The HIV/AIDS vulnerability framework applied to families: a reflection

O REFERENCIAL DE VULNERABILIDADE AO HIV/AIDS APLICADO ÀS FAMÍLIAS: UM EXERCÍCIO REFLEXIVO

EL REFERENCIAL DE VULNERABILIDAD AL HIV/AIDS APLICADO A LAS FAMILIAS: UN EJERCICIO REFLEXIVO

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ABSTRACT

The objective of this study is to reflect upon the vulnerabilities experienced by the families dealing with the Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/Aids), and is based on the pertinent literature. To do this, we attempted to propose consideration related to the plurality of families in contemporaneity, and present the understandings and development regarding the vulnerability framework to the Aids epidemics. Finally, the study presents a description of the reflections made about the vulnerabilities to HIV and/or falling ill with Aids to which the families are exposed to in their personal, social and pragmatic levels. In conclusion, it is emphasized that knowing these specific vulnerabilities experienced by the families is essential in order to guide and develop the health care actions.

DESCRIPTORS

Family
Acquired Immunodeficiency Syndrome
Vulnerability
HIV

RESUMO

Objetiva-se realizar um exercício reflexivo acerca das vulnerabilidades que se apresentam no contexto das famílias que convivem com o Vírus da Imunodeficiência Humana/Síndrome da Imunodeficiência Adquirida (HIV/Aids), tendo como fundamentação a literatura pertinente. Para tanto, buscou-se tecer considerações em relação à pluralidade das famílias na contemporaneidade, bem como apresentar as compreensões e desdobramentos do referencial de vulnerabilidade à epidemia da Aids. Por fim, foram descritas aproximações e reflexões referentes às vulnerabilidades à infecção pelo HIV e/ou adoecimento por Aids a que estão expostas as famílias, em seus planos individual, social e programático. Conclui-se a enorme importância de se conhecer estas vulnerabilidades específicas vivenciadas pelas famílias, a fim de que se possa nortear e desenvolver as ações de cuidado em saúde.

DESCRITORES

Família
Síndrome da Imunodeficiência Adquirida
Vulnerabilidade
HIV

RESUMEN

Se objetiva realizar un ejercicio reflexivo acerca de vulnerabilidades que se presentan en contexto de familias convivientes con el Virus de Inmunodeficiencia Humana / Síndrome de Inmunodeficiencia Adquirida (HIV/Aids), teniendo como fundamento la literatura pertinente. Para ello se buscó tejer consideraciones en relación a la pluralidad de las familias en la contemporaneidad, así como presentar las comprensiones y desdoblamientos del referencial de vulnerabilidad a la epidemia de Aids. Finalmente, se describieron aproximaciones y reflexiones referentes a las vulnerabilidades a la infección por HIV y/o padecimientos por Aids a los que están expuestas las familias, en planos individual, social y programático. Se concluye creyendo en la importancia de conocer tales vulnerabilidades específicas experimentadas por las familias, a fin de que se pueda orientar y desarrollar acciones de cuidado de la salud.

DESCRIPTORES

Familias
Síndrome de la Inmunodeficiencia Adquirida
Vulnerabilidad
VIH

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INTRODUCTION

Different fields have recently focused on the investigation of family contexts because many researchers[1-3] have found that is within the family that the production of health and disease occurs. The family is also responsible for actions that promote the health of and prevent diseases in its members and care for them. Health disciplines in particular have become interested in understanding the transformations, adaptations, and organizations that have occurred among families over time and their implications and challenges for care provided in health and disease.

In this context, it is worth noting the onset of a new disease in the beginning of the 1980s – AIDS – which, being incurable with no treatment available at the time affected male homosexual individuals, sex workers, intravenous drug users and individuals with hemophilia. Many families were then affected by the disease and experienced discrimination mainly given a lack of knowledge concerning forms of viral transmission, the small number of government initiatives to prevent and control the disease and a panic prevalent in society. However, with changes in the disease's epidemiological profile, demonstrated by the frequency with which heterosexual individuals, women and young individuals become infected by the disease, families were perceived to be vulnerable to HIV/AIDS.

It is therefore important to stress that families present vulnerabilities related to elements that compose the individual, social and programmatic planes[4-5]. Hence, this study aims to perform a reflexive exercise concerning the vulnerabilities present in the context of families living with AIDS.

