



# Transitioning adolescents living with HIV/AIDS to adult-oriented health care: an emerging challenge

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## Abstract

**Objective:** To review the literature on transition from pediatric to adult-oriented health care and discuss this issue in the specific context of chronic conditions.

**Sources:** MEDLINE and LILACS were searched for relevant English and French-language articles published between 1990 and 2010.

**Summary of the findings:** The transition of adolescents with chronic diseases from pediatric care to adult-oriented services has been a growing concern among pediatric specialties. In recent years, young people living with HIV/AIDS have begun to reach adulthood, giving rise to several challenges. The studies reviewed herein discuss such relevant topics as: the difference between transfer, an isolated event, and transition, a gradual process; the transition models used in different services; the importance of transitioning in a planned and individualized manner; the need for comprehensive interaction between pediatric and adult-oriented care teams; the importance of joint participation of adolescents, their families, and health professionals in the process; barriers to and factors that promote successful transitions; and the special needs of adolescents with HIV/AIDS in this important period of life.

**Conclusions:** Several authors agree that transitioning adolescents to adult-oriented health care should be a gradual process not determined by age alone. It requires a plan established with ample dialogue among adolescents, their families, and pediatric and adult care teams. However, there is little evidence to support any specific model of health care transition. This should prompt researchers to conduct more prospective studies on the theme, especially in more vulnerable groups such as adolescents living with HIV/AIDS.

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## Introduction

Over the past few years, a noticeable change has taken place among children living with HIV due to mother-to-child transmission: this population is entering adolescence and reaching adulthood.<sup>1</sup> This scenario was made possible by the advent of highly active antiretroviral therapy (HAART), which, alongside various prophylactic measures, has decreased morbidity and mortality rates in this group.<sup>2-5</sup>

In Brazil, 11,607 cases of childhood AIDS due to mother-to-child transmission were reported between the years of 1980 and 2008.<sup>6</sup> Clinical observation and follow-up of this

population has shown that, as the HIV/AIDS wears on, the challenges faced by care providers and patients have also changed. If improvement of diagnostics, prevention, and therapy were the focus of attention in the early days of HIV/AIDS, other issues are now coming to the fore and becoming increasingly relevant.

This new picture of HIV/AIDS as a chronic disease has given rise to a new topic of discussion among professionals who care for this population: transitioning adolescents who were treated by pediatricians throughout their lives to

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adult-oriented health care services. This transition has been beset by challenges of various natures, such as structural and organizational issues in health care services, social issues, and issues associated with the psychological and cultural sense and significance of transitioning from youth to adulthood. Many of these adolescents will explicitly refuse this change; others will not provide any immediate verbal manifestations of their struggle, but display it by failing to attend appointments or visits at the facility to which they were referred, thus discontinuing treatment and follow-up. Care providers also face objections to this topic, which are compounded by the scarcity of literature on the theme focusing on the HIV/AIDS epidemic – a research gap that is made even more evident by a search for qualitative scholarly investigations of this phenomenon. The development of a transition clinic is thus one of many current challenges in caring for this group of patients.

The literature shows that this concern is not restricted to care of patients with AIDS, but is in fact evident in several areas of pediatrics that deal with potentially chronic conditions.<sup>7-10</sup>

The objective of this study was to review the topic of transition, with a particular focus on adolescents living with HIV/AIDS, through a review of the available literature on the theme. LILACS and MEDLINE searches were conducted using the MeSH descriptors "HIV," "adolescent," "chronic disease," and "health facility moving." Both searches were limited to articles published between 1990 and 2010 and with full text available in English or French. Despite their absence from the MeSH database, the descriptors "*transition*," "*pediatric care*," and "*adult care*" were mentioned as keywords in several of the articles cited, and were therefore included in the search strategy as well.

