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QUALITY OF LIFE OF CHILDREN AND ADOLESCENTS INFECTED WITH HIV[1]

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ABSTRACT
Estimates indicate that about 84% of the cases of Aids in individuals up to age 13 in Brazil occur due to vertical transmission. The HIV/Aids impact on these children can affect quality of life negatively. The objective of this study was to evaluate the quality of life in children and adolescents infected with HIV by vertical transmission; according to the vision of the child and the caregiver. This is an observational study, like a transversal and analytical investigation, carried out at the Universidade Federal do Triângulo Mineiro (UFTM), with children and adolescents infected with HIV. 24 children and adolescents and their caregivers participated. The emotional dimension of quality of life was the most affected in the childs or adolescents perception (61.88 points). The caregivers reported a greater impact in relation to educational performance (60.83 points). The evidence of lower school assessment scores, in the opinion of the participants, indicates a negative influence on the quality of life of the research participants.

Keywords: Quality of life. Acquired Immunodeficiency Syndrome. Child. Adolescent.

INTRODUCTION

One of the ways of transmission of Human Immunodeficiency Virus (HIV) is the vertical way, that is, from mother to child. In Brazil, between 1980 and 2011, 14,127 cases of AIDS in children under five years(1) have been reported.

The impact of HIV / AIDS on the lives of these children can negatively affect their quality of life.

According to WHO (World Health Organization), quality of life is a multidimensional concept that encompasses the physical, social, psychological and environmental domains, evaluated according to the vision of the individual, with respect to their culture and values(2). Even with the advances promoted by the introduction of antiretroviral therapy, there are still many challenges in the prevention and care of patients with HIV/AIDS. Understanding the quality of life of these patients is crucial to know the repercussions of living with the disease in various studied fields(3).

Studies on the quality of life of HIV-infected population conducted in recent years have evaluated the physical and psychosocial dimensions and thereby made it possible to devise strategies to act in these ways, in order to improve their quality of life(4).

With the improvement of therapeutic measures, patients with HIV, as well as health professionals, have come to see the disease and its consequences differently(5). The assessment of quality of life is an important measure of well-being of the patient and, in association with clinical and laboratory assessments, allows for a better understanding of the effectiveness of interventions and factors that influence the daily lives of patients(6). Among children and adolescents with HIV, this assessment is more relevant as, when taking therapeutic decisions, one should take into account their impact on longevity(5).

The importance of self-assessment of children and adolescents about their health, skills

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and emotions is increasingly recognized both in medical practice and in scientific circles. However, evaluation of the quality of life of adults with HIV have received greater emphasis than the measure of this among children and adolescents(7).

Understanding the biopsychosocial impacts inherent to the disease, through the description of the profile of the health of HIV-infected people, enables wider perception of the damage caused by the infection as well as targeting of health policies and the adequacy of interdisciplinary support services.

In view of this, this research possessed the following orientating question: what is the quality of life of children and adolescents with HIV?

The aim of this study was to evaluate the quality of life of children and adolescents infected with HIV through vertical transmission, according to the vision of the child and the caregiver.

MATERIALS AND METHODS

This is an observational study, cross-sectional descriptive type, analytical survey, developed at the Federal University of Triangulo Mineiro (UFTM), Uberaba, MG.

Children and adolescents between 5 and 18 years old, diagnosed with HIV infection, and their caregivers participated in this study. The exclusion criteria were association with other comorbidities, cognitive disability to answer the questionnaire and changing of the reference center. The concept of caregiver adopted was:

> "The individual who lives directly with the child or adolescent being primarily responsible for meeting the needs of everyday life, and provide or coordinate the resources required for the care given to them" (8:32).

During previously performed evaluation, a population of 29 children and adolescents was found, aged between 5 and 18 years, that were regularly monitored at the pediatric clinic of UFTM. Because it is a small population group, sample size was not calculated. This population, three individuals did not participate because they fit the exclusion criteria, two of which have changed their reference center and one had functional cognitive inability to respond to the questionnaire. Two individuals refused to participate.

