Connection = Retention

An Overview of ACDR's HIV & Youth Peer Engagement Program

ACDR.

Background

- One population in particular is often underrepresented in conversation about HIV - namely those children born to an HIV positive parents who were themselves infected with the virus.
- Many of these children, born at the height of the epidemic were not expected to live to adulthood, and indeed, many lost one or more of their parents to AIDS related illnesses during the late 1980s and 1990s. However, with the successful roll-out of ART (antiretroviral treatment) in pediatric populations, more children are surviving into adolescence and are emerging into adulthood.
- With this, comes a new focus on the process of transition, which poses particular challenges for young people living with HIV as they age.

What is Transition?

- The purposeful, planned movement of adolescents with chronic medical conditions from child-centered to adult-oriented health care

Pediatric Care

Adult Care

Transition is not an EVENT that occurs at age 18 years but rather a PROCESS that takes place over many years

Understanding Teenagers

- Independence from parents/guardians
- Adopting peer codes and lifestyles
- Assigning increased importance to body image
- Establishing sexual, ego, vocational identities

Teen Brain: Cognitive Development

- Concrete to abstract thinking
  - Black and white
  - Difficulty generalizing rules
  - Take things literally
  - Non-linear growth: natural regression during stress and illness
- Egocentric
- Risk-taking behaviour
  - Infertile
  - Immortal
  - Immune

Blame it on the Brain

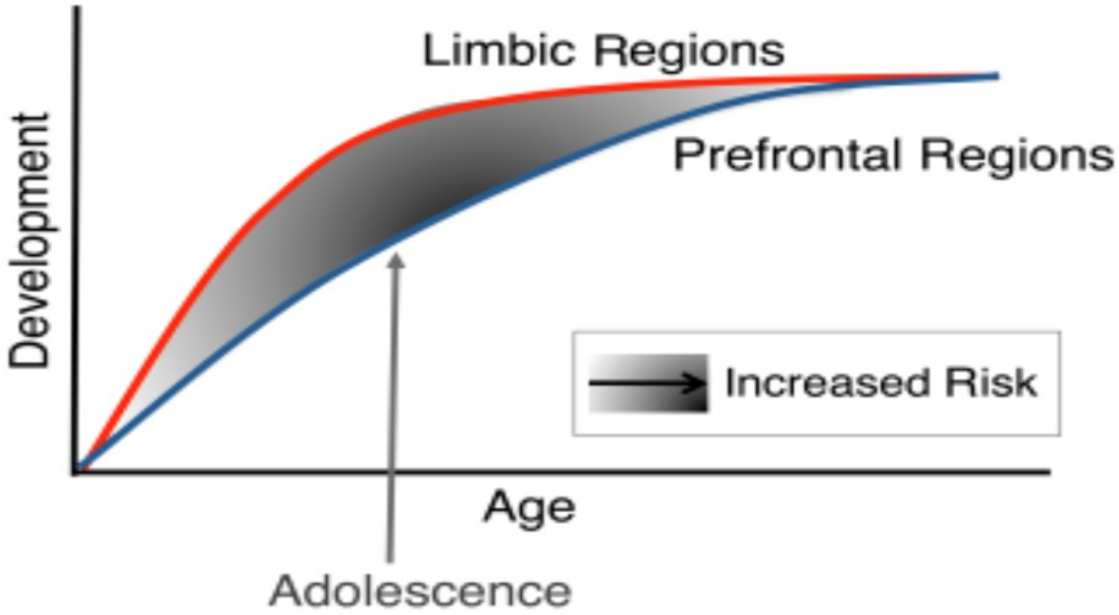


FIGURE 1 Neurobiological model depicting later development of top-down prefrontal regions relative to subcortical regions involved in desire and fear. This imbalance in development of these systems is proposed to be at the core of risky choice behavior in adolescents in contrast to the popular view of adolescent behavior being due to the protracted development of the prefrontal cortex alone (From Somerville, Jones, & Casey, 2010).