### Transitioning

The transition into adulthood is a critical stage of human development, during which youths leave adolescence behind and take on new roles and responsibilities, which give rise to various emotional challenges and prompt major decisions and choices. They feel compelled to construct a psychological identity as adults by finding themselves; wish to conclude the process of severing ties to their actual parents and to any symbolic parent figures; tend to engage in fewer group activities; and no longer need to intellectualize and indulge in fantasies on emotional and social questions so often. Crises and fluctuations in religious beliefs abate, and oppositional social attitudes are somewhat replaced by acceptance of the cultural and political order. The concept of time is experienced more keenly, with greater awareness of the past and of the future, and the frequent contradictions of adolescent behavior shift to a linear overall stance toward the demands of life. In the sphere of sexuality, autoeroticism tends to give way to mature, outward affection. Finally,

after the young adult ceases mourning the loss of his or her fluctuating adolescent identity, mood and affect become more constant, with remission of the so-called "syndrome of normal adolescence."<sup>11</sup> It is thus a complex process that calls for constant adjustment on several dimensions.<sup>12,13</sup>

One definition of transition often used in the literature is that proposed by the Society for Adolescent Medicine,<sup>14</sup> which regards transitioning as a deliberate, planned process that addresses the medical, psychosocial, vocational, and educational needs of adolescents and young adults with chronic conditions when moving from a pediatric service to adult-oriented care. This transition should be recognized as merely one part of the broader set of educational, personal, family-related, and social transitions that adolescents experience.

The World Health Organization defines adolescence from age 10 to 19 (starting at the onset of puberty).<sup>15</sup> Although 18 is the legal age of majority in most countries, reaching this age does not mean automatic acquisition of adult behavior, nor does it mark a watershed moment at which the turbulence of adolescence simply disappears. The age at which adolescent patients usually transition to the adult clinic therefore coincides with the period of life during which at-risk behaviors are at their peak.<sup>16</sup>

Moving from care and monitoring at one health service or facility to another requires a substantial capacity to adapt to new situations. Having grown up under the care of a team of health providers makes many young adults – as well as their family members and these providers involved in their care – take a reluctant stance toward transition.

The literature on transition offers a wealth of examples from pediatric subspecialties that manage patients with chronic conditions such as cystic fibrosis, asthma, sickle cell anemia, various rheumatic, endocrine, and heart conditions, cancer, and post-transplant care, as well as from the management of children with special needs.<sup>7,8,10,17,18</sup> The overarching theme of these studies is the need to accomplish a planned, smooth, and uninterrupted transition to ensure successful treatment progression.

The first position statement on the topic by the Society for Adolescent Medicine was published in the early 1990s, and identified some features of the pediatric-to-adult-oriented care transition process. The authors considered that the process involves not only medical care, but also the psychological, social, and educational needs of the adolescent or young adult. Furthermore, the timing of transition is different in each family, as it depends on factors such as readiness or preparedness on the part of the adolescent and family dynamics, and may be more complex in patients whose overall health condition is less favorable.<sup>19</sup>

Many years ago, some authors stressed the importance of distinguishing between the terms "transfer" and "transition"<sup>20</sup>. Transfer is defined as the action of moving someone or something from one place to another, and is

therefore regarded as a single event. Transferring a patient from one service to another is likewise perceived as no more than an event, unlike transition, which is regarded as a life-change process that patients, family members, and health professionals should experience jointly, and for which strategies should be devised to increase the likelihood of success. Hence, in the health care context, the word "transition" carries the additional meaning of a process of psychological adaptation to a change or break.<sup>13</sup>

### **Models for transition from pediatric to adult health care**

Several models for transition have been reported, each depending on the particulars of the services in which they are implemented. At the present time, there is no evidence of a superior model in terms of patient satisfaction, cost-effectiveness, or medium and long-term outcomes.<sup>10</sup>

Sawyer et al.<sup>20</sup> found that three transition models were used for adolescents with chronic conditions, the first being a disease-centered model in which patients were transferred from a pediatric subspecialty to the corresponding adult subspecialty. It bears noting that, even if this type of transition occurs within a single institution, physical proximity alone may not be able to overcome the differences in care between pediatric and adult services. The second model takes place through the primary care setting and is coordinated by general practitioners, which may lead to obstacles in communication between these physicians and specialists involved in the patient's care. The third model employs specialized adolescent health services and thus places specialists in adolescent medicine in charge of patient care.

