

HIV/AIDS: Coping Strategies Used by Families Living with Seropositive Children

HIV/AIDS: estratégias de enfrentamento em famílias convivendo com crianças soropositivas

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ABSTRACT

This is a descriptive study using a qualitative approach, which sought to describe the strategies developed by families of seropositive children to better deal with and adapt to HIV/AIDS. The sample was composed of twenty-two seropositive mothers, volunteers, registered at the ambulatory facility of a public hospital specialized in infectious diseases in Natal, Brazil. Following the signing of a free and informed consent form and approval by the institutional research ethics committee, the data were collected using a semi-structured interview. Content analysis was used, creating categories that emerged from the discourse itself. The prevalent strategies for coping with HIV/AIDS were: hope, religious belief, adhering to treatment, underestimating HIV, concealing the diagnosis and resignation. This study showed that despite the difficulties imposed by AIDS, the families developed strategies that enabled them to cope and better deal with this daily experience.

Keywords: AIDS, HIV, Family, Seropositive children, Coping strategies.

RESUMO

Trata-se de um estudo descritivo com abordagem qualitativa, no qual se buscou descrever as estratégias desenvolvidas por familiares de crianças soropositivas para melhor enfrentarem e se adaptarem ao HIV/AIDS. A amostra foi formada por vinte e duas mães soropositivas, voluntárias, inscritas no ambulatório do hospital público de referência para doenças infecciosas em Natal/RN. Após a assinatura de um termo de consentimento livre e esclarecido, e aprovação no CEP, os dados foram coletados com a aplicação de uma entrevista semi-estruturada. Para análise utilizou-se da técnica de análise de conteúdo, criando-se categorias que emergiram do próprio discurso. As categorias prevalentes em relação às formas de enfrentamento ao HIV/AIDS foram: esperança, crença religiosa, adesão ao tratamento, subestimação do HIV, ocultação do diagnóstico e resignação. Este estudo mostrou que apesar das dificuldades impostas pela AIDS, os familiares desenvolvem estratégias que possibilitam enfrentar o cotidiano e conviver melhor com essa experiência.

Palavras-Chaves: AIDS, HIV, Família, Crianças Soropositivas, Estratégias de enfrentamento.

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INTRODUCTION

The World Health Organization estimates that 40 million individuals are living with the Human Immunodeficiency Virus (HIV), classifying AIDS as the most important contemporary epidemic. Approximately half of all infected adults are women and 2,500,000 children are infected with the virus, with the situation particularly serious in Sub-Saharan African countries, where nearly 85% of these children live. In 2004, 604,000 new cases were recorded in children worldwide¹⁷. In Brazil, up to June of 2004, 9,122 confirmed cases of AIDS had been reported in individuals under 13 years of age¹⁰.

The diagnosis of HIV/AIDS represents an event of devastating personal impact and represents a landmark in the life of the families who are subjected to this disease. Another important point is the fact that AIDS imposes new habits, such as the undergoing of rigorous treatment, the ingestion of drugs, frequent medical visits and examinations, all of which are considered very painful both for the family and for the child¹³.

It is important to point out that for children, suffering from AIDS may represent an experience of intense psychic suffering, for, besides limiting their daily activities, such as playing, running and expressing themselves due to the physically debilitating consequences caused by opportunistic diseases, it may promote over-protective or discriminatory attitudes on the part of the persons around them, including those who provide care¹⁵.

Living daily with an HIV-carrying child causes the family to seek ways of adapting to the new situation and develop strategies for coping with the disease and the various situations that arise from it. It is in this context that the present study was developed, seeking to identify and analyze the strategies developed by the families of seropositive children for coping and adapting to living with HIV/AIDS and its treatment.

METHODOLOGY

This is a descriptive study using a qualitative approach, developed at the ambulatory facility of Giselda Trigueiro Hospital (GTH), specialized in AIDS treatment, in Natal, Brazil.

