The Brazilian Journal of
INFECTIOUS DISEASES

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Original article

Adolescents growing with HIV/AIDS: experiences of the transition from pediatrics to adult care

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ARTICLE INFO

Article history:
Received 14 May 2015
Accepted 28 December 2015
Available online 2 March 2016

Keywords:
HIV
AIDS
Health care transition
Adolescent

ABSTRACT

The main objective of this work is to describe the formation of the Transition Adolescent Clinic (TAC) and understand the process of transitioning adolescents with HIV/AIDS from pediatric to adult care, from the vantage point of individuals subjected to this process. A qualitative method and an intentional sample selected by criteria were adopted for this investigation, which was conducted in São Paulo, Brazil. An in-depth semi-structured interview was conducted with sixteen HIV-infected adolescents who had been part of a transitioning protocol. Adolescents expressed the need for more time to become adapted in the transition process. Having grown up under the care of a team of health care providers made many participants have reluctance toward transitioning. Concerns in moving away from their pediatricians and feelings of disruption, abandonment, or rejection were mentioned. Participants also expressed confidence in the pediatric team. At the same time they showed interest in the new team and expected to have close relationships with them. They also ask to have previous contacts with the adult health care team before the transition. Their talks suggest that they require slightly more time, not the time measured in days or months, but the time measured by constitutive experiences capable of building an expectation of future. This study examines the way in which the adolescents feel, and help to transform the health care transition model used at a public university. Listening to the adolescents' voices is crucial to a better understanding of their needs. They are those who can help the professionals reaching alternatives for a smooth and successful health care transition.

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http://dx.doi.org/10.1016/j.bjid.2015.12.009
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Introduction

Globally, there is increased health care burden of perinatally-infected human immunodeficiency virus (HIV)-infected adolescents who survive into adulthood. The advent of highly active antiretroviral therapy (HAART), alongside various prophylactic measures, has decreased morbidity and mortality rates in this group.[1] The majority of these patients receive their medical care in a pediatric or adolescent medical setting.

The transition into adulthood is a critical stage of human development, during which young individuals leave adolescence behind and take on new roles and responsibilities.[2]

Although these changes provide opportunities for positive growth experiences, they are accompanied by new vulnerabilities.

The World Health Organization defines adolescence between 10 and 19 years of age, beginning at the onset of puberty.[3] Although the majority age is 18 years in most of countries, reaching this age does not ensure acquisition of adult behavior.

Health care transition (HCT) is defined as the purposeful planned movement of adolescents and young adults with special health care needs from child-centered to adult-centered health care.[4] For many adolescents, this transition is disorganized and results in both impaired adherence to treatment and loss of consistent health care.[5]

HIV-infected young people between birth and 24 years of age are considered a developmentally diverse group.[6] Adolescents with HIV may have experienced several psychosocial stressors such as stigma, parental illness and loss, that can make HCT an even more complex process.[7] It is important that young people continue to receive appropriate care throughout and following the transition from pediatric to adult services.

Previous studies have shown several obstacles to transition, including a lack of communication between pediatric and adult providers,[8] adult services that are not equipped to meet the needs of adolescents, and differences in pediatric and adult health care philosophies (i.e., the family-focused approach versus the responsible self-care focused individual). In addition, the adolescent's emerging need for independence and the family's need to 'let go'[9] are challenges faced by parents, adolescents, and health care providers.

It has been generally agreed that HCT for adolescents with chronic illnesses is a process that starts with a preparation program in the pediatric setting, followed by active transfer strategies, and finally, a period of consolidation and evaluation in the adult setting.[4] At the present time, there is no evidence of a superior model for this transition in terms of patient satisfaction, cost effectiveness, or medium and long-term outcomes.[10]

In this article, we present the experiences of the HCT of a group of perinatally HIV-infected adolescents, whose voices we identify as crucial to a better understanding of their needs.

Objectives

The purposes of this study were to describe the implementation of the Transition Adolescent Clinic (TAC) and identify the needs, feelings, and experiences of HIV-infected adolescents included in an HCT program.

Study setting

The Transition Adolescent Clinic (TAC)

Since 2007, the Transition Adolescent Clinic (TAC) is a component of the Division of Pediatric Infectious Diseases in the Department of Pediatrics that follows perinatally HIV-infected adolescents older than 16 years of age. This special clinic was developed after a series of failures in previous attempts of transitioning these adolescents to an adult-centered clinic at the age of 18 years. Therefore, the aim of TAC was to facilitate the transition of this vulnerable population from pediatric to adult care. The TAC team is interdisciplinary and includes five physicians (four pediatricians and one adult infectious disease physician), two pediatric nurse practitioners, one social worker, and one psychologist. This clinic is located at the same facility as the Pediatric AIDS Unit, and when the adolescents reach 16 years of age, they step into a transitioning program. This follows a model based on the perspective that both a multidisciplinary team and a good interaction between the pediatric and adult services are essential to a successful HCT. Upon discovering that a protocol for this issue was non-existent at the time,[4] the TAC team developed the three steps of a transitioning protocol described as the following:

Step 1: When adolescents reach 16 years of age, the pediatricians begin the discussions with them regarding the transition process. During this period, the readiness to transition is evaluated through specific parameters, by both a pediatrician and a psychologist[4] (Table 1).
Step 2: Adolescents and youths (18 years or older) meet the adult infectious diseases physician formally for the first time at the TAC. They begin to have routine clinic appointments at the TAC, conducted by the adult infectious disease physician. One pediatrician remains responsible to discuss the progress of the transition process with the adult infectious disease physician.
Step 3: Adolescents and youths start having the appointments at the adult infectious disease clinic, with two to three extra appointments at the TAC during the following 12 months, to detect barriers to transition that continue to exist. Discussions are undertaken involving the TAC team for closing the transition process.

Although there are some steps indicated by age, the overall formal transition process is not based on the patient's chronological age, but on the level of maturity and preparedness of the young patient, which can be assessed by specific parameters previously described.[4]

This transition program is delivered at the local level, although it is supported by a policy establishing a national standard for care regarding the issue.

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