Forbes et al.<sup>21</sup> described four transition models, according to the degree of complexity of the interaction between the pediatric and adult care teams:

- 1) Direct transition: involves a single-step transition from pediatric to adult care, with or without communication or information sharing.
- 2) Sequential transition: provides an intermediate step between pediatric and adult services, which may include one or all of the following: a transition clinic, an adolescent-oriented service or a young adult service.
- 3) Developmental transition: includes instrumental training and development of support systems.
- 4) Professional transition: includes moving of expertise and skills between child and adult services.

Scal<sup>8</sup> identified 126 interdisciplinary programs geared to care of adolescents with various chronic conditions in the United States, 62% of which were specific for a certain condition or subspecialty (the remaining 38% were general programs). The latter understand that young patients with various chronic diseases prefer to meet and get to know

the team that will care for them prior to transfer.<sup>7,14,22,23</sup> This practice conveys the message that pediatrics and adult care teams work together, and helps both teams train for transition care.

None of these models is ideal when regarded as an immutable, isolated entity; instead, adapting them to the particulars of each patient, service, institution, time, and place may be more appropriate.

### **Factors associated with adequate transition**

Betz<sup>24</sup> noted some aspects that should be assessed in preparation of adequate transition, with special emphasis on the capacity of adolescents to take charge of their own treatment, prior patient involvement in disease management, displays of responsibility, independence, and the patient's relationship with his or her team of care providers.

In recognition of the relevance and urgency of this topic, the American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians-American Society of Internal Medicine published a consensus statement seeking to establish a policy for transition of young patients to adult care. This document provided evidence of the need for a professional in each service charged with planning and coordinating the transition process, as well as the need to prepare teams to meet the various needs of young adults. Patient records must be easily accessible to the receiving team, and a transition plan should be devised with input from the patients, their health care providers, and their family members.<sup>13</sup>

### **Pediatric subspecialties and their views of "transition"**

Authors in different areas and subspecialties of pediatrics have addressed different aspects of transitioning. Some articles focus more on organizational aspects of the transition and on describing services.<sup>10</sup> Others have discussed the lack of specific structures for adolescent patients, who, in some services, are treated in the same place as infants, toddlers, children, or much older adults, and stressed the extent to which health professionals are unprepared to meet the needs of teenage patients.<sup>18</sup>

Other authors have focused on the difficulties some pediatricians may experience in "letting go" of their now grown patients, either because they do not believe these patients are truly independent or because they are not confident in the care they will receive at adult services.<sup>25,26</sup> In this context, it is reasonable to assume that pediatricians and their teenaged patients alike experience a degree of affective ambivalence, as they had thus far been playing psychosocial roles equivalent to those of a parent-child pair, which includes use of all conscious and unconscious psychological defensive mechanisms available to avoid the anguish associated with abrupt separation. Overall, authors

agree that the timing of transition is best individualized and arranged so as not to coincide with any significant clinical events. Furthermore, authors also agree that age is not the best predictor of transition readiness.<sup>27</sup>

Although all of the articles reviewed stress the importance of transitioning adolescents and young adults with chronic conditions to adult-oriented care, there is little consensus on when and how this transition should take place.<sup>28</sup> In fact, the dearth of studies capable of providing evidence of best practices in transition care is a prominent theme in the literature.<sup>29</sup>

An English study of 16 young renal transplant recipients found that attendance rates declined 1 year after transfer to the adult service.<sup>30</sup> This is a highly worrisome finding, and confirms those of a qualitative study by McCurdy et al.,<sup>31</sup> who found that adolescent solid-organ transplant recipients reported feeling unprepared to attend adult-oriented services.