The population was composed of HIV-positive mothers,

with seropositive child/children, attended to at GTH. The sample was composed of 22 mothers who voluntarily accepted to participate in the interviews, obeying the following inclusion criteria: a) voluntary participation; b) signing of a free and informed consent form; c) medical diagnosis confirming HIV; d) be over 18 years of age; e) have at least one child with confirmed HIV diagnosis; f) be a user of the GTH ambulatory facility and having a medical consultation on the day of the interview.

The exclusion criteria were: a) not signing the free and informed consent form; b) mothers of children under 18 months of age with unconfirmed diagnosis and c) mothers who desired to abandon the study during the collection period.

The collection instrument used was a structured interview, previously assessed by expert researchers in the area and validated through a pilot study.

After authorization was granted by GTH management and approval obtained by the Research Ethics Committee at the Federal University of Rio Grande do Norte, the data collection process was initiated, covering the period between March and June of 2005.

The interviews were recorded, subsequently transcribed in their entirety and grouped into categories that emerged from the discourse itself, obeying content analysis according to Bardin¹. The quantitative data were grouped into frequency and percentage tables.

To ensure the anonymity of the participants, their names were substituted for names of flowers. In the same way that in nature a flower shelters and protects the seed that propagates the species, the behavior of the mothers in our study resembles that of flowers, since they are responsible for the care of their seropositive child.

RESULTS AND DISCUSSION

The results are presented and discussed considering sample characteristics and analysis of the interviews, with categories originating from the discourses themselves.

Characterization of the participants

Twenty-two HIV-carrying mothers were interviewed, with ages ranging from 20 to 36 years, mean 28 years, and predominantly in the 25 to 30 year age group (40.9%). With respect to education, it was observed that the majority

(11) did not complete elementary school, corresponding to 50% of those interviewed; 7 (31.8%) concluded their elementary education and only 4 (18.2%) attended secondary school, but did not finish. The predominant family income in the sample studied was one minimum monthly salary (US\$125.00), earned by 17 (77.3%) of the participants, while 5 (22.7%) earned up to two minimum salaries (US\$250.00). The prevalent form of contamination, according to the interviews, was through heterosexual transmission (81.8%) by a stable partner. A further 4 (18.2%) acquired the virus through intravenous drug use. The greatest number of diagnoses occurred in 2001 (27.4%).

These results coincide with the profile of women with AIDS throughout the country, according to studies performed from 1980 to 2004¹⁰. Studies by the Ministry of Health indicate that 55% of seropositive women 19 years of age or over, have not completed an elementary education level⁸. Current Ministry of Health data reveal that the highest percentages of AIDS cases in reproductive-age women (between 25 and 34 years) occurred in the 1990s. There was a 15.2% increase in infected pregnant women in 2000 compared to 1980⁹. Our study demonstrates that 45.6% of the women were contaminated between 2000 and 2001.

Coping strategies of mothers faced with HIV/AIDS

In accordance with the objectives of the present study, this section will present some categories that will assist in understanding the strategies and mechanisms used by mothers and families to better cope with the daily presence of HIV/AIDS. Emanating from the discourses of the mothers themselves, and according to the questions asked, six category groups are highlighted: motivation and adhering to the treatment; denying and underestimating HIV; concealing the disease; resignation; religion and hope.

Motivation and adhering to the treatment

Despite the many difficulties reported by the mothers such as transportation to the hospital and abandoning the home (many are from rural areas, secondary expenses, collateral reactions), the mothers see the possibility of their child having a normal, healthy development. This is the predominant perception that justifies adherence to treatment and to prophylactic procedures.

The following discourse suggests such a characterization:

“...for my son to grow up healthy, I follow all the doctor’s recommendations. She told me that if he takes his medication correctly and if I bring him regularly to his appointments, he will live for a long time”. (Lily)

Much has been reported about adhering to drug therapy, mainly after the appearance of antiretroviral therapy, which involves a large amount of tablets, side effects and difficulties in adhering to a regular pill-taking schedule^{2,4}.

