



# Transitioning from Adolescent to Adult Care in HIV

## Questions

- What are the challenges of transitioning from adolescent to adult care for people living with HIV?
- What strategies ensure effective transition to adult care among people living with HIV?

## Key Take-Home Messages

A range of social, psychological, economic, structural and cultural factors affect adolescents' ability to transition from pediatric HIV care to adult care. Compared to HIV-negative adolescents, adolescents living with HIV face unique challenges during the transition process. For example, adolescents living with HIV:

- may want to keep their medical histories private and may not be willing to disclose their status to new health care providers (1)
- may lack the knowledge and skills necessary to successfully transition to adult care (1)
- may not be not aware of what to expect during the transition period because care providers may not have shared this information with them (2)
- may encounter health care facilities that lack transition policies, making the transfer and sharing of health-related information difficult (3)
- experience a higher prevalence of mental health disorders than their HIV-negative peers (4)
- may face a more difficult transition to adult care due to their sexual orientation (4).

To overcome these challenges, a number of strategies have been recommended, including: education and skills training, assessment of patient readiness, the creation of clear transition policies, and

## References

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2. Fair CD, Sullivan K, Dizney R, Stackpole A. "It's like losing a part of my family": transition expectations of adolescents living with perinatally acquired HIV and their guardians. *AIDS Patient Care & STDs* 2012;26(7):423-9.
3. Michaelis AP. Helping young adults succeed in a world where "you can't": Transitions to healthy adulthood for HIV-positive youths in Baltimore, Maryland. US: The Johns Hopkins University; 2009.
4. Dowshen N, D'Angelo L. Health care transition for youth living with HIV/AIDS. *Pediatrics* 2011;128(4):762-71.
5. Boudreau ME, Fisher CM. Providing effective medical and case management services to HIV-infected youth preparing to transition to adult care. *Journal of the Association of Nurses in AIDS Care* 2012;23(4):318-28.

improved communication between patients and providers and between providers themselves. In addition, the provision of social services and mental and sexual health care, training sessions for care providers, and ongoing monitoring and evaluation are essential for successful transition.

## ! The Issue and Why It's Important

With the advent of highly active antiretroviral therapy (HAART), life expectancies of youth (15-24 years) with HIV have increased significantly (5-7). As a result, a growing number of adolescents living with HIV are faced with making the transition from pediatric care to adult care (4). The transition can be stressful for those who need to establish new relationships with care providers while developing the knowledge and skills necessary to manage their health (8).

Unlike HIV-negative adolescents, adolescents living with HIV face unique challenges during the transition process, including:

- stigma and the need to disclose their HIV status to friends, family and adult care providers (4)
- neurocognitive impairments and mental health problems associated with HIV (9)
- recognition that they face the risk of transmitting HIV to future sexual partners and possibly children (7).

It is important to note that, as youth face these challenges, they are transitioning to adult HIV clinics that are quite different from the pediatric care they are accustomed to receiving. For example, compared to adult care centers, pediatric care centers usually have lower patient-care provider ratios and they provide more integrated physical and mental health services (3;10).

According to a study by Cervia, 50% of youth with perinatally acquired HIV reported difficulty with medication adherence during the transition period (11). Adherence to medication can be significantly affected as adolescents try to accommodate their usual dosing into new adult schedules (5). Adherence can also be affected by psychosocial issues such as depression and substance abuse (4).

Unsuccessful transition can result in:

- high rates of youth lost to care
- youth developing weaker immune systems
- increased morbidity and mortality, and
- the possibility of youth developing drug resistance (12-14).

6. Bundock H, Fidler S, Clarke S, Holmes-Walker DJ, Farrell K, McDonald S, et al. Crossing the divide: Transition care services for young people with HIV—their views. *AIDS Patient Care & STDs* 2011;25(8):465-73.

7. Fair CD, Sullivan K, Dizney R, Stackpole A. Knowledge of disease markers and quality of patient-provider interaction among adolescents with perinatally acquired HIV: Implications for transition to adult care. *Vulnerable Children and Youth Studies* 2014;9(2):167-73.

8. Fair CD, Sullivan K, Gatto A. Best practices in transitioning youth with HIV: perspectives of pediatric and adult infectious disease care providers. *Psychology Health & Medicine* 2010;15(5):515-27.

9. Committee On Pediatric Aids. Transitioning HIV-infected youth into adult health care. *Pediatrics* 2013;132(1):192-7.

10. Newman C, Persson A, Miller A, Cama E. Bridging worlds, breaking rules: Clinician perspectives on transitioning young people with perinatally acquired HIV into adult care in a low prevalence setting. *AIDS Patient Care & STDs* 2014;28(7):381-93.

11. Cervia JS. Easing the transition of HIV-infected adolescents to adult care. *AIDS Patient Care & STDs* 2013;27(12):692-6.

12. Barrett A, Hutton N, Agwu A, Arrington-Sanders R. What factors matter most in HIV infected youth who transition from adolescent to adult HIV centered care? *Journal of Adolescent Health* 2010;46(2 Suppl 1):S25-S26.

One UK study that followed 248 youth transitioning from 14 clinics between 2003 and 2011 found 11 deaths (seven due to AIDS-related complications) during this period (13).

## What We Found

### Challenges associated with transitioning to adult care

#### Patient's Knowledge and Skills

A patient's lack of knowledge and self-care skills can be a challenge to transitioning to adult care. A qualitative study conducted by Sharma et al. involving 15 participants between 15 and 24 years of age with perinatally acquired HIV found a self-perceived lack of transition readiness. Many participants reported a lack of knowledge about their health needs and a lack of skills necessary to live independently (1).

A mixed methods study involving 39 caregivers and 12 adolescents living with HIV noted that a lack of knowledge about HIV and HIV medication was a barrier to transition (15). Similarly, in a qualitative study of 18 adolescents living with HIV, 15 parents, and nine pediatric care providers in the U.S., pediatric care providers perceived that adolescents lacked the basic life skills required to live independently with HIV (15). The pediatric care providers also observed that, in many cases, the adolescents were not taught these self-care skills as they were assumed to have short life expectancies (15).

#### Communication Difficulties

An interview conducted by Fair et al. among youth with perinatally acquired HIV demonstrated that poor communication is a key barrier to successful transition (4). A majority of the young people did not know what to expect during transition to adult care.

A review article by Dowshen and D'Angelo also identified poor patient-provider communication with regards to when a patient would transition to adult care and what the process would entail (4). According to a study by Fair et al. with 40 adolescents, understanding HIV disease markers correlated significantly with patient-provider interaction: patients with more knowledge had better interaction with their care providers (8).

#### Stigma and Discrimination

Stigma is a significant challenge for people living with HIV. Adolescents living with HIV have reported discrimination, violence and rejection upon disclosing their HIV status (11). Some youth who acquired HIV in adolescence (as opposed to being born with HIV)

13. Hussen SA, Chahroudi A, Boylan A, Camacho-Gonzalez AF, Hackett S, Chakraborty R. Transition of youth living with HIV from pediatric to adult-oriented healthcare: A review of the literature. *Future Virology* 2014;9(10):921-9.

14. Wiener LS, Kohrt BA, Battles HB, Pao M. The HIV experience: Youth identified barriers for transitioning from pediatric to adult care. *Journal of Pediatric Psychology* 2011;36(2):141-54.

15. Vijayan T, Benin AL, Wagner K, Romano S, Andiman WA. We never thought this would happen: Transitioning care of adolescents with perinatally acquired HIV infection from pediatrics to internal medicine. *AIDS Care* 2009;21(10):1222-9.

16. Katusiime C, Parkes-Ratanshi R, Kambugu A. Transitioning behaviourally infected HIV positive young people into adult care: Experiences from the young person's point of view. *Southern African Journal of HIV Medicine* 2013;14(1):20-3.

17. Valenzuela JM, Buchanan CL, Radcliffe J, Ambrose C, Hawkins LA, Tanney M, et al. Transition to adult services among behaviorally infected adolescents with HIV - a qualitative study. *Journal of Pediatric Psychology* 2011;36(2):134-40.

18. Persson A, Newman C. When HIV-positive children grow up: a critical analysis of the transition literature in developed countries. *Qualitative Health Research* 2012;22(5):656-67.

19. Maturo D, Powell A, Major-Wilson H, Sanchez K, De Santis JP, Friedman LB. Development of a protocol for transitioning adolescents with HIV infection to adult care. *Journal of Pediatric Health Care* 2011;25(1):16-23.

have expressed concerns that they will be identified as HIV-positive if they attend an infectious disease clinic (4).

HIV stigma can make adolescents cautious when seeking new health care providers (13). One study found that adolescents living with HIV wanted to keep their medical histories private and did not want to disclose these histories to new care providers (1).

### Co-morbidities

Adolescents living with HIV experience higher rates of mental health disorders (e.g. depression, anxiety), substance use issues, attention deficit hyperactive disorder and post-traumatic stress disorder as well as neurocognitive and behavioural problems than their HIV-negative peers (4). Psychosocial stressors may include discrimination due to HIV stigma, poverty, parental death, foster care placement, abuse and homelessness (9).

### Patient-Provider Relationship

Many articles described a strong relationship between patients and pediatric HIV care providers which can affect the transition process (2;9;11). A study conducted in Australia reported the perspectives of 12 pediatric and adult care clinicians on transitioning youth with perinatally acquired HIV. Pediatricians expressed fear of letting their patients go after establishing long-term relationships with them. Adult care clinicians expressed dissatisfaction that adolescents were being transferred without adequate preparation and information about expectations and adult care processes (11).

Adolescents living with HIV reported fear and anxiety around being able to trust their adult care providers as much as their pediatric providers (1). Many youth with perinatally acquired HIV compared losing their relationship with their pediatric providers to the loss of a family member (4).

### Health System Logistics

Certain challenges at the health care system level can also affect the transition process. According to a mixed methods study of 59 youth living with HIV, participants reported that adult care providers did not understand the specific medical and psychosocial needs of youth living with HIV (14). About a third of participants identified a lack of psychological support services in the adult care environment as a significant challenge during transition (14). The study also highlighted that pediatric and adult care providers did not recognize the need to consider adolescents' developmental and competency levels when the transition process was initiated (14).

Some health care system logistics have also been described as barriers to transitioning adolescents living with HIV to adult care—

20. Andiman WA. Transition from pediatric to adult healthcare services for young adults with chronic illnesses: The special case of human immunodeficiency virus infection. *Journal of Pediatrics* 2011;159(5):714-9.

such as long wait times and limited time with adult care clinicians (16;17).

Some youth living with HIV perceive adult care environments as less stimulating and friendly compared to pediatric care clinics (2;10;14).

Other health system concerns include a lack of transition policies and coordinators, as well as a lack of information regarding the transferring and sharing of patients' health information (3).

### Sexual and Gender Health

Sexual and gender health has been observed by some authors as a transition barrier (4;18). A review article by Dowshen and D'Angelo documented that adolescents living with HIV expressed concerns about their sexual health during the transition with regard to parenting and pregnancy (4).

In addition to HIV care, lesbian, gay, bisexual and transgender (LGBT) youth living with HIV struggle to access LGBT-friendly health care environments and providers knowledgeable about their specific health requirements (4).

### Other Challenges

Language and cultural differences may also compound challenges during the transition process (3). Cultural differences may exist between adolescents who acquired HIV perinatally and those infected during adolescence (9). The differences in psychosocial characteristics between youth with perinatally and behaviourally acquired HIV infection may affect their acceptance of HIV, their self-efficacy and their adherence to HIV medications (9).

## Strategies for improving transition to adult HIV care

While there are several challenges that may act as barriers for youth making the transition to adult care, there are also strategies to reduce these barriers, including:

- a **multidisciplinary team** approach involving pediatricians, adult care

providers, clinic nurses, social workers, peer educators, psychologists and nutritionists tailored to individual specific needs (9;11;19).

- a **transition plan** before the transition takes place (11). A review by Andiman et al. (20) advised that health care professionals should consider a patient's developmental age in delivering care. The transition plan should address any special care needs of youth living with HIV, such as the need for psychological support, counselling, appointment reminders, transportation funding, housing and employment (8;20). The transition plan should also address the potential impact of cultural differences that may exist among youth with perinatally and behaviourally acquired HIV (9).
- **education of adolescents** living with HIV about the transition process so they can acquire the life and care skills necessary for greater autonomy (9;11;19).
- some authors emphasized the usefulness of evaluating a **patient's transition readiness** (including knowledge and skills) using checklists and workbooks (4;8). At the institutional level, strategies such as creating a formal written transition policy and a registry for the regular monitoring and evaluation of transition may be helpful (9).

Effective patient-provider and provider-provider communication is also key to successful transition (5;9). Direct provider-provider interactions should start early, using electronic health records or portable health care records before a patient's first contact with an adult care provider (9). Follow-up contacts by a nurse or social worker from the pediatric care team are needed post-transition (9). In a qualitative study of 19 professionals in the US who had cared for adolescents living with HIV, frequent written and verbal communication between pediatric and adult care providers was identified as a best practice for achieving successful transition (8).

A review article by Boudreau et al. (5) emphasized

the need to provide sexual and reproductive health services with regards to sex education and screening for sexually transmitted infections and cervical cancer. Medication adherence support services also need to be provided as adolescents try to accommodate their medication dosing into new adult schedules (5).

Finally, effective health care system approaches include training adult care providers about the special needs of youth living with HIV (particularly mental health care needs) (11;13) and creating transition HIV care clinics to facilitate the transition process (15). It is important to connect adolescents who have mental health needs to community providers before the transition (17).

Considering the strong emotional attachment between patients and pediatric providers, pediatric care providers should encourage their patients to transition to adult care when it is appropriate based on their development (13).

## Factors That May Impact Local Applicability

All studies cited in this review were conducted in high income countries. However, we have removed references to private insurance or to the inability to pay for care, since these issues are not applicable in the Ontario context.

## What We Did

We searched Medline, Embase and PsycInfo using HIV (text term or MESH term) in combination with child\* or p\*ediatric or youth or adolescent\* or young (text terms) AND transition to adult care (MESH term for Medline and Embase) or transition\* adj3 care (text term). The search was conducted on 10 April 2015 and articles were limited to those published since 2005 in English. We only included studies from high-income countries.

## Rapid Response: Evidence into Action

The OHTN Rapid Response Service offers quick access to research evidence to help inform decision making, service delivery and advocacy. In response to a question from the field, the Rapid Response Team reviews the scientific and grey literature, consults with experts, and prepares a brief fact sheet summarizing the current evidence and its implications for policy and practice.

### Suggested Citation

Rapid Response Service. Transitioning from Adolescent to Adult Care in HIV. Toronto, ON: Ontario HIV Treatment Network; July 2015.

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