Challenges faced by HIV-positive youth transitioning to adult care and evidence-based practices to address them

Questions

- What challenges arise when youth living with HIV transition to adult care?
- What evidence-based practices and resources facilitate successful transition to adult HIV care?

Key Take-Home Messages

- The barriers to successful transition to adult HIV care include lack of preparation, psychosocial stressors, loss of relationships, stigma, and barriers within the adult health care system (communication, distance to travel, differences from the pediatric environment) (1).
- Factors facilitating successful transition to adult care include formal transition processes, preparation and readiness, adequate timing, adequate communication between pediatric and adult-care clinicians, and support from peers, family, case managers, and health care professionals (1).
- Transition planning should be a standard part of care for all youth and young adults, and every patient should have an individualized transition plan (2). Several toolkits, models, and recommendations on how to manage care transitions are available (3-19).
- Transition plans should be developed at least one year in advance, and the pediatric provider should arrange for one or more meetings between the adult care provider and the patient before transfer (5).
- Developmentally appropriate transition plans must take into account the educational, housing, and employment needs of the patient, and include psychological and case management services (5).

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The Issue and Why It's Important

Within the field of chronic illness, transition has been defined as the "purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-orientated health care systems" (20).

Transitioning from pediatric or adolescent HIV care to adult HIV care involves many challenges. Many children and youth growing up with HIV are used to family-centered, child-friendly, multidisciplinary primary care teams that might involve pediatricians, pediatric nurse practitioners, nurses, social work case managers, child life therapists, psychologists, nutritionists, chaplains, and other dedicated caregivers (21). Long-term bonds often exist between these care providers, patients, and families (21).

In contrast, the adult care model is more fragmented – with medical care, mental health care, and social services being offered separately – and requires more independent navigation of the healthcare system. Youth in transition must also confront the possibility of discrimination and stigma when disclosing their HIV status to new providers and other patients (22).

Research has found that many young people living with HIV feel that 18 is too young to transfer to adult care (23). Furthermore, this transition occurs at a crucial developmental stage, when inadequate care and support may negatively affect health outcomes. Youth who have acquired HIV perinatally may be especially vulnerable, as they often have more advanced disease than horizontally infected patients (24), and are more likely to be treatment resistant and require more complex antiretroviral regimens (24, 25). Youth living with HIV, in general, are also the least likely of any age group to be linked to care, which is defined as visiting a health care provider within 90 days of learning their HIV status (26). Retention in care and viral suppression are also low in this age group – according to data from 2012, only 21% of 18 to 24 year-olds living with HIV in the U.S. had been prescribed antiretroviral treatment, and only 16% were virally suppressed (24, 26).

Difficulty transitioning to adult care can have further impact on health outcomes. In one U.S. study, immune function trended downward among a cohort of young adults transitioning from pediatric to adult care, with 45% of patients reporting that the transition was more difficult than expected, and 32% being unable to find emotional support services (27). A recent study from Quebec also found that, among perinatally infected adolescents transferred to adult care, over two-thirds of study participants had detectable viral load, CD4 counts below 200 cells/mm3, and/or triple-class drug resistance (28). Similarly high resistance rates were reported among Spanish adolescents (29), and a multicentre audit in the UK and Ireland found

4. Maturo D, Powell A, Major-Wilson H, Sanchez K, De Santis JP, Friedman LB. Transitioning adolescents and young adults with HIV infection to adult care: Pilot testing the "Movin' Out" transitioning protocol. Journal of Pediatric Nursing. 2015;30(5):e29-35.

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8. ICAP. Adolescent HIV care and treatment, a training curriculum for health workers. Module 13: Supporting the transition to adult care. Participant manual. Available from: http://files.icap.columbia.edu/files/uploads/Module_13_-_PM_Adolescent.pdf. 2012.

complex medical and psychosocial issues among some young adults following transition to adult care, as well as mortality rates much higher than the age-matched, HIV-negative population (30).

What We Found

Transition in the literature is represented as a highly complex process that can involve a range of barriers (1). For instance, a recent qualitative meta-synthesis observed that a common experience for youth in transition was the feeling of being "in a kind of limbo between different cultures" (31). This feeling can be compounded by the challenges of changing care relationships, preparing for transition, and taking responsibility for managing health issues (31).

Successful transition is a process that takes time and requires a coordinated system-based approach (1). Much of the literature on this topic argues that disease-specific models are most successful in achieving this systems-based approach to transition, as this allows for tailored guidelines (1).

