talked to her, explained from the beginning to the end how she became ill, but to little avail. (F4)

First, I said that she had a tumor on her head; that she had to take medicine otherwise the situation will become dangerous and she could die. It was useless; when the time arrived she didn't take it. Then, I talked to the doctor, who called the psychologist to talk to her - she agreed (to take the medicine). But soon she rejected the medication again. She was hospitalized and stayed for about a month. But it was useless. She liked, she loved to stay in the hospital. It was not possible. Then I told her..... I was very young and without knowing I transmitted the disease to you, I told the name (HIV), you have this disease and have to take the medication if you don't do it, it will be useless, you have to take it if you want to have a family, have children, have a husband, for helping care for your sister – I explained and she agreed.(F5)

In this regard, the disclosure of HIV/AIDS diagnosis

means to reveal the person being and living with a fatal disease, or socially disapproved. Under these conditions, to be a patient means losing the social identity and the possibility of establishing social interactions. In other words, this means that if the patient is already affected by an unexpected or scary event, he will be even more troubled by feelings of loss, of social isolation and by the challenge of uncertainty for which was not prepared.

Confronted with the limits of the unknown: decline, live and death.

The feelings of death and dying become part of everyday life, for the family and for the child affected by the disease. For some, the disease is perceived as the death of existential aspects, for others it is a gradual process of dying by the lack of understanding or by the breaking of links in the network of relationships and social interactions.

This latter finding is related more specifically to those who cannot process the limits of the unknown, decline, live and death, that is to say, the consideration of the disease under a new perspective of being and living in society. Thus, the death is expressed by the lack of faith, lack of dynamism, and will to win and fight for a new existential organization.

To die ... there are several kind of deaths.... But if we know how to deal with the disease is much better. Today I can better deal with the situation. (F2)

And they told me that she had HIV but, they didn't give me any explanation of how I should deal with it and stuff like that, I wondered if she had HIV she would die, right?

I was just thinking only about death ... nothing more had sense. We are faced with the limits. (F3)

I felt very scared, sure. I always thought she would die. You know ... we die slowly together with her. The suffering is very big. (F4)

You know, it's very hard, very painful! You learn to live with the reality, but I am very afraid of death. Sometimes it seems that everything is over, but you need to continue living and adapting. (F5)

The results show that despite the growing number of studies and surveys, the HIV/AIDS is still characterized as a stigmatizing illness, focusing on the disease as an end in itself. The individual - the human being – carrier of the disease is perceived as passive object, and therefore unable to reorganizing themselves in society.

Based on the analyzed data, we propose - as researchers and above all as nurses, therefore defenders of life and well-being and better social relations - to discuss the data from the perspective of the complex thinking. It is believed, that is possible to go beyond the hegemonic reductionism, which focuses on the disease and not on the human being - that is to say in the individual as a unique one, complex and multidimensional, capable of continuously organize themselves or capable of emancipation, to obtain a good life in society.

DISCUSSION

By the perspective of complexity, the human being cannot be understood merely as a biological being. His nature is preeminently unique and multidimensional. He is a member of a society, with identity and defined role. That is to say, there is something else than the "singularity or difference from individual to individual - is the fact that each individual is a subject", regardless of their color, gender, economic condition or the disease from which suffers⁽¹⁴⁾.

The complex thinking is antagonistic and complementary, contradictory and ambivalent; singular and multiple, singular and diverse, local and global, supported by a interdependent fabric, interactive and inter-retroactive⁽¹⁰⁻¹¹⁾. Therefore, reinforces the creativity and the possibilities of organization, that is, allows new adaptive ways of living and experiencing the process of health and disease.

By the perspective of complexity, nothing is lost, but everything is possible and able to be reorganized. Thus, understanding the meaning of "being a family member of a child with HIV/AIDS" means accepting the process of order-disorder-organization that integrates the human life. It means understanding the human being as a complex being capable of continuous self-organization or capable of emancipate itself, whether in health or disease, either in joy or pain or in the losses suffered every day. It means to cope and live with the order and disorder, to negotiate with uncertainties, to bargain with adversities and to create strategies capable of establishing a new organization, by means of reinforcing the child resources. It means to conceive and to integrate the singleness of the multiple and the multiplicity of the one⁽¹⁵⁾.

To think on the person/family, carrier of a chronic disease, which appears in front of the health care professional (nursing) in a vulnerable condition, requires levels of understanding, acceptance and bonds of inter-subjective trust, sustained in the light of concepts that holds the multiple variables that took part in the health-illness process.

It can be seen by the perspective of simplification, that the starting point, with few exceptions, is still today the disease or the understanding of disease, as an end in itself and not the BEING that shelters the disease. The uniqueness of the HUMAN BEING is eventually reduced to the understanding of a passive being (patient) or as someone incapable of interacting and adapting to the prevailing social standards.