The perspectives of youths with various disabilities or special health care needs, their family members, and their care providers were discussed by Reiss et al.<sup>32</sup> in a study whose participants viewed transition as a process composed of three stages: "envisioning a future," "age of responsibility," and "age of transition." The first stage, "envisioning a future," begins as soon as a disease or disability is identified. This stage includes discussions between the patient's family and pediatrician or care team with questions about the future, such as possible employment options, education, and independent community living. The authors hypothesize that this planning would make achievement of future independence easier. The second stage, the "age of responsibility," is the period during which family members delegate more responsibilities to the patient in terms of daily living and care, such as expressing their own health-related complaints during health care provider appointments or visits, and knowing and taking their medications, with the advent of the concept of treatment adherence by patient empowerment. Many participants associated this period with the stage preceding the onset of adolescence. The third stage, the "age of transition," was divided into two periods: adolescence (defined, for the purposes of this study, as ages 12–17) and young adulthood (ages 18–23), and is the stage at which patients should start receiving care at adult-oriented services and living more independently.<sup>32</sup>

In a study of young people with chronic kidney disease, Alpay<sup>33</sup> viewed the transition process as having four stages. In early adolescence, young patients are seen with their parents or caregivers, but with the message that they will soon be able to attend visits without a chaperone. At a second stage, adolescents take a more active role in their physician visits, while their guardians become complementary. The importance of one-to-one visits and confidentiality rights are discussed with both. The adolescent should be encouraged to express opinions before his or her parents or caregivers

do. During the third stage, around the age of 13–16, young patients should be ready to choose whether they will be accompanied during a visit or will be seen alone, but the presence of a parent or guardian is still important in situations that require decision-making. The last step comes when the adolescent is seen alone during the visit and feels comfortable in doing so. This would be a good time to discuss plans about the future, such as education and employment opportunities.<sup>33</sup>

Bearing cross-cultural variations in mind, it is worth considering that studies by professionals involved in caring for youths with diabetes<sup>29</sup> stress the need for providing special attention to those between the ages of 18 and 25 – the range known as "emerging adulthood" within Arnett's contemporary theory of development.<sup>34,35,36</sup> Arnett holds that so-called "young adults" only acquire mature features after the ages of 25 to 30, and believes youths between the ages of 18 and 25 are experiencing an intermediate period in which they simultaneously desire and fear independence. Weissberg-Benchell et al.<sup>34</sup> note that young diabetic patients in this age range are more prone to treatment adherence issues and poor blood sugar control, and therefore have specific needs during this vulnerable transition period.

Studies of young adults with sickle cell anemia have found a lack of preparedness for transition to adult services and a lack of adequate follow-up.<sup>37,38</sup> These studies explored the expectations of adolescents and their family members regarding adult-oriented services. The expectations of young patients included finding a less child-oriented environment, attending visits by themselves, and receiving constant updates on their condition from their care providers. Family members had similar expectations, but also hoped that care providers would address sexually transmitted disease prophylaxis and encourage young patients to continue their studies and not miss or skip visits.<sup>32</sup>

Since 1995, the Canadian model for treatment of adolescents with rheumatic diseases has provided a special clinic for patients over the age of 18 who still feel unprepared to transition to an adult service.<sup>28</sup> Pediatric and adult rheumatologists see patients at the same facility, which also has other on-site professionals (nurse, social workers, occupational therapists) ready to provide joint pediatric/adult care and provides vocational counseling services. This model provides a supportive, educational environment so adolescents can become independent and empowered enough to transition at a later date, around the ages of 22 to 24.

### **Key elements of an effective transition program**

There is no "right time" for transition; it is paramount that the process be flexible. Authors are unanimous in stating that the most adequate timing depends on the extent to which adolescents are ready to transition, on their health condition, and on the preparedness of the adult-oriented

service to receive them. Although some services base the timing of transition on chronological age (15–20 years) or parallel social milestones, such as leaving high school, these should not be regarded as definitive parameters<sup>39,40</sup>; the subjectivity experienced must be closely and continuously tied to the external world in a balanced manner.