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FAMILIES AND AIDS

The family is configured as an essential institution to human beings. It is through it that one comes into existence as a person, and has the possibility to develop potentialities and abilities and also recognize needs and limitations. The family core is responsible for welcoming, recognizing, protecting and caring for the human being, especially in the first years of life in which humans are fragile and vulnerable to phenomena that occur in the biological, psychological, educational, social and historical spheres.

Technological and scientific achievements associated with the process of globalization have contributed to transformations in the lives of people, in relations established between people and the social context, in the family cycle, in the routine of family organizations. The genesis of such transformations lies in a series of movements that occurred, mainly in the 20th century, and which have re-oriented health care delivery.

Standing out among these transformations are the population's increased life expectancy, gay and feminist movements, the emergence of contraceptive methods that resulted in the decoupling of the sexual act from its procreative function, and the development of legal statutes concerning children, adolescents and elderly individuals. These events had repercussions on society and have influenced transformations that occurred in the structure and organization of families.

There are currently attempts to re-signify how human groups are perceived and understood and, for that, one needs to go beyond a pre-established, delimitated and generalized concept of family. It is believed that instead of a concept defining it, the search should be for descriptions, since *it is possible to describe various structures or modalities families have assumed over time, but not define it or find some element common to all the forms human groups present themselves*[6].

One of the possible descriptions of a family is that it is a dynamic unit composed of individuals who, *a priori*, perceive themselves to be a group and have a continuous movement of (affective, economic and educational) relationships among the group's members, while these relate with other individuals and social institutions. These individuals live together for a time as an organization and structure in transformation, establishing common objectives and constructing a history of life[3,6].

One has to consider the multiplicity of manifestations assumed by families to identify and understand the various ways they present themselves. Families have to be considered in the plural (not as fixed entities) and present a variety of forms and social dynamicity[1-2]. *One cannot talk about the family, but of families, in order to contemplate the diversity of relationships that exist in society*[1].

Families represent units of experience and insights for its members and are significant in the health disease continuum since when a disease affects one member, the entire group is affected, which generates crises. Such crises *comprise the accumulation of experiences and a better definition of objectives*[6] and should be understood as reorganizing and readapting factors, essential to the development of human beings, families and societies.

It is through the understanding of this meaning of crisis that the experience of families should be analyzed. Issues such as dialogues about sex and sexuality are always necessary; separation and divorce are increasingly more frequent; homosexuality is no longer something the belongs to another's family; the establishment of relationships that precede marriage and living with the complexity of chronic diseases (such as AIDS) are some of the phenom-

ena that permeate families' lives and can be considered generators of crises.

Epidemiological data from the Ministry of Health[7] shows that 544,846 cases of AIDS were reported up to June 2009; 356,427 were male individuals and 188,396 were females; 14,184 were individuals younger than 13 years old, while 86.1% of these infections occurred due to vertical transmission (from mother to child) and 11,786 cases included adolescents (from 13 to 19 years of age). Such data however only partially portrays the reality, since care actions (promotion, prevention, care/treatment) should not only be devised for people who live with HIV/AIDS but also for those who live with these individuals, who are also affected by this epidemic as the remaining family members, friends, and neighbors, among others.

In the context of HIV/AIDS, grandparents, siblings, foster parents, and neighbors replace biological parents, which reinforces the need to go beyond the view of families formed by members who have consanguinity. Additionally, there are matters related to orphanhood to which children and adolescents are susceptible due to the chronic nature of the disease and the complex antiretroviral treatment among adults, which frequently culminates in a high number of deaths caused by AIDS[8]. As a result, children and adolescents end up living in shelters and form new family groups in these places.

Therefore, families can be considered entities that provide support, sources of affection, responsibility, availability and happiness[9], respecting the potentialities and limitations to help, inherent in each of them. Hence the importance of health care to be developed not only for the individual with AIDS, but also his/her family, is observed for two main reasons: first due to the fact the family will be, for the most part, responsible daily for helping, supporting and caring for its infected/sick members and second, because the family needs help and support and for that, it is essential to know its structure, resources and needs.