Establishing an authentic relationship or a bond of trust with the person/family-member, carrier of a stigmatizing chronic illness - means to receive and dialogue with the inter-subjective individuality and to allow that individualities involved could express their uniqueness and historicity without fear, resentment or doubts⁽¹⁶⁾.

By understanding the identity and complexity of the

HUMAN BEING, bearer of a chronic illness, and at the same time, bearer of autonomy or freedom of choice, the family-member or the professional care giver achieves a position of differentiation, of reciprocity, of exchange and complementarity and stands not any more in a hierarchical position - holder of truths and ways of being and of caring the others.

To live with and take care of human beings – a BEING complete and complex, it's necessary that this human being must be understood as a singular being, autonomous, different and sociable. When understood in that way, the professional will be expanding its field of view and giving meaning to interactions which can be more intense according to the capacity of differentiation and potentiation of inter-subjective possibilities⁽¹⁷⁾.

Under the logic of complex thinking, relations and interactions are magnified and potentiated by the understanding of the sense of the human being as unique and autonomous, independent of having a disease, of being dependent on care, of being in a bed at the hospital or at home. Therefore, what matters is the wide perspective and the dynamics of the interactive process that takes place between different entities which in a situation of disease, are intensified by the unique experiences of pain, discomfort, uncertainty, social and family isolation, among others.

The aspiration to complexity has a tendency to multidimensional knowledge due to the respect of the various dimensions⁽¹⁰⁾ that the process of carrying a chronic disease requires. Involves experiencing the uniqueness and adversity, the understanding and the misunderstanding, the real and the utopia, the life and the death.

We must therefore weave a web based on different knowledge and walk toward a complex experience/support, full and flexible and thus a paradigm of humanization, in which the human being is apprehended not by the disease that carries, but by the uniqueness that transforms him in a special and unique BEING in the universe⁽¹⁷⁾.

In summary, the complex thinking proposes a new awareness of the world, of the society, of the individual, of the healthy being, of living with a disease or be a carrier of a stigmatizing disease. It proposes in place of an individual that holds the assurance of absolute certainties, an individual that thinks, that questions and that mobilizes new organizational processes. Rather than propose a point of equilibrium for the emerging problems, among them HIV/AIDS, proposes to find a new well based foothold for multidimensional perspective.

The ability to self-organization, knowledge, responsibility and active participation of all citizens constitutes an increasingly important tool for human emancipation. Then, it is necessary to think over and deconstruct the historical and cultural barriers of models based on the hegemonic and traditional care Cartesian thinking that are closed to

self-discovery and discovery of the other.

The nurse, by being recognized as an element of coordination and integration of different knowledge, especially because she is closer and is capable of establishing links more effective, can also be an important interlocutor as protagonist of health practices that value the human dimension related to the disease, the network of relationships and interactions related to vertical actions and the uniqueness of the BEING related to any action that may harm the human dignity.

CONCLUSIONS

This study was not aimed at presenting or stating absolute truths, which would be a new reductive conception. The study aimed to investigate, to question and to point out new perspectives on the disease or on the carrier of a stigmatizing disease, which is also a great challenge to family members, nurses, caregivers and society in general. Therefore, we must confront the HIV/AIDS not as an end in itself but as a possibility of a new individual, family and social organization that has as objective the emancipation of human beings.

Understanding the meaning of "being a family member of a child with HIV/AIDS", by the perspective of complexity implies to admit the feelings and daily experiences that underlie and are part of the everyday life

of all who belong to the relationships and interactions of the individual who carries the disease. It involves integrating and living with anxiety, uncertainty and pain of everyday death. Implies to experience of order, disorder and organization of being a family member of a child with HIV/AIDS. It means to engage in dialoguing with the certainties and uncertainties of whether revealing or not the diagnosis to the child with HIV/AIDS and to confront the limits of the unknown, decadence, live and death.

The duty of nursing is to promote the best way of living and the best way of dying, valuing the human life, the best moments of living in adverse conditions, accepting and living with the order/disorder, certainty/uncertainty, unknown/decadence, in the multiple relationships of being in constant reorganization of caring actions for the BEING in its completeness.

Finally, it is important that researchers, professionals and scholars in general, consider the human being, carrier of a disease or family member caregiver, as the protagonist and author of his history - as someone exposed to all sorts of conflicts, uncertainties, instabilities and chaos, but able to continually organize and reorganize - based on the multiple interactions and on the family and social relationships. This study allows stating, in short, that the HIV/AIDS does not necessarily constitute an end in itself, but it is a possibility of understanding a new existential dynamics, motivated by integration of the uniqueness and the multi-dimensionality.

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