Tunala et al¹⁶ describe that adherence also means a learning process, resulting from economic, social and individual needs, since the infection is currently prevalent in less privileged social classes with low education levels. With respect to adherence, it should be underscored that communication between mother, family and medical team must allow not only the sharing of information about the risks and concerns of the disease, but also moments of mutual exchange and learning where mothers have the opportunity to express their anxieties and doubts.

Denying and underestimating HIV

Since AIDS is still a disease associated with death, one form of surviving with the HIV diagnosis and face the disease is to relegate this condition to the second level, not permitting it to occupy a large place in their lives. The excessive thinking about AIDS was reported by the women as a form of surrendering to the disease. This surrender is refused by the denial by some and by the underestimation of others in an attempt at reestablishing normalcy in order to better cope and deal with the disease.

It was possible to perceive in the discourses that the women know that they have AIDS and that their son has the virus, but they are reluctant to face reality that, besides being painful, imposes a new direction in their life, as evidenced by the following statements:

“...I tell my son that we only have the virus and that we shouldn’t think of it; he then feels more relieved”. (Tulip)

“...just take the cocktail and look at it as any other drug, the viral load goes down and you go on living

normally. Now, if we put it in our head that we're going to die of AIDS, then we die for sure". (Geranium)

Ruiz ¹¹ affirms that there must be an effort for AIDS not to be everything in the life of an infected individual, given that excessive thinking about this condition may represent a form of surrendering to the disease.

Kübler-Ross ⁵ demonstrates in his studies that when individuals discover that they have an incurable disease, they experience a range of feelings that cause conflicts; however, these are common and are part of the coping mechanisms of their insecurities. These feelings are generally: denial, anger, bargaining, depression, isolation and acceptance, with each individual experiencing them individually and at different intervals and sequences. The same author reports that having AIDS means not only being afflicted with an incurable disease, such as cancer, but also carries considerable social stigma.

Concealing the disease

Not revealing to children that they are HIV-carriers nor sharing their diagnosis with others is a form of dealing with AIDS and an escape from the problems emerging as a result of the seropositive condition.

Observe the following discourse:

"Nobody in my house knows that I have AIDS. When I returned from the maternity I didn't nurse my son, I pretended that my milk was weak. My mother said a lot of things but I put on a good act and didn't tell her anything". (Rose)

In accordance with Tunala et al ¹⁶, this silence with respect to the infection, besides impeding a sharing with other individuals who might be able to help her in dealing with the disease, compromises treatment adherence both by the difficulty in taking medication in the presence of others and by being obliged to explain unusual behavior, such as not nursing. This silence may constitute a manner of coping with the disease.

This recourse was also used by Violet:

"After I receive the medicine at the hospital, as soon as I get home I remove the labels so that my son doesn't read them and my parents don't suspect. I always say they're vitamins". (Daisy)

Even considering concealment as denial and a normal stage in the relation with diseases and serious situations, Lent and Valle ⁶ emphasize that a majority of seropositive individuals conceal the fact of being infected, for the longest time and best way possible. With this they attempt to avoid the social isolation to which they could be submitted to if they were to admit their seropositivity. According to Ferraz and Stefanell ³, fear of rejection and social discrimination induces the HIV/AIDS carriers to try by all means available to conceal their diagnosis, fearing family reaction or not being accepted in other social groups to which they belong. Furthermore, many individuals hide bottles of antiretroviral medication or change the packaging; they refer to their infection as being some other disease or seek treatment in centers far from the cities in which they reside for fear of being recognized.