In accordance with other health fields, nursing has directed its focus to the care delivered to families, which has repercussions on the increase of scientific investigations and production of new (and separate) knowledge. *The growing body of knowledge available in the nursing literature means there is progress in this field of knowledge*, and the main contributions refer to three axes: the disease experience (its meanings and impact on daily family life), context of care (environments where care is provided and into which families are inserted) and interventions (strategies of interventions and actions with families experiencing the disease)[3].

Given these considerations we understand that *the vulnerability of families in a situation of disease can be defined as feeling threatened in its autonomy, under pressure due to the disease*[10]. Hence, given these perspectives and transformations present in the organization of families over time, combined with the complex issues inherent to HIV/AIDS, researchers and scholars have currently put effort into the analysis of implications and repercussions related to the concept of vulnerability when applied to several and different family groups.

Vulnerability: a reference in the context of AIDS

The concept of vulnerability has its origin in the field of international legal practice in the context of the Universal Declaration of Human Rights. Vulnerability is related to fragile groups or individuals, both in legal and political terms, in regard to the protection, promotion and guarantee of citizenship[4]. This framework has been used in several disciplines and has gained attention in studies, actions, and policies related to HIV/AIDS.

This concept emerges to fill gaps left by concepts of group and risk behavior, widely disseminated and associated with the initial period of HIV infection. It occurred, mainly because of the inadequacy of these concepts to enable understanding related to the future of the epidemic, to provide explanations beyond those of cause-and-effect, and in restricting actions and public policies with inefficacious responses to the rise of the epidemic[11].

It is important to consider that the concept of risk, inherited from the medical epidemiological field, does not by itself, enable a broader and contextualized view of AIDS. The conceptual use of risk holds the individual as the focus as well as the possible causal relations existent among conditions or pathological and non-pathological events[5,12]. It is focused on the physiopathological nature of the phenomena of illness, which somehow limited associations among individuals, the dynamic health-disease continuum and the collective.

Two issues that can be cited as examples and which were not encompassed by explanations of risk: what risk behavior, in relation to HIV, does a homemaker present, being in a stable relationship with a single and fixed partner? What risk behavior, in relation to HIV, does a fetus present in intrauterine life? Changes in AIDS reports were noticeable at the beginning of the 1990s and as in the case of these questions, responses were not obtained in relation to correlations of the concept of risk in the prevention or care delivery contexts.

It is in the search for explanations and actions to respond to such events that the construct of vulnerability emerges. Vulnerability is seen as

> a movement that considers the chance of people to be exposed to illness as a result of a set of, not only individual, but also collective and contextual aspects that lead one to be more susceptible[5]

to infection and/or illness. When using this reference one has to consider the flexibility existing between theory and practice, the individual and the collective, reflection and action. One has to be able to contextualize the individual or group that experiences situations of vulnerability and seek more effective and efficacious responses to fight the epidemic.

Vulnerability can be broken down into three basic analytical planes (individual, social and programmatic), which relate in a dynamic and interdependent manner[5]. Individual vulnerability refers to cognitive and behavioral aspects, that is, it includes behaviors that may increase the chances of an individual becoming ill or being infected, while these are associated with the level of awareness an individual has in relation to HIV/AIDS and to its power to transform such attitudes.

The social component of vulnerability is related to the access of individuals to information, health and educational institutions, conditions of well being and leisure, as well as *the power to influence political decisions, face cultural barriers and be free of violent coercion of any nature*[13]. Programmatic vulnerability refers to the level of the government commitment to the AIDS epidemic, preventive and educational actions, investing in and financing care and preventive actions, the existence of human and physical resources, program quality management and monitoring, continuity and sustainability of such actions, among others.

The concept of vulnerability has made it possible, as far as it is possible, to re-structure actions and government and non-government polices, helping to reduce and control HIV/AIDS cases. This framework has allowed one to rethink issues intrinsic to the epidemic, for instance, that the fact of being infected with HIV or becoming ill with AIDS is also projected beyond aspects inherent to an individual and his/her behavior. It is related to the social, cultural, economic, political, and religious contexts of an individual, among others. This framework

> enlarges the need to go beyond traditional behavioral approaches of individual strategies to prevent HIV, opening up new and promising perspectives to identify and intervene in the AIDS epidemic[14].