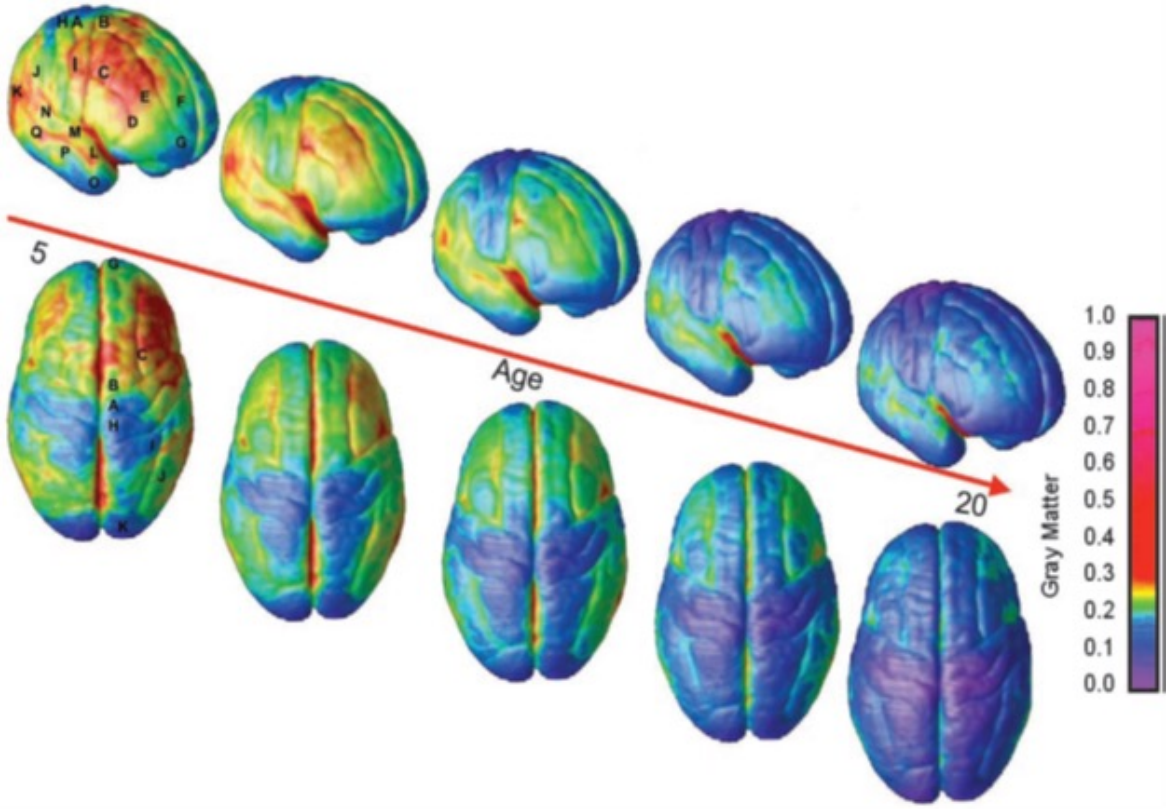
Limbic System:
Social-Emotional –
Matures earlier – leads to risk-taking, impulsivity, sensation-seeking
Important for learning and formation of identity

Prefrontal Cortex:
Cognitive control – decision-making, rational thought, organization
Matures later

Teen Brain: Cognitive Development

- Frontal Lobe
  - Last to fully develop – sometimes 3rd decade of life
  - Gives rise to “executive functions”
    - Organization
    - Planning
    - Self-regulation
    - Selective attention
    - Inhibition

(Casey, et al., 2000; Sowell, et al., 1999)



The Teen Brain and Implications for Clinical Practice

- Adolescent is expected to take on tasks
- Self management of condition
  - Plan ahead for appointments
  - Arranging to be away from school or work
  - Focusing on dialogue in clinic
  - Management of medications and symptoms
  - Problem solving

Difficult to do while executive functioning is developing!

DIFFERENCES

Pediatric Care

Family-centered, the patients and their parents and guardians are all involved in treatment decisions and care

Child friendly - colourful, warm and inviting environment.

One stop shop - multidisciplinary care teams including doctors from different fields, social workers, child therapists, case managers, nutritionists etc. who all work in concert to provide holistic care

Health providers spend more time with patients and families, explain things more thoroughly, and are more involved in all aspects of the care process

Relationship with doctors and health providers are strong and well developed. For many patients they have had the same care team all their lives.

Parents or guardians are present at all appointments, and have final say on treatment and care decisions.