Resignation

The mothers who participated in the study tend to compare their child's disease to that of other seropositive or non-seropositive children who present with a more serious clinical picture. These comparisons occur during conversations between mothers in hospital waiting rooms and ambulatory facilities. In addition to making comparisons, these encounters allow the mothers to exchange experiences and unburden their emotions. The comparison of an HIV-positive child with other seropositive children arouses in some a feeling of resignation. We can recognize this form of coping in the statement below:

"...when I take my son to the doctor, there are other mothers there with their children; so I take advantage of this to talk with them and I hear so much suffering. I see children with HIV losing weight, with pneumonia, tuberculosis, and mine has none of this. I look at my son and I see nothing compared to the many things I see in other children..." (Wildflower).

Parents, when comparing their child with other children, observe that there are individuals in worse situations and realize that these are more health-compromising and that there are families with greater conflicts than theirs. In this experience, what can be observed is a sense of consolation, relief from suffering, for even with the disease, the situation could be much worse. Small & Graydon ¹⁴ describe these

comparisons as positive and beneficial, as they facilitate the psychological adaptation of patients in high-risk situations. However, we must consider this affirmation with reservations, since such a situation may also demonstrate the level of seriousness that the disease can reach and arouse feelings of impotence and despair.

Religion and hope

Religious belief was cited as a strategy used by mothers to accustom themselves to the child's seropositivity. Spirituality, faith and beliefs give them the strength needed to care for their child as well as for themselves and not to feel alone in the struggle for life.

The following discourse illustrates this situation:

"...I am holding the hand of God, He is with me in this struggle and it is He who strengthens me. He is my companion when I am alone. I have faith in Jesus that a cure will come. After this damned disease I began to implore God" (Orchid)

According to Silveira ¹², religious belief helps to deal with the disease process. By attributing a supernatural meaning to the determinations that govern existence, this belief functions as a means of strengthening individuals, giving them motivation to continue struggling.

Maintaining the hope of a better future revealed itself in this study as a form of persisting in the combat against the suffering imposed by AIDS. The data from the interviews show that the family preserves hope even in cases where the patient is in a progressively worsening situation.

As Miller ⁷ points out, hope is considered a positive phenomenon, serving as a supportive force, helping individuals avoid hopelessness and prolong life in spite of everything. In the case of AIDS, the family know that there is no cure, but even so, understand that there is hope for a better future, free from the suffering imposed by the disease.

The account below confirms this situation:

"I hope to see a cure for the disease one day, to see my son cured, then the desert will become a sea once more, then I will smile again, this is how I forget the hard reality of living with this disease". (Jasmine)

CONCLUSION

This study verified that, despite the difficulties and limitations imposed by HIV/AIDS, as a result of its treatment and the daily uncertainties that it generates, the families, represented here by mothers of HIV-carrying children, develop strategies that enable them to better cope and deal with the disease.

Among the various strategies reported, the following predominated: motivation and adherence to treatment; denying and underestimating HIV; concealing the disease; comparing the child with other seropositive or non-seropositive children; religion and hope. Adherence did not consist only of receiving the medication but rather appears to be founded on life expectancy itself; denial did not prevent individuals from seeking resources and attention, but did minimize pain; concealing the disease arose as a form of coping with prejudices; comparison relieved the suffering, while religion and hope appeared as forms of resistance.

Planning actions, developing human resources and policies that attend to the needs of patients and family members of HIV-carrying children must also consider these strategies, so that they can be recognized and strengthened and included in patient care protocols as indicators that lead to more qualified caregiving, all the while searching for better ways of dealing with AIDS.

Similarly, awareness of these strategies could give rise to preventive actions being instituted in waiting rooms, in basic care units and in homes, mainly because it must be considered that many strategies adopted may, depending on the moment, not yield the results described in this study.

It is important to underscore, therefore, that when caring for a seropositive patient, one must go beyond the purely clinical aspects of controlling the disease and extrapolate to the meaning of the experiences lived by these individuals, and seek to incorporate these meanings to caregiving, thus promoting more humanized and qualified health assistance.

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