The concept of vulnerability

> seeks to establish a conceptual and practical synthesis of social, political-institutional and behavioral dimensions associated with different susceptibilities of individuals, population groups and even nations to HIV infection[15]

and worsening to AIDS. It has enabled a change in the focus of attention solely centered on the personal to contemplate the individual as one who influences and is influenced by the social sphere and being part of it, as it has also enabled restructuring and reorganizing preventive and educational health actions.

Finally, some difficulties and limitations are highlighted when vulnerability is used as a premise: 1) its use in the context of AIDS is recent and further studies are needed to acquire a better understanding of its benefits and limitations; 2) because it is a comprehensive and complex concept, which does not have a directional focus, it may seem more theoretical than practical and may hinder the choice and establishment of actions and policies; and 3) vulnerability is a multidimensional concept, is dynamic and presents different degrees; *people* are *not vulnerable; they 'become' vulnerable to something, at some level and in some form, at a certain point of time and space*[5].

Families' vulnerabilities to HIV/AIDS: a reflexive exercise

Families, as has already been pointed out, are going through a process of re-signification and individual and social restructuring, given the important changes occurring in family organization. Coupled with this, there are also cultural, political, social, religious and economic transformations that have occurred in society, especially when one analyzes the context of changes in the field of health such as those represented by scientific and technological advancements, increased life expectancy, chronic diseases (hypertension, diabetes mellitus, AIDS) and degenerative diseases (Alzheimer, Parkinson's).

Hence, in this project, a reflection-abstraction will be carried out, an exercise of approximation with interfaces of families in the three planes of vulnerability. This framework allows us to contemplate a unit in its individual and social aspects; the unit is seen beyond the strict concept of the word, but as a category, which can be the individual, a group of individuals, the family, or many families in a community or region, among others.

This is because

> born from gaps and silence that discourses of risk factors, groups and behavior left as indivisible assets of its contributions, this new discourse is constitutively fragmented, multiple, unsystematic, dissonant[15].

However, there is a dynamicity among the individual, the collective and the pragmatic aspects[5,16], while some aspects can be specific to a given plane or belong to all, and also can be included in one of them for the purpose of this reflection, not impeding its movement.

Aiming to make this reflexive exercise, we propose a specific example of family structure. For that, the following fictitious case will be considered: Mario, 47 years old, with a bachelor's degree, public employee is married to Maria, 42 years old, incomplete college education, and homemaker. The couple has two children: Marcia, 9 years old, attending primary school, 4th grade; Marico, 18 years old attending a pre-university course. The family is middle class and has good living conditions and leisure opportunities.

Looking at the individual plane of vulnerability, we perceive the family is composed of different individuals who occupy distinct internal positions, who have specific potentialities and limitations, and exert different levels of power over themselves and, therefore, present diverse relations within the context of HIV/AIDS, which represent their vulnerability to infection and their chances of defending themselves. They can be contextualized based on different levels of autonomy, power, awareness, and respective actions/attitudes developed by the individuals and, therefore, construct the vulnerability of the family as a unit, whether in relation to HIV prevention or to avoid becoming sick with AIDS.

Considering this fictitious family, let us take the adolescent son for instance. He may be seen as the most vulnerable to the HIV/AIDS epidemic because he does not have a fixed partner, however, the couple may be actually more vulnerable given the difficulty in negotiating the use of condoms. Additionally, due to gender issues, women in this family may be considered more vulnerable, or even the daughter given her limited awareness and understanding in relation to HIV. These are only some of the possibilities to make a reflexive exercise related to the individual vulnerability of this family group.

However, it is worth noting that the vulnerability of families to HIV/AIDS needs to be understood beyond the system that results from the association (sum) with different vulnerabilities to which its members are exposed. That is, the individual vulnerability of families is not only a result of the sum of the vulnerability of Individual 1 with that of Individuals 2 and 3. There is a dynamicity, complexity and movement that makes one more or less vulnerable depending on the situation, time, and circumstance under analysis. Hence, it is understood that

> the vulnerability of a group to HIV infection and illness is a result of a set of characteristics of political, economic and socio-cultural contexts that enlarge or dilute aspects related to the individual plane[17].

The social plane has a close relationship to the individual plan, because the vulnerability of individuals who compose the family is in constant movement and association with its social way of being and with the way of other individuals in the collective. However, the family should be perceived as a unit that belongs to the community, influencing it and being influenced by it at the same time. The family's social vulnerability is revealed by its greater or lesser access to educational and health systems, to its socio-economic conditions, to the greater or lesser power it exerts in its social surrounds, its (lack of) opportunities for leisure, freedom, and autonomy among others.