Adult Care

Focuses on the patient.. Doctors typically do not work with families, and aren't trained in family-centered care.

Creating a warm environment is not a priority in adult care clinic. Could be lacking color and vibrancy or not feel quite as warm.

Care is much more fragmented and specialized. HIV treatment, general medical care, mental health and social services are offered separately. Requires independent navigation of service by patient.

Doctor talks directly to patient and expects them to be able to make independent decisions about their care. Medical appointments may feel shorter or even rushed..

Patients must form new relationships with doctors they don't know. Patients often have to disclose their HIV story to their new providers.

Parents/guardians are only present with patients consent. Patient is expected to be their own advocate and has the final say in care decisions.

Keys to Successful Transition

Communication Across Care Systems

Adequate Preparation

Social and Psychosocial Support

HYPE

ACDR

What does HYPE actually do?

Capacity Building

Reduce Social Isolation

Facilitate Cooperation

Capacity Building

Create opportunities for youth to participate in educational workshops on: the importance of remaining in care and treatment, strategies for adhering to medication and attending care appointment, navigating the disclosure of their status to partners, friends and loved ones, transmission prevention aimed at keeping their negative partners healthy, self care, anti-black racism, financial planning and ways to decrease isolation.

This includes ongoing assessments on changes in knowledge level, and behaviour.

Reducing Social Isolation

Establish a network of peer leaders across Ontario where long term survivors who are doing well in care can mentor the newly infected or younger positive youth.

These leaders will:

- Lead educational and social “Pozzy Meet-Ups” in their communities.
- The Peer Leaders will also create and manage online tools to facilitate ongoing communication and sharing of resources and best practices.
- Coordinate a province wide meet-up, where youth can interact with their peers from across Ontario.
- Create a matching program that finds youth who are doing well in care, and matches them with those who are struggling or new to transition. The goal of the matching program is to link youth a person within their community who can provide support which may include attending clinic visits with them, taking medication at the same time (in-person, or over video chat), or simply answer questions that may have.

Facilitating Cooperation

Working closely with pediatric clinics, the AIDS Service Organizations that support positive youth and the youth who are navigating the transition process, a document was created to inform adult clinics about the needs youth as they transition. The Transition Accord is a guide developed in the spring of 2016 that aims to ensure a successful transition from pediatric care to adult care. The

The HYPE Program will deliver presentations to adult clinic and service provider staff to inform issues unique to positive youth, and aims to get adult care clinics to change practices by adopting and implementing the recommendations in the Transition Accord.

The key goal of this strategy is to open up communication between pediatric and adult care providers, and to share best practices across these systems and challenge anti-black racism in the Healthcare system.

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Communication Across Care Systems

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Social and Psychosocial Support

Connection = Retention

“I attended HYPE last year and it was the first time I'd attended an occasion that had all poz youth. As I was coming up as child, [sic] there wasn't anything like it for me. I was forced to join grown women because nothing like HYPE existed at the time. The best way I can describe my experience last year is that it was like when you just feel free. I could talk about HIV with no fear whatsoever. The event was so well organized they catered to people's needs like they had Faith workshops, pregnancy, Blackness. [...] As I age out, my hope is that there will be more like this summit because being in a room with other poz young people without feeling like you're living two separate lives even though it was just four days does wonders for the spirit.”

Connection = Retention

“Before HYPE I was not taking my medication well and I struggled accepting my status! I was very depressed and I felt really alone. When I met Adrian [executive director of ACDR] and got connected with my HYPE people, things started to change for me. I became more positive, no pun intended! I had a support system and started taking my meds and taking care of myself. It felt great to have other people to talk to openly about my struggles and my small victories. I felt understood and no longer alone. HYPE helped me explore different ways to disclose my status which is something I struggled with; I still struggle with it but I have a few strategies to deal with this. I met my partner a few years after HYPE. Now I'm in a serodiscordant relationship with a man I love and we just had a bubbly negative baby.”

Connection = Retention

"I am on the Editorial Board of the Journal of Adolescent Health and am Associate Editor for the Global Health Section of BMC Public Health. In these roles, I review hundreds of papers per year that report on research and programming to improve the health of youth around the world. To date, I have not come across the report of any other program that accomplishes what I witnessