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ORIGINAL ARTICLE

Experiences of adolescents seropositive for HIV/AIDS: a qualitative study



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Received 25 May 2015; accepted 16 August 2015

Available online 2 March 2016

KEYWORDS

HIV infection/
psychology;
Life-changing events;
Qualitative research;
Adolescent

Abstract

Objective: Explore the meanings attributed by young individuals about “living as an adolescent with HIV” in a group of patients that acquired the infection at birth and the elements involved with the adherence to antiretroviral treatment.

Methods: Qualitative study, involving 20 subjects (aged 13–20 years), followed at services specialized in the treatment of pediatric AIDS in São Paulo, Brazil. Semi-structured interviews were carried out of which script consisted of questions about their personal histories, experiences and difficulties they must face while living with HIV/AIDS.

Results: Being “normal” and “different” were central issues voiced by the participants. However, a normal life situation is guaranteed by being responsible with one’s health, the condition that the diagnosis be kept secret and concerns about HIV transmission and dissemination to a sexual partner. The answers about treatment show that adherence is a dynamic process and involves moments of greater or lesser interest in relation to care for one’s health. The adolescents have plans and projects and although HIV is considered a stressor, positive perspectives for the future prevailed.

Conclusions: To live as an adolescent with HIV involves subtle dimensions that need to be recognized and legitimized by professionals who follow the trajectory of these young individuals. It is necessary to allow a space in which the adolescents can reflect and find support regarding issues related to the construction of their sexuality and care of one’s own body.

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PALAVRAS-CHAVE

Infecção pelo HIV/psicologia; Acontecimentos que mudam a vida; Pesquisa qualitativa; Adolescente

Vivências dos adolescentes soropositivos para HIV/Aids: estudo qualitativo**Resumo**

Objetivo: Explorar os significados atribuídos pelos jovens a “viver a adolescência com o HIV” em um grupo de pacientes que adquiriu a infecção ao nascimento e os elementos implicados na adesão ao tratamento antirretroviral.

Métodos: Pesquisa de natureza qualitativa, com 20 sujeitos (13 a 20 anos), acompanhados em serviços especializados no tratamento da Aids pediátrica em São Paulo, Brasil. Foram feitas entrevistas semidirigidas cujo roteiro foi composto por questões sobre suas histórias pessoais, dificuldades e experiências que enfrentam diante da infecção pelo HIV/Aids.

Resultados: Ser “normal” e “diferente” foram questões centrais no discurso dos participantes. Entretanto, a condição de uma vida normal é garantida mediante a responsabilidade com a saúde, a ressalva de que seja mantido o segredo do diagnóstico e as preocupações com a transmissão do vírus e divulgação do HIV ao parceiro sexual. As respostas sobre o tratamento apontam que a adesão é um processo dinâmico e envolve momentos de maior ou menor interesse em relação aos cuidados com a saúde. Os adolescentes têm planos e projetos e, apesar de o HIV ser considerado um agente estressor, prevaleceram perspectivas positivas diante do futuro.

Conclusões: Viver a adolescência com o HIV envolve dimensões delicadas, que necessitam ser reconhecidas e legitimadas pelos profissionais que acompanham a trajetória desses jovens. Trata-se de possibilitar um espaço no qual o adolescente possa refletir e encontrar apoio para as questões relacionadas à construção de sua sexualidade e cuidados com seu próprio corpo.

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Introduction

In the third decade of the human immunodeficiency virus (HIV) epidemic, health professionals, researchers and caregivers are faced with the first generation of young individuals who became infected through vertical transmission. Over the years, one sought to ensure access to treatment that would allow increased life expectancy of these children and contemplates their psychosocial needs. The appalling demands of a newly described disease did not allow the professionals who treated these children to suspect that they could reach adolescence, with all the challenges that are associated with it. This population group has distinct characteristics from adult or young individuals that contracted the disease during adolescence.¹ Many of them have lost their parents as a result of the human immunodeficiency syndrome (AIDS – Acquired Immune Deficiency Syndrome), which results in early bereavement, disruption of affective bonds and family rearrangements.²

In addition to adolescence, a stage of life permeated by changes, discoveries, search for identity and autonomy, they have a disease full of stigmatizing attributes and the complex legacy of secrets involving families affected by HIV. Qualitative studies have identified that the main difficulties reported by HIV-positive young individuals included diagnostic disclosure to third parties, interpersonal relationships, adherence to treatment and the psychological burden of living with a chronic illness associated with death, prejudice and social exclusion.^{3,4} Research suggests that the challenges related to HIV-infected adolescents are

constant and therefore need to be identified and further investigated.^{5,6}

For professionals seeking to care for their patients in all their dimensions, it is critical to identify the particularities, desires and difficulties, from the perspective of the adolescents themselves. The objective of this study was to explore, through the qualitative methodology, the meanings attributed by young individuals to the phenomenon of “living the adolescence with HIV” in a group of patients who acquired the infection through vertical transmission and the elements involved in the adherence to the antiretroviral treatment.

Method

Qualitative research, carried out through interviews with open questions, comprising situations found in the experiences of young individuals in the presence of HIV/AIDS: (1) Life history; (2) Adolescence and seropositivity and (3) Health care and treatment.

The population of this study comprised 20 adolescents, selected from a group of 268 participants in the longitudinal study Adoliance, an international cooperation project for the study of psychosocial factors related to the life experiences of HIV-positive young individuals, which started in April 2009. In this phase of the work, carried out between November and December 2011, we included subjects aged 13–20 years, enrolled in four services that provide care in pediatric AIDS, located in São Paulo, Brazil. The choice of candidates was intentional and we sought to diversify the

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