Still considering the fictitious family, we may consider the social vulnerability of this family in relation to health services, that is, whether they have access to consultations and exams when they need them, whether they have their needs noticed, whether there are HIV/AIDS prevention programs and educational health actions (directed to men, women, children, adolescents, and elderly individuals). Yet, we may consider the level of freedom this family has to discuss matters with other families and make decisions of common interest: its relation to religious institutions, the existence of projects at school aimed to create a family and social network and social support to cope with adverse situations, among other aspects.

One needs, when analyzing the family, to reflect on the interdependence between the individual and social planes, That is, it is composed of individuals who present specific vulnerabilities, and the relations existing among these will determine a greater or lesser degree of (individual) vulnerability of the family in relation to a phenomenon in a given time and space. Yet, this family group composes a community together with other family groups and the way each of them establish proximity to and relationships with society, the way they act and insert themselves at institutional levels, will help the identification of a greater or lesser (social) vulnerability of the family.

The programmatic plan of analysis considers government policies and programs related to families, how much they seek to mobilize these groups for the development of actions and attitudes aimed at individual and collective changes, how much they mobilize families to participate in an autonomous and responsible manner in their social surroundings and reflect on their vulnerability in relation to HIV/AIDS.

Programmatic vulnerability, in relation to this family, is related to the scope of health services, to the existence of government policies in the field of health prevention and promotion, to the availability of resources to continue these actions and extent of the local sustainability of projects in partnership with other institutions (schools, NGOs). Additionally, the scope of these actions at the diverse levels (federal, state, city and local) may be taken into account, the qualification of the team to develop projects, and health education programs related to each one of the family members in their different aspects (physical, cognitive, gender, age), among others.

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Hence, amid this exercise, one has to consider that the analysis and reflections presented here were based on a specific type of family group and what was discussed is intended only to enable an exercise and think about some aspects of the three vulnerability planes applied to the family. The reflections would be otherwise in a case where a family is composed of two individuals of the same gender – with or without children – and taken as example, or a family composed of more individuals in different age ranges and who presented other types of diseases and types of inclusion in society, for instance.

Therefore, in relation to the HIV/AIDS epidemic, one has to also consider issues such as orphanhood to which children and adolescents are exposed and their consequent institutionalization, the silence existing within families in relation to the diagnosis of their members, a family code of silence[9] in relation to the community, to the health services and school/day care. There are also increasingly common relationships between serodiscordant individuals, the existence (or absence) of preventive actions and policies, and family vulnerability to HIV/AIDS.

CONCLUSION

This paper indicates the need to use the theoretical-methodological framework of vulnerability not only in relation to individuals, but also in relation to families, to devise strategies that contemplate their plurality and social dynamicity. When other aspects that make different families more or less susceptible to HIV/AIDS are taken into account, as well as the fact that there is a dependency and complexity among planes, the construction of actions and policies encompassing subjective, inter-subjective and emotional aspects in addition to technical-scientific matters will be possible.

Therefore, it is necessary to consider and define the contexts of inter-subjectivity that generate vulnerabilities, as well as (jointly) consider and define inter-subjective contexts that favor the construction and implementation of responses to minimize these vulnerabilities to HIV/AIDS. It currently represents one of the newer, and important, even decisive challenges to the prevention and care delivery in the face of the HIV/AIDS epidemic. From this perspective, one will be able to understand the needs, limitations, and potentialities of each person and each family, as an individual and a collective, educational and preventive terms, to develop a humanistic care with problem-solving capacity to be delivered in the situations of health and disease.

Concluding, it is essential to realize that in addition to the vulnerability inherent to humans as unique and singular beings in their way of living and placing themselves in society, there is also a vulnerability (in its three planes) in which families are included. When this framework is considered from the perspective of family groups, one needs to take into account that families are composed of different individuals, who exert and also suffer from different influences and degrees of mobility in the social context. Vulnerability is also related to governmental, political and programmatic support and investment. The set of these situations experienced by families will determine whether they will be more or less vulnerable to the HIV/AIDS epidemic.

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