93 - THE PROCESS OF THE TAKE CARE OF THE HIV-POSITIVE CHILD: HIV-POSITIVE WOMEN OPINIONS AS USERS A SPECIALIST CENTER IN DISEASES INFECTOCONTAGIOSAS

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INTRODUCTION

The epidemic of AIDS represents one of the most serious problems of public health in present time. With dynamic profile since its sprouting, the epidemic changed its transmission pattern, leaving risk groups as homosexuals, for an increasing trend of heterosexual transmission. This change on transmission patterns makes one find a growing frequency of infected women and, therefore, a larger incidence of congenital AIDS (TOMAZELLI, 2003).

In most families, the mother is responsible to provide the care for the son, mainly the infected one, what creates a work overload. She has the responsibility of coordinating treatment and daily activities (GAZZINELLI, 1997). The presence of an infected child can perform a change in the dynamics of interaction between HIV-positive mothers and their HIV-positive children and this relation tends to be full of fears, blames and suffering.

The aim of this study was to identify feelings of HIV-positive mothers when living the experience of taking care of their HIV-positive children.

METHODOLOGY

This is a descriptive research with qualitative approach, carried in the clinic of Hospital Giselda Trigueiro (HGT), which is reference in the treatment of AIDS in the city of Natal - Rio Grande do Norte/Brazil.

The population was constituted of HIV-positive mothers with HIV-positive children attended in the reference center. The sample was composed by 33 mothers who accepted to participate voluntarily of the interviews, with the signature of a free and clarified assent term, obeying the following inclusion criteria: a) to agree to participate of the research as a volunteer; b) signature of a free and clarified assent term by the participants; c) to have medical diagnosis of HIV-positive confirmed; d) to be older than 18; e) to have, at least, one child with HIV-positive diagnosis confirmed; f) to be in consultation in the clinic of the Hospital on the day of the interview. Exclusion criteria were: the non-signature of the assent term; mothers of children younger than 18 months, with diagnosis still not confirmed and mothers who, voluntarily, quit the study during the period of collection.

After authorization by the HGT Directory and approval of the project on the Ethics Committee in Human Research of Federal University of Rio Grande do Norte, nº 142/04, data collections were started and lasted from March until June/2006.

As collection instrument, it was used an interview with structured questions validated through a pilot study. Interviews were recorded and then completely transcripted and grouped in categories that emerged from the proper speech, according to BARDIN's content analysis (BARDIN, 1991).

RESULTS

Results will be presented considering sample characterization and analysis of interviews with categories according to the questions made.

Overprotection and fear

One observed at mothers speech that the daily routine of an HIV-positive child is frequently marked by presence and risk of opportunistic diseases creates a feeling of protection and fear in mothers if their child suffer any violence for being HIV-positive. The disease appears as a constant threat and fear appears not only related to illnesses and death, but also for the expected prejudice and the uncertainty of future. The following talk suggests such characterization:

"I protect my son excessively, because I am afraid he suffers any violence for having this disease" (Interview 12)

Donation

The way how mothers express the donation feeling evidences certain guilty about their child's illness. However, one observed that their HIV-positive condition does not seem to be an important concern. In their talks it is possible to realize that their priority is children healthcare and for it they use all their potential, according to this sentence:

"I try to satisfy my son totally; everything is for him; I think I do this to relief my guilt". (Interview 9)

Faith and Hope

To have faith in God and hope that one day it will be discovered the cure for this disease were manifestations of many interviewed mothers, which referred to these feelings as a way to live the AIDS and to support the anguishes and fears created by the routine of care and diseases. Report below express this situation:

"I have a hope that one day I will see the cure for this disease, to see my son cured, then desert will turn sea again, I will smile again; thus I forget the hard reality to live with this illness". (Interview 6)

DISCUSSION

About interview data that tried to describe these women's emotions and feelings, mainly about the fact of having an HIV-positive child, one can evidence that overprotection and donation feelings and hope in the discovery of the cure of the illness were present in almost all speeches

Irvin et al. (1992) affirm that parents concern about their child's future, guilt and unsolved anger cannot determine an overprotecting behavior. This exactly feeling, that means extreme goodness and patience, is evidenced in studies made with mothers of children with chronic diseases (BRADFORD, 1997). Despite the inevitable separation in some hospitalization situations in the universe of HIV-positive people, there is fear of falling ill and dying, permanently (CASTRO, 2004; GUIMARÃES, 2002).

AIDS is a disease that deeply marks infected people, therefore it affects their physical, mental and social well-being and involves negative feelings as depression, anguish and fear of death, interfering with their identity and self-esteem (CARVALHO, 2004).