Thus, there were 24 children and adolescents and their guardians who participated in the study, and those with the following degrees of kinship: grandmother, grandfather, birth mother, adoptive mother, sister and aunt.

This investigation began after project approval by the Ethics Committee for Research with Humans (CEP) protocol n◦ 1584/2010, following the ethical principles of Resolution 196/1996, legislation in force during the process of data collection .

Data collection was conducted at the Pediatric Clinic of UFTM in the period June-August 2010. Children and adolescents as well as their caregivers, who met the inclusion criteria, were addressed before regular routine visit time and invited to participate in the study, receiving the necessary clarifications and signing the Instrument of Awareness and Consent.

The Economic Classification Criterion Brazil were used for socioeconomic assessment, which can evaluate the purchasing power of households and the education level of the household head, classifying them by points obtained in economic classes: A1 (42-46); A2 (35 to 41); B1 (29-34); B2 (23 to 28); C1 (18 to 22); C2 (14 to 17); D (8 to 13) and E (0 to 7)(9).

The generic questionnaire on pediatric quality of life (PedsQL 4.0) was used to evaluate the quality of life. The permission to use the instrument for academic and non-profit was granted by Mapi Research Institute (MAPI RESEARCH INSTITUTE) on May 22, 2009. The PedsQL 4.0 comprises 23 items divided into four domains: physical functioning (8 items); emotional functioning (5 items); social functioning (5 items); school functioning (5 items). The evaluation of each item is made using scales constructed and staggered by the method of summed points – Likert's method. The scales range from 0 to 100, with higher scores indicating better function or sensation. It is comprised of two parallel questionnaire formats, one for the child and teenager and another one for the caregivers, the latter designed to assess the perceptions of the caregivers regarding the quality of life related to the health (HRQOL) of their children. The instrument was applied individually, without contact between the participants and in the consulting room, before the routine appointments.

Data was stored in Excel® and was later transported to the Statistical Package for Social Sciences (SPSS 16.0). Descriptive analysis from absolute frequencies and percentages for categorical variables and measures of centrality (mean) and dispersion (standard deviation and minimum and maximum) for numerical variables was used.

The numerical data was subjected to the Kolmogorov-Smirnov test to verify the normality and homogeneity of variances. As the said distribution was normal, the correlation was made using the Person test. Comparisons were performed using the Student t test.

The analyses were considered significant, taking into account the level of significance of 95% ($p < 0.05$).

RESULTS AND DISCUSSION

The average age of the children and adolescents was 13 years, with a minimum age of 9 and maximum of 17 years. There was a prevalence of female participantes represented by 14 (58.3%).

These findings indicate that the female population was more prevalent (58.3%) compared to male; similar data was found in another study, where the prevalence of females was 51.4% of 492 children and adolescents participating in a study of children exposed to HIV(10).

As for the economic classification, the C class was the most frequent affected (45.8%), followed by class D (25%), B2 (20.8%) and B1 (8.3%). According to the National Association of Research Companies (ANEP), the average wage of the related population was R$ 927.00 (11). It is emphasized that assistance to HIV infected persons requires a greater knowledge and preparation from the caregivers. The low socioeconomic status, which implies the degree of instruction of the family provider, can cause problems in adherence to therapies, as well as affect the ability to cope with the disease(12-13). Study reports that the performance of a psychotherapeutic group intervention for families of children with HIV was more effective among participants with higher cultural level(13).

Scores found in the analysis of the PedsQL 4.0 are shown in Table 1. Among the areas surveyed in the questionnaire, there were higher scores in social functioning withaverage of 85.63, followed by physical functioning with 78.39, with regards to the perception of the children and adolescents. With regards to the perception of those responsible, higher scores were found in physical functioning, 80.21 points, and the social functioning, 76.46.

