TRANSITION OF HIV INFECTED ADOLESCENTS TO ADULT CARE IN BRITISH COLUMBIA

Introduction

Initiatives to improve the transition of adolescents with chronic diseases from pediatric to adult specialized care are being developed at the provincial and national levels in Canada as well as in other countries. Gaps in continuity of care or loss to follow-up after discharge from the pediatric clinics lead to frequent drop out of care, poor health outcomes, increased use of emergency services, and increased costs.

In a policy paper by BC's physicians **"Closing the Gap: Youth Transitioning to Adult Care in BC"** (December 2012), ten recommendations were made to health authorities, care programs and the BC Ministry of Health. These include **having a family physician for every youth with a chronic illness**, an individualized **transition plan**, resources to manage the transition, **collaborative** processes **between pediatric and adult services**, **prolonged pediatric care when needed**, a method of **tracking after transfer** and **analyses of youth transition data**.

In April 2013, a group of professionals providing care to youth living with HIV in the largest Canadian centres attended a CTN Prevention & Vulnerable Populations Pediatrics-Adolescent-Transition (PVP-PAT) research planning meeting in Toronto on "Improving the Transition Process for HIV-Infected Adolescents in Canada". It was agreed to coordinate activities in the various sites in order to offer similar supports to transitioning youth across Canada, which would 1) be beneficial to the youth and 2) allow for future cohort or intervention studies. The proposed activities of "**CITHIA: Canadian Initiative for Improved Transition of HIV-Infected Adolescents"** are detailed later in this document.

Adolescents with HIV

In this era of combined antiretroviral therapy(cART) and greatly reduced HIV-related morbidity and mortality for HIV+ individuals with maximal adherence, most perinatally HIV infected children grow well into adolescence and adulthood, and have a long life expectancy. Canadian national surveillance data show that a third of those who were alive in 2010 had transitioned to adult care; the proportion is similar in BC, and is expected to grow in the next few years.

HIV infection poses **specific challenges** compared to other chronic conditions in adolescence:

- When HIV is acquired perinatally, the mother and possibly other members of the family are also infected. Familial support is weakened when the parents have their own health issues and psychological stressors. Many HIV-infected youth are orphaned, in foster care or adopted.
- Due to the **persisting stigma** around HIV infection, youth living with HIV rarely share their diagnosis, which limits their possibilities of receiving support from friends, relatives or community organizations.
- Sustained adherence to multidrug treatment regimens is more difficult to maintain when the diagnosis has to be kept secret.

- Taking responsibility of disclosing their status and avoiding transmission to sexual partners are added expectations for HIV+ youth.
- Some HIV infected youth are particularly vulnerable due to impairment of cognitive or adaptive functions, as a result of *in utero* drug or alcohol exposure (FASD), HIV encephalopathy in infancy and/or growing up in a suboptimal social environment.
- Some are new immigrants and are adjusting to a new culture and language which is very different from that of their country of origin.
- The majority of HIV infected youth live in poverty.
- Youth in the care of the Ministry of Children and Family Development (MCFD) or Vancouver Aboriginal Child and Family Services Society (VACFSS) are discharged at age 19 which leads to a sudden loss of support/housing.
- Some live at a distance from the HIV care centres and HIV specialists.

Current practice

The Oak Tree Clinic is the referral centre for HIV infected children and youth (<18) in British Columbia. Most HIV infected youth who are followed at the Oak Tree Clinic since childhood transition to an adult provider at the same clinic, while a few choose to be referred to other adult HIV clinics closer to their home.
For a successful transition we anticipate that **additional outreach / nursing / social work support will be required**, which is currently not available.

Proposed Oak Tree Clinic Policy for transition to adult care

The Oak Tree Clinic is committed to a smooth transition from childhood to adolescence to young adulthood care. This process requires collaboration between patients, their families, the pediatric team and the adult care team.

1. **All HIV infected children and youth should have a family physician, ideally before their transition to adult care.** Family physicians are expected to provide primary care into adulthood. They should receive consultation letters and, when appropriate, medication reconciliation forms. Telephone communication between the HIV specialist and family physician is encouraged to improve continuity of care.

2. **Preparation to transition will be individualized.** The youth should be involved as much as possible in planning all aspects of their transition plan.
   By age 12 years, adolescents will begin **transition planning,** having full disclosure about their HIV status and beginning to have their pediatric visits partially without their parents present.
   By age 16 years, youth will participate in their own care as adults, with modifications as needed for youth with special needs. They will gain gradual understanding of their condition and treatment, autonomy in managing their own health, taking their medications, re- ordering them, making and keeping medical appointments, organizing transport etc. They will be educated about HIV transmission modes, counseled around safer sexual practices, contraception and legal aspects of HIV disclosure to partners.
   By age 18 – 22 years, all patients will have "graduated" from pediatric care and will receive care from an adult HIV provider.