AIDS patient isolation is exacerbated by fears or rejection observed in healthy people, spouses, relatives, friends, work and school mates (CARVALHO, 2004). With children, the experience at school environment many times appears as source of discrimination (TURNE-HENSON et al., 1994). In these situations, professors need to be informed to serve as emotional, material and informational support to the child and its family (GARWICK et al., 1998).

As previously mentioned, despite the set of fears and anguish lived by mothers, in this trajectory there is an overcoming experience. In this aspect, love, faith, spirituality, hope, beliefs and other feelings are used as strategies for survival and renewal of positive feelings. In most part of the cases they give meant and sustentation for confrontation with the illness, changes and losses that accompany it (GAZZINELLI, 1997). Hope, considered as a complex human experience, is presented as a sustentation force that assists people to avoid discouragement and to live longer in spite of any adversity (MILLER, 1992).

Pinheiro (1992) described the experience of mothers of children with cancer, demonstrating that they presented a strong feeling of uncertainty and hope for the cure of this disease. In a study with mothers of children with chronic illness, it was observed that hope in a better life and free from the illness was a common report, where this hope was the strategy used as a way to face the disease and to keep searching treatment and cure (GAZZINELLI, 1997).

CONCLUSION

For this group of interviewed women, aspects as youth, HIV-positive themselves and live the experience of taking care of their HIV-positive son, disclosed involved feelings as overprotection, fear, donation, where, despite the adversity, mothers keep feelings of hope and faith as a support for the lived situation.

Finally, one expects that discussion of this subject contributes for a better understaning of the complexity that involves AIDS in childhood and in women and, that it stimulates professionals approaches based in sensitivity to attend integrally the needs of those who live with AIDS particularities.

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THE PROCESS TO PROVIDE THE CARE FOR THE HIV-POSITIVE CHILD: HIV-POSITIVE WOMEN OPINIONS AS USERS A SPECIALIST CENTER IN DISEASES INFECTOCONTAGIOSAS

ABSTRACT

INTRODUCTION: 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 child. OBJECTIVE: Identify feelings and expectations of HIV-positive mothers when living the experience of care for their HIV-positive children. METHODS: This is an exploratory descriptive study with qualitative approach. The sample was composed of 33 HIV-positive volunteer mothers, enrolled in the clinic of the reference public hospital for infectious illnesses, in the city of Natal/RN/Brasil. After the signature of a free and clarified assent term, data were collected by the application of a semi-structured interview, whose reports were recorded and transcripted literally. For analysis, it was used the technique of content analysis, creating categories that emerged from the proper speech. RESULTS: The prevalent categories in relation to the experience of care for an HIV-positive son were: protection, fear, donation, faith and hope. The condition of the mother as an HIV-positive herself was not evidenced as the biggest concern. Mothers prioritize the needs of the child and the care for the children and the family. CONCLUSION: These data reveal a suffering on the mothers which guides us for a better qualified attention, carried in a perspective of reinforcement of their self-esteem and self-care.

KEYWORDS: AIDS/HIV, care, children.

LE PROCESSUS DE SOINS AU FILS PORTEUR DE VIH: OPINION DE FEMMES SEROPOSITIVES QUI FREQUENTENT UN CENTRE SPECIALISE EN MALADIES INFECTIEUSES CONTAGIEUSES

RESUME

INTRODUCTION :Le diagnostique de porteur de VIH représente un événement d'impact personnel, c'est une borne dans la trajectoire de vie des familles pendant leur cohabitation avec la maladie. Un autre point important est le fait que le SIDA impose de nouvelles habitudes, tels que réaliser un traitement rigoureux, ingérer des médicaments, réaliser des consultations et des examens fréquents, considérés comme extrêmement éprouvants autant pour la famille que pour l'enfant. OBJECTIF : Identifier les sentiments de mères porteuses du VIH/SIDA qui vivent l'expérience du soin aux enfants séropositifs.

METHODOLOGIE : Il s'agit d'une étude descriptive exploratrice avec un angle qualitatif. L'échantillon est composé de 33 mères séropositives, volontaires, inscrites au service de consultations externes de l'hôpital public de référence pour les maladies infectieuses dans la commune de Natal-Rio Grande do Norte. Après la signature d'un terme de consentement libre et éclairé, les données ont été collectées pour l'application d'une entrevue semi-structurée, dont les rapports ont été enregistrés et transmis littéralement. Pour l'analyse nous avons utilisé la technique de l'analyse thématique, en créant des catégories qui ont émergé du propre discours. Les catégories dominantes liées au vécu et à l'expérience du soin d'un fils séropositif ont été : la protection , la peur , la don, la foi, et l'espoir. Le fait que la mère soit séropositive n'a pas été identifié comme une préoccupation majeure. Les mères donnent priorité aux besoins de l'enfant, aux soins des enfants et de la famille. CONCLUSION : Ces données révèlent un souffrir de la part des mères qui renvoie à une attention mieux qualifiée, réalisée dans la perspective de renforcer l'amour propre et l'autosoin des propres mères.

MOTS-CLES : SIDA/VIH, Soin, Enfants.

EL PROCESO DEL CUIDAR AL HIJO PORTADOR DE VIH: OPINIÓN DE MUJERES SOROPOSITIVAS QUE FRECUENTAN UN CENTRO ESPECIALIZADO EN ENFERMEDADES INFECTOCONTAGIOSAS

RESUMEN

INTRODUCCIÓN: El diagnóstico de portador del VIH representa un evento de impacto personal, siendo un hito en la trayectoria de vida de las familias durante su convivencia con la enfermedad. Otro punto destacable es el hecho de que el SIDA impone nuevos hábitos, tales como, realizar un tratamiento riguroso, ingerir medicamentos, realizar consultas y exámenes frecuentes, siendo estos extremadamente penosos tanto para la familia cuanto para el niño. OBJETIVO: Identificar los sentimientos de madres portadoras de VIH/SIDA al vivir la experiencia del cuidado a sus hijos seropositivos. METODOLOGÍA: Se trata de un estudio descriptivo exploratorio con abordaje cualitativo. La muestra ha sido compuesta de 33 madres seropositivas, voluntarias, inscritas en el ambulatorio del hospital público de referencia para enfermedades infecciosas, en el municipio de Natal/RN. Tras la firma del documento de consentimiento libre y aclarado, los dados han sido recogidos aplicando una entrevista semi-estructurada, y su respuesta grabada y transcrita literalmente. Para el análisis se utilizó la técnica de análisis temático, creándose categorías que surgieron del propio discurso. RESULTADOS: Las categorías destacadas en relación a la vivencia y experiencia de cuidar a un hijo seropositivo fueron: protección; miedo; duda; donación; fe y esperanza. La condición de que la madre fuera seropositiva no fue evidenciada como la mayor preocupación. Las madres priorizan las necesidades del niño, el cuidado de los hijos y de la familia. CONCLUSIÓN: Esos dados revelan un sufrimiento por parte de las madres que nos orientan hacia una atención mas cualificada y realizada con la perspectiva de reforzar el autoestima y el autocuidado de las propias madres.

PALABRAS CLAVE: SIDA/VIH, Cuidado, niños.

O PROCESSO DO CUIDAR AO FILHO PORTADOR DE HIV: OPINIÃO DE MULHERES SOROPOSITIVAS QUE FREQÜENTAM UM CENTRO ESPECIALIZADO EM DOENÇAS INFECTOCONTAGIOSAS

RESUMO

INTRODUÇÃO: O diagnóstico de portador do HIV representa um evento de impacto pessoal, sendo um marco na trajetória de vida das famílias durante sua convivência com a doença. Outro ponto marcante é o fato de que a AIDS impõe novos hábitos, tais como, realizar um tratamento rigoroso, ingerir medicamentos, realizar consultas e exames freqüentes, considerados extremamente penosos tanto para a família quanto para a criança. OBJETIVO: Identificar sentimentos de mães portadoras de HIV/AIDS ao vivenciarem a experiência do cuidado aos seus filhos soropositivos. METODOLOGIA: Trata-se de um estudo descritivo exploratório com abordagem qualitativa. A amostra foi composta de 33 mães soropositivas, voluntárias, inscritas no ambulatório do hospital público de referência para doenças infecciosas, no município de Natal/RN. Após a assinatura de um termo de consentimento livre e esclarecido, os dados foram coletados pela aplicação de uma entrevista semi-estruturada, cujos relatos foram gravados e transcritos literalmente. Para análise utilizou-se da técnica de análise temática, criando-se categorias que emergiram do próprio discurso. RESULTADOS: As categorias prevalentes em relação à vivência e experiência de cuidar de um filho soropositivo foram: proteção, medo, doação, fé e a esperança. A condição da mãe em ser soropositiva não foi evidenciada como a preocupação maior. As mães priorizam as necessidades da criança, o cuidado dos filhos e da família. CONCLUSÃO: Esses dados revelam um sofrer por parte das mães que remetem para uma atenção melhor qualificada, realizada numa perspectiva de reforço à auto-estima e ao autocuidado das próprias mães.

PALAVRAS-CHAVES: AIDS/HIV,Cuidado,crianças.