Barriers to successful transition

There are a number of issues identified in the literature that could be characterized as barriers to successful transition to adult HIV care (1). These barriers include:

- A *lack of preparation for adult care* due to the particularly intense and multidisciplinary nature of services available to children with HIV. In pediatric care, youth are guided and supported in their health care practices, and many rely on parents or caregivers to remind them to take their medication. In adult care, they are expected to have much more responsibility for medication and appointment adherence (32-34), while ending relationships with pediatric health care professionals who they might be very close to (21, 32, 34-37).

- A *lack of emphasis on teaching youth the skills* required to function independently as adults, including in the areas of sexual health and partner notification (1, 22, 38). Sudden transition can also be overwhelming for young people (36), and can lead to issues in building trust with adult care providers, and concern for the privacy of health information (33, 36).

- *Psychosocial stressors*: Comorbid cognitive or mental health issues (1, 22); deceased parents or other family members; experience of adoption or foster care (38, 39); poverty, unemployment, homelessness, or illicit drug use (34, 39).

9. ICAP. Adolescent HIV care and treatment, a training curriculum for health workers. Module 13: Supporting the transition to adult care. Presentation manual. Available from: http://files.icap.columbia.edu/files/uploads/Module_13_Adolescent.pdf. 2012.

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13. New York State Department of Health AIDS Institute. NYS Adolescent HIV Transition Guidelines. Transition to adults care guideline. Available from: http://www.hivguidelines.org/adolescent-hiv-care/transitioning-to-adult-care/. 2011.

- *Stigma* in both health care and family context can have a negative impact on disclosure and delay transition (1, 22, 27, 32, 34, 38). Youth who identify as gay, lesbian, bisexual or transgender can also face particular issues during transition, such as finding a provider who is knowledgeable and understanding of the special requirements of caring for them (22).

- In addition, some elements of the adult health care system in general may also negatively affect transition to adult HIV care. These factors include communication between clinicians (22), distance and transportation (34, 36), and unfamiliar and different environments compared with pediatric care (1, 27, 36, 38).

Facilitators of successful transition

There are a number of factors that can facilitate a successful transition to adult HIV care. These factors include:

- *Adequate preparation:* Transition discussions should begin with youth living with HIV and their families in early adolescence (36, 39), so that young people can acquire the independence, organisational, and communication skills they will need in adult care (1). Youth should be provided with options, such as choosing their preferred adult care clinician (36). Youth living with HIV also need to develop the skills to manage the transition – including making appointments, communicating directly with clinicians, and filling medication prescriptions (27, 32, 33, 39-41). Documentation and charting tools, such as checklists for knowledge and life skills, may help to build independence and autonomy (34, 39). The use of cell phones may assist young people in direct communication with their health care providers (6, 12).

- *Timing:* Transition should be a long and planned process, allowing young people sufficient time to adjust to the concept and prepare for the change (6, 32). Providing youth living with HIV with choice regarding when to transition can be very helpful (32, 35, 40). Developmentally appropriate transition is preferred over age dependent processes, but all young people need to be introduced to the concept of transition during adolescence (5, 27, 32, 39). Transition should be viewed as a process, rather than as an event (1, 22, 32, 34) and should be reviewed continuously to ensure care and treatment arrangements are appropriate (39).

- *Communication across the HIV care systems:* It is very important for pediatric and adult clinicians to

14. Next Step, MassCARE (Massachusetts Community AIDS Resource Enhancement). Moving On Positively. A guide for youth, caregivers and providers. Available from: https://www.k4health.org/sites/default/files/Moving%20on%20Positively%20Transition%20Guide.pdf. 2012.

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communicate well when exchanging medical and psychosocial information (22, 27, 40, 42). Some youth living with HIV may have concerns about disclosing information again to a new clinician (27, 32, 33), so collaboration between clinicians is essential (22). To support the adjustment, the pediatric clinician could accompany the young person to their first appointment in adult care (39, 40, 42). Contact with pediatric clinicians should continue during and after the transition process (27, 34). Adult clinicians should have open conversations with youth living with HIV about issues such as disclosure, risk behaviors, and sexuality (6, 22, 32), and help youth develop the skills necessary to manage HIV (27, 32).

- *Social and psychological support*: Youth living with HIV could benefit from meeting peers who have already transitioned into adult care, or from touring adult clinics with peers, case managers, or family members (3, 34, 39). Psychosocial support for youth is also helpful, particularly in relation to housing, transport, access or referral to mental health services and sexual health education (27, 34, 36). Since many youth living with HIV heavily depend on their family and other caregivers during pediatric care, some have expressed a preference for these individuals to continue their involvement during adult care (27).