Table 1 - Average scores of quality of life of children and adolescents infected with HIV, according to the child, the adolescent and the caregiver. Uberaba / MG, 2011.

Functioning	**Mean (Standard Deviation)**	**Minimum**	**Maximum**
Children and Teens			
Physical Health	78.39 (± 14.18)	50	100
Emotional	61.88 (± 18.7)	25	95
Responsibility	85.6 (± 15.83)	45	100
School	67.29 (± 16.28)	25	95
Caregivers			
Physical Health	80.21 (± 17.21)	40.62	100
Emotional	65.63 (± 15.63)	25	90
Responsibility	76.46 (± 25)	30	100
School	60.83 (± 21.65)	10	90

The quality of life was most affected in terms of the emotional functioning in the perception of the child or adolescent, obtaining 61.88 points. The questioned factors in this area were the frequency of fear, sadness, anger, change in sleep pattern and concern for the future.

A high frequency of anxiety symptoms was observed in a group of young people infected with HIV, associated with a significant degree of depressive symptoms among their caregivers (10). In another study it was shown that environmental factors and psychosocial problems had a significant negative impact on quality of life of children with the virus and their families (14).

A study conducted in Italy which evaluated the quality of life of HIV-infected through the PedsQL 4.0 questionnaire children, showed that they reported worse scores on psychosocial functioning. The perception of caregivers of infected children, in the psychosocial context, was lower than when compared to the perception of caregivers of children from the comparison group. According to the evaluation of the caregivers, the children showed worse scores due to presenting recurring frustrations, fear of the future and changes in sleep patterns(15), which corroborates the results of this work.

A study describing the factors related to lack of adherence to antiretroviral treatment showed that behaviors such as a missed dose, unwillingness to take medication and the association of medication with the fact of being ill, were significantly correlated with the manifestation of psychological distress(16). In view of the possibility of stigmatization and prejudice, many caregivers feel a need to hide the illness of the child or adolescent, which may be a hindrance in this adherence to treatment(17).

The neuropsychological assessment of young people infected with HIV has been demonstrated in the literature as essential in the treatment, especially in those patients who have emotional and behavioral problems(18).

It should be noted that the daily life of a HIV-infected child is not always accompanied by a mother figure. Many mothers die, others are hindered with physical and psychological conditions. In many situations, the child is institutionalized for lack of a family caregiver, and a guardian assumes the role, becoming the biggest influence for these children. These caregivers should be considered in the attendance, and their perceptions, values and esteem are fundamental in childs' care(19).

Caregivers have observed a more affected quality of life in relation to the school functioning, averaging 60.83 points. This domain is related to frequency of attention deficit, forgetfulness, difficulty of following the class and absenteeism due to illness or to go to the doctor.

A similar result was found in a study conducted in Thailand, in which caregivers of HIV-infected children reported that school-related problems and studies were those that had the greatest impact on the daily lives of these children. The problems that were identified were learning difficulties and lack of interest. Most children presented a high rate of absenteeism due to medical appointments or the need for hospitalization. This scenario led to a low school performance, stress and low self-esteem(20).

A negative, statistically significant weak inverse correlation (p = 0.016, r = -0.485) was found by the Pearson correlation test with regard to the economic score and scores found in the physical functioning, in the perception of caregivers. The other areas were not correlated with the economic condition, both in the perception of HIV-infected individuals and in their caregivers'.

It can be argued that higher education can facilitate access to information and thus enhance the ability to talk about the disease, identify symptoms or manifestations and understand the treatment(12-13). In this case, we can infer that caregivers with better education levels, by having a higher level of information, were more judicious by assigning lower scores to this area.

Comparing the perception of quality of life of HIV-infected individual with the caregiver, no statistically significant difference was found.

CONCLUSION

The results of this study, that aimed to evaluate the quality of life of children and adolescents with HIV, infected by vertical transmission, showed lower scores in emotional and school domains in both the vision of the infected children and adolescents and in the view of their carers, indicating a negative influence of HIV towards the quality of life of the research participants.

It was found that the highest scores were related to social and physical functioning, which allows to infer that the condition of living with HIV has resulted in less negative impact on quality of life, with respect to those dimensions.

These results show the potential of health programs adopted in Brazil, facing this population, providing access to health services, and the provision of specific treatment. Such actions have repercussions in maintaining and improving the physical conditions of HIV-infected persons.

However, there is still need to structure and strengthen actions aimed at improving mental and emotional health of these citizens, they still lack the support needed to live with the situation and overcoming the impact caused by the diagnosis.

A limitation to the study was the small number of subjects. The results, however, corroborate the literature, demonstrating the importance of these studies, identifying a possible influence of HIV on the quality of life of children and adolescents.

Therefore, knowing the quality of life of these children and adolescents gives a rare opportunity of understanding the main negative factors in their lives. This knowledge enables better planning of the care for these people.

Given the above, it is important to direct resources to the evaluation of the issues that have negative influences on children and adolescents and, from this, to promote interventions and educational activities for theses HIV-infected people, their caregivers and the multidisciplinary team in order to improve the quality of life of these households and the care for these children and adolescents, providing for all their needs.

QUALIDADE DE VIDA DE CRIANÇAS E ADOLESCENTES INFECTADOS PELO HIV

RESUMO

Estima-se que cerca de 84% dos casos de Aids em indivíduos com até 13 anos de idade no Brasil ocorram devido à transmissão vertical. O impacto do HIV/Aids na vida dessas crianças pode afetar negativamente a qualidade de vida. O objetivo deste estudo foi avaliar a qualidade de vida de crianças e adolescentes infectados pelo HIV por transmissão vertical, segundo a visão da criança e a do cuidador. Trata-se de um estudo observacional, tipo inquérito transversal, analítico, desenvolvido na Universidade Federal do Triângulo Mineiro, com crianças e adolescentes infectados pelo vírus HIV. Participaram 24 crianças e adolescentes e seus responsáveis. A qualidade de vida foi mais afetada em relação ao domínio emocional, na percepção da criança ou do adolescente (61,88 pontos). Os cuidadores observaram maior impacto em relação ao domínio escolar (60,83 pontos). A evidência de menores escores nos domínios emocional e escolar, na visão dos participantes, indica uma influência negativa para a qualidade de vida dos participantes da pesquisa.

Palavras-chave: Qualidade de vida. Síndrome de Imunodeficiência Adquirida. Criança. Adolescente.

LA CALIDAD DE VIDA DE LOS NIÑOS Y ADOLESCENTES INFECTADOS POR EL VIH

RESUMEN

Se estima que alrededor del 84% de los casos de SIDA en personas menores de 13 años de edad en Brasil se producen debido a la transmisión vertical. El impacto del VIH / SIDA en las vidas de estos niños puede afectar negativamente la calidad de vida. El objetivo de este estudio fue evaluar la calidad de vida de los niños y adolescentes infectados con el VIH por transmisión vertical; de acuerdo con la visión del niño y el cuidador. Se trata deinvestigación observacional, transversal, analítico, desarrollado en la Universidad Federal de Triangulo Mineiro, con niños y adolescentes infectados por el VIH. Un total de 24 niños, niñas y adolescentes y sus padres. La calidad de vida fue la zona más afectada en relación con la percepción emocional del niño o adolescente (61,88 puntos). Los cuidadores comunicaron un mayor impacto para la escuela de campo (60,83 puntos). La evidencia de las puntuaciones más bajas para emocional y académico en vista de los participantes, indicando una influencia negativa en la calidad de vida de los participantes en la investigación.

Palabras clave: Calidad de Vida. Síndrome de Inmunodeficiencia Adquirida. Niño. Adolescente.

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