### ***The transition clinic***

One of various proposed strategies for better transition is the recommendation that a member of the pediatric care team “chaperone” the adolescent during his or her initial visit at the adult service.<sup>41</sup> An improvement on this recommendation has also been proposed: that the initial visit be followed by appointments with the adult-oriented provider, but in the pediatric environment. Only at a later, third stage would the young patient start to receive care from the adult-oriented provider at an adult practice or service.

### ***Barriers to successful transition***

Countless barriers to successful transition have been identified,<sup>34</sup> some organizational, some technical, and some behavioral. Notable examples include:

- Abrupt transfer with little or no prior preparation;
- Poor or absent planning;
- Resistance on the part of patients, family members, or even pediatric care providers;
- Delay in booking appointments at the adult clinic after transfer from the pediatric service;
- Poor preparedness on the part of adult-oriented services to receive and treat young adults with childhood-onset chronic conditions;
- Differences in care between pediatric services (which usually employ a more supportive, family-centered approach) and adult-oriented services (in which a greater degree of individual independence is expected);
- Poor or absent communication between pediatric and adult-oriented services;
- Poor or absent institutional support.

### ***Recommendations for good transition practices***

- Transition planning should be regarded as an essential component of care quality in adolescent-oriented health services.
- Services should be flexible and focus on young patients’ needs.
- Each general or specialist pediatrician should have a specific policy for transition. More formal transition programs are required in facilities with a large contingent of adolescents being transferred to adult-oriented services.

- Youths should not be transferred unless they have the conditions to attend an adult-oriented service and are past the growth and puberty stages.
- One person each from the pediatric and adult-oriented teams should be in charge of managing the transition.
- Good communications and connections between both services are a requirement.
- Large pediatric services should develop a “transition roadmap,” detailing how and where the process occurs in each specialty.

Constant assessment of how the process is going, with particular emphasis on young patients being treated at adult-oriented services, must take place for some time after the transition has been completed.<sup>33,34</sup>

However, we must note that these guidelines are based on limited experience and mostly reflect the viewpoints of U.S. and Australian services, where private care is common and subspecialization of pediatrics is highly widespread.<sup>33</sup> Development of a transition policy adapted to the Brazilian reality requires comparative studies that assess the various models described and evaluate the progression of each.

### ***Transition in the pediatric AIDS clinic***

The importance of this topic to the care of adolescents living with HIV/AIDS was first addressed in the Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection, published in 2006.<sup>42</sup> The corresponding Brazilian document also provided for discussion of this topic in its latest (2009) revision.<sup>43</sup> The chapter that addresses care of HIV-positive adolescents also notes key points for successful transition – that it be determined not by age (18 years) but by maturity, as measured by certain capabilities: being aware of the condition and its treatment, displaying ability to manage one’s own appointments, and being relatively clinically stable. The document also suggests that services employ a shared transition clinic where pediatricians and adult-oriented providers can interact during patient care until youths are ready to receive definitive care at an adult-oriented service.

The international literature on transitioning HIV-positive youths to the adult clinic is scarce. The theme is compounded by the social stigma of the condition and by questions surrounding burgeoning sexuality and risk of HIV transmission.<sup>44,45</sup>

### ***Adolescence and HIV/AIDS***

At some point during adolescence, youths living with HIV/AIDS must face issues such as fear of illness, fear of body changes associated with HIV infection or HIV treatment, and uncertainty surrounding progression of the disease

and the possibility that it may lead to death. During this period, adolescents begin to wonder about their future and whether they will be able to fulfill their aspirations. Fear of inadvertent disclosure of their HIV status may lead youths to postpone their educational and professional goals, all of which influences formation of the adolescent identity.<sup>46</sup>

In stark contrast to the substantial number of articles addressing transition in several subspecialties of pediatrics, the few studies on the theme within the specific context of HIV/AIDS infection are listed below.