Tools and evidence-based practices for successful transition to adult care

Principles common to all transition approaches

To facilitate successful transition to adult care, several tools have been proposed, implemented, and tested. There are a number of principles common to all sets of transition recommendations (5):

- Health care providers should deliver developmentally appropriate (not simply age-appropriate) care transition as a deliberate, coordinated process, not an event.
- Psychological and case management services should be available to the patient at all stages of the transition.
- A transition plan should be developed at least one year before the event, and the pediatric provider should arrange for one or more meetings between the adult care provider and the patient before transfer.
- The transition plan should take into account the educational, housing, and employment needs of the patient (5).

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Checklists to assess readiness for transition to adult care

Kronschnabel et al. (2016) proposed a transition readiness model to enable youth living with HIV to assume greater responsibility for their own health care (12). This model is based on three themes that influence transition readiness: social cognition; responsibility and skill development; and dealing with health-related stressors (12). The authors suggest the following benchmarks for assessing a youth's readiness for transition:

- comfort communicating with staff and encouragement to develop independence with care.
- comfort talking about their diagnosis with medical professionals and knowledge about their role in managing their illness.
- familiarity with the names and dosages of their medications and ability to provide their medical history to an adult clinic, whether by obtaining records from their pediatrician or by providing the phone number of the pediatric office where the medical records can be accessed.
- knowing the name of their health insurance program, and having contact information for any insurance-related questions.
- sole responsibility for filling prescriptions, scheduling all medical appointments, and having a reliable method of keeping track of future appointments, whether that is a mobile phone or paper calendar (12).

The New York State Department of Health has enumerated a set of skills that are crucial in facilitating healthcare transitions for youth living with HIV (13). Most of these skills are equally applicable to teens and young adults with other chronic conditions. They include, but are not limited to:

- making and keeping appointments
- learning what symptoms require urgent or emergent care
- learning how to fill and re-fill prescriptions
- developing daily routines that result in strict adherence to a pharmacologic regimen
- fuller understanding of HIV (13).

The New York State Department of Health suggests that success also be measured by the degree to which patients achieve personal

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and medical independence. Personal achievements include those associated with education, job training, parenting, and independent decision-making (13).

Yale-New Haven Children's Hospital has designed a Maturity Index Checklist that provides concrete evidence of a patient's level of readiness for transition (5). In addition to the skills in the checklist prepared by the New York State Department of Health (13), the Yale-New Haven checklist includes the ability to:

- arrange transportation to appointments
- know how to apply for available health and income assistance
- articulate educational and vocational goals; and know the names of medications (5).

Checklists, models, and protocols for the process of transitioning

In 2013, the American Academy of Pediatrics released recommendations for transition to adult HIV care that include four steps:

1. development of written policies to guide transition
2. joint creation of a transition plan by youth, family and providers
3. planned facilitation of youths' connection to adult clinics as transition is initiated
4. communication between adolescent and adult clinics during the transition process for quality assurance review (39).

A recent study conducted across 12 adolescent medicine clinics in the U.S. underscored the value of adhering to these transition recommendations (16).

The "Movin' Out" Transitioning Protocol developed at a special adolescent clinic in Miami in 2011 envisages a 5-step process for transition (3, 4):

1. Discussions between the client and the Special Adolescent Clinic team regarding the need to transition to adult care.
2. The client meets the adult infectious disease physician at the Special Adolescent Clinic during a regularly scheduled care appointment.

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37. Wiener LS, Zobel M, Battles H, Ryder C. Transition from a pediatric HIV intramural clinical research program to adolescent and adult community-based care services: Assessing transition readiness. Social Work in Health Care. 2007;46(1):1-19.

3. The client is seen at the Special Adolescent Clinic, but care is provided by the adult physician.

4. The client has his or her first appointment at the adult infectious disease clinic, with care provided by the adult infectious disease physician. If the visit is not successful (as determined by the client and/or the adult physician), the client may return to Step 3.

5. One year after the successful completion of Step 4, a follow-up appointment is conducted with the patient and the Special Adolescent Clinic's social worker and peer advocate. Any issues identified at this appointment are communicated to the Special Adolescent Clinic team and the adult physician (3, 4).

The "Movin' Out" protocol was tested in 2015 at a university-based adolescent medicine clinic in Miami with 38 young people living with HIV and transitioning to adult care (4). Results showed that, despite the small sample size, the protocol appears to be useful in guiding the transition process of adolescents and young adults with HIV to adult care; however, the authors note that more research is needed with a larger sample to fully evaluate the protocol (4).