3. **Patients can choose whether they will continue to have their care at the Oak Tree Clinic or transfer to another HIV clinic.** While Oak Tree Clinic is predominately a women's and children's clinic, young adult male patients are welcome to continue receiving their care at the same location. Transition is anticipated to be smoother with a single switch of physician (pediatrician to adult provider) when the location, allied care providers (nurses, pharmacist, social worker, dietitian, front desk etc.) and the clinic setting remain the same. The youth is encouraged to transition to a different physician than their parents to preserve confidentiality and conflict of interest, but can go to their parent's physician if they choose to. If they do choose an alternate clinic, Oak Tree Clinic will facilitate the transition by communicating a summary letter and other documents as below (8). Resources should be available for Oak Tree to offer support from an outreach worker to make their first appointment to the adult clinic and attend the first 1-2 adult visit(s) with the youth, if they chose so.

4. **CITHIA – Canadian Initiative for Improved Transition of HIV-Infected Adolescents** is proposing to follow a checklist of tasks by age (from 13 to 17 years), including:

    - The "Good2go transition readiness checklist for patients" (SickKids questionnaire, assessing skills in managing their own health independently)
    - The "Good2go 3-sentence summary" (patient can give their past HIV history and treatment in 3 lines)
    - The "CITHIA specific knowledge form" (physician assessment of youth's knowledge of medications, viral load, CD4 count, resistance, modes of transmission, disclosure to partners)
    - A 16th birthday invitation letter to become part of the medical team as an "expert" and a graduation certificate from the pediatric HIV clinic (optional)
    - A consent for follow-up after transition
    - A template for the discharge summary letter

5. **Other strategies** to prepare youth for transition can include:

    - Phone calls, text messaging or social media contact to support adherence or appointment attendance, as per the youth's choice
    - In-person introduction of the adult care provider by the pediatrician. One or more initial **combined pediatric-adult visits** will be offered
    - Referral to one of the clinic outreach workers for psycho-social support around transition time
    - Outreach help with transportation to the adult clinic
    - Offering to attend the 3-monthly YOUTH GROUP CLINIC (started at the Oak Tree Clinic in July 2015). The clinics are scheduled in the late afternoon to allow for afterschool attendance. Youth start with an individual medical visit and participate in an educational group session facilitated by YouthCO. Topics of discussion are selected with the youth; an older youth may be invited as a mentor; food is provided. YouthCO then invites the group to a recreational outing for the evening. Outreach staff provides support with safe transportation. The goal is to maintain engagement in care and medication adherence

throughout the transition period by fostering peer connections and mentoring. Different clinic dates are planned for youth age 14-18 and 19-29 years.
- Referral to a peer support group (YouthCo)
- Referral to the Adolescent Medicine team, BCCH
- Referral to the Mindfulness Awareness and Resilience Skills for Adolescents (MARS) program

6. **Some patients may need prolonged pediatric care.** In cases where more time is needed to achieve autonomy, the youth should continue to receive pediatric HIV care until age 22. The youth, parents/guardians and pediatrician together will determine when the youth is ready to transition. It is understood that in case of hospitalization the youth will be admitted in an adult hospital.

7. **Support will be individualized based on the needs of the youth.** For example, youth with special needs may need help to fill in the questionnaires, and the knowledge form may need to be adjusted.

8. **Oak Tree Clinic team will ensure adequate information sharing with adult services.** The pediatricians insure timely transfer of comprehensive medical records to the adult HIV care provider with a summary letter including history of illness, antiretroviral and other medications history, immunization status, other health issues and specialists involved, social history etc.
   Allied health professionals will connect with their counterparts in the adult team as appropriate (social worker, dietitian, pharmacist, counselor, psychiatrist etc.)
   After transfer, the adult provider is expected to copy the first medical report(s) to the Oak Tree Clinic to keep the pediatric team informed of the outcome of the transition.
   Pediatric and adult teams should collaborate to keep track of each individual patient transferred to adult care, and to keep them engaged or re-engage them if lost to follow-up. ***Case management and intervention of the STOP AIDS team to get patients back in care should strongly be considered for youth who are not engaged in care***.

9. **Services for youth living outside the Lower Mainland:** Tele-Health consultations with their family physicians should be offered to help the transition for patients residing in remote areas. Tele-Health is available at the Oak Tree Clinic and many other locations throughout the Province. Youth should continue to receive specialized HIV care as adults, either in their area of residence or in Vancouver.

Note

This document was created by A. Alimenti, L. Sauvé and Neora Pick in September 2013. The authors, together with the Oak Tree clinic team, acknowledge the current insufficiency of resources to implement all recommendations adequately at this time, in particular, the lack of a dedicated provincial social worker for youth in transition.
The authors are committed to adapt these recommendations in the future, in alignment to further recommendations made by the ON TRAC initiative for youth with chronic diseases in BC and the CITHIA group for HIV positive youth in Canada.

References

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