In 2004, an NIH-funded program for 18-year-olds living with HIV/AIDS had to be discontinued for 12 months due to a reallocation of resources. In light of this decision, youths treated by the program had to be transitioned to other primary care facilities in their communities. This process was the subject of a scholarly investigation, during which researchers found that poor transition readiness was associated with higher levels of anxiety. However, transition readiness and degree of anxiety were not associated with disease severity. This may suggest that difficulty transitioning from one facility to another could be influenced more by the loss of a major affective bond than by disease severity or fears associated with the condition.<sup>39</sup>

A qualitative study by Vijayan et al.<sup>45</sup> highlighted two topics that arose from interviews with 18 adolescents, 15 parents or guardians, and nine health care providers: challenges in caring for these young patients and possible barriers to the transition process. Among the various challenges identified, three stood out: treatment adherence, sexuality, and disorganized social environments. Potential barriers to adequate transition were a lack of autonomy, negative perceptions or experiences of HIV/AIDS, and difficulty letting go of relationships between family members, adolescents, and care providers.<sup>40</sup>

Gilliam et al.<sup>47</sup> recently published an article on current features and practices of the transition of adolescents followed at a research network for HIV-positive youths, the Adolescent Trials Network for HIV/AIDS Interventions. The authors interviewed 19 people treated at 14 network clinics. Findings showed that the concept of a successful transition is still not well defined among all participating centers, and that there was no consensus on what points are important to a transition program. The authors also highlighted the lack of strategies for assessing follow-up of these young patients after transition to adult-oriented care.<sup>47</sup>

In Brazil, the model suggested by Schidlow & Fiel,<sup>48</sup> which employs a transition clinic, was introduced in 2007 at the Universidade Federal de São Paulo Pediatric Infectious Diseases Clinic, and is still at the assessment stage (personal communication, 06/02/2010). In this transition service, which uses the same physical space of the pediatric clinic, young patients who reach the age of 18 start to receive care from an adult infectious diseases specialist in conjunction with the pediatric care team. The team (pediatricians, a

nurse, a psychologist, and a social worker) starts discussing the transition process when patients reach the age of 16, at which time they are still under pediatric care. This strategy seeks to gradually introduce the patient to the idea of care by a new team of providers in a new environment, and provides a period during which caregivers can assess the patient's level of maturity and capacity to take on new responsibilities and envision the importance of playing a new role in his or her own care.

### ***Issues associated with poor or absent transition planning***

According to Viner,<sup>39</sup> poorly planned transitions may be associated with increased risk of treatment nonadherence and loss to follow-up. This may have disastrous consequences, such as increased complication rates, disease progression and consequent increases in mortality, and social and educational repercussions.<sup>49,50</sup>

### **Conclusions**

Transitioning adolescents from pediatric care to adult-oriented services is a process that requires flexibility and interaction between services and prior planning devised by the pediatric team in conjunction with patients themselves, their family members, and care providers in the receiving team. The timing of transition should not be determined by age alone, but by the preparedness and maturity of the young patient, which can be assessed by specific parameters.

Adolescents living with HIV/AIDS need special attention due to the particularities involved in their care, such as safer sex issues, disclosure of HIV status to partners, early experiences of loss in the family, constant struggling with the possibility of severe illness and/or death, and exposure to discrimination and prejudice, which makes this population even more vulnerable to the usual challenges of this turning point in life.

### **Final considerations**

A recent report by the Joint United Nations Programme on HIV/AIDS highlighted the lack of programs geared to people living with HIV/AIDS as a clear coverage gap, and recommended that efforts be made to implement and monitor disease prevention and health care actions targeting this population.<sup>51</sup> Health interventions should not only seek to prevent disease, but also provide the means for individuals and populations who may become infected to recover or adapt to their new reality with dignity.

Studies seeking a better understanding of how adolescents living with HIV/AIDS experience this moment in their lives may help develop integrated, contextualized health practices and thus favor a more healthy and aware transition of this population to adult-oriented care.

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