Boudreau et al. (2012) suggest that health care providers can meet the needs of youth living with HIV by:

- connecting them with adult medical benefits and providers
- using their chosen methods of communication (e.g., cell phones, e-mail)
- developing individualized medication adherence strategies
- addressing sexual health and family planning issues
- providing developmentally appropriate prevention tools (6).
- Health care providers should also focus on a youth's strengths and coping skills and should solicit the youth's input throughout the transition process (6).

Columbia University's International Center for AIDS Care and Treatment Programs (ICAP) provides a detailed training curriculum for health workers in adolescent HIV care and treatment (7-9), which emphasizes that adolescents require support both within and outside of the clinic to take greater ownership over their health care, behavior, lives, and adherence (7-9). Effective transitions must allow for the fact that adolescents are undergoing changes that impact much more than just their clinical care (7-9).

Health care workers and adolescent peer educators can help

38. 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.

39. Committee on Pediatric AIDS. Transitioning HIV-infected youth into adult health care. Pediatrics. 2013;132(1):192-7.

40. 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.

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prepare for the transition process by:

- reviewing the client's medical history with them and encouraging the client to ask questions
- ensuring that the client understands their diagnosis, medications, adherence, and how to live positively
- promoting linkages to adolescent peer support groups and support groups at the adult clinic
- transitioning adolescents to adult care in cohorts or groups
- organizing health talks for transitioning adolescent clients
- encouraging older adolescents to take responsibility in making and keeping appointments and adhering to medicines (e.g. by using appointment and medicine calendars)
- familiarizing adult providers with the necessity of youth-friendly services through meetings, orientations, and training
- accompanying the client to the adult clinic for an orientation
- transferring the client's medical records to the new clinic and holding a case conference to discuss key issues
- involving peer educators, social workers, and counselors when planning for a client's transition, especially for those most at risk
- using a variety of youth-friendly activities, such as journaling or creating a "Transition Workbook"
- connecting youth living with HIV to other community-based services (7-9).

The Next Step project in Boston found that improving communication between patients, providers, and caregivers, and having peers help those who had transitioned or who were going through the process, facilitated transition (14). The Next Step project also found that: helping young people practice calling in prescriptions and managing their own paperwork gave them more agency before transition (14); establishing a transition coordinator, ensuring access to case management, and providing support around issues of adherence, disclosure, and mental health were important. The Next Step project stressed that young people are excited to grow up, take responsibility, and become successful adults. While leaving a pediatric family may be hard, they argue that treating transition as an accomplishment, rather than a dreaded reality, will make it easier (14).

In British Columbia, a proposed policy at The Oak Tree Clinic, which is the referral centre for HIV infected children and youth, requires collaboration between patients, their families, the pediatric team, and the adult care team, emphasizing that:

- all HIV-positive children and youth should have a family physician, ideally before their transition to adult care
- preparation to transition should be individualized
- patients can choose whether they will continue to have their care at the Oak Tree Clinic or transfer to another HIV clinic (17).

The authors of this proposal, however, acknowledge the challenges to implementing all recommendations, in particular, the current lack of a dedicated provincial social worker for youth in transition (17).

Toolkits for patients and health care providers

The Hospital for Sick Children in Toronto provides online information focused on helping youth successfully transition to adult care and on their "Positively Good 2 Go" program http://www.sickkids.ca/Go-Positive/index.html (19). This program provides information on HIV basics, sexual health, medications, substance use, adult clinic options, and links to other helpful websites

and resources. The website also provides transition tools including a readiness checklist, a MyHealth Passport (a wallet-sized card listing medical conditions and medical history), a transition booklet, a transition timeline, and information to make the first adult appointment easier (18).

A toolkit for youth living with HIV developed by Camp Sunrise and The Ohio AIDS Coalition (15) focuses on disclosure, treatment adherence and secondary prevention, entitlements, and legal protections for people living with HIV (15).

Cicatelli Associates, Inc. offers a toolkit for implementing a comprehensive program to support HIV-positive youth transitioning from adolescent to adult HIV care (10). It also provides information on how to set up and supervise a program for young adult leaders on self-management and life skills (10).

A guide developed by Jacob and Jearld (2007) provides tools to facilitate the transition process, focussed on six areas: self-advocacy and self-care, sexuality, employment, social network, permanency planning, and entitlements (11).

Factors That May Impact Local Applicability

All studies cited in this review were conducted in high income countries. Despite this, factors such as population demographics, socio-economic factors, the availability of specialized HIV medical facilities, and health care providers' expertise may limit relevance and transferability in the local context.

What We Did

We searched Medline using a combination of text terms HIV and transition* and (youth or adolescent* or young). All searches were conducted on August 9, 2017 and results limited to English articles published from 2007 to present. Reference lists of identified articles were also searched. The search yielded 354 references from which 42 studies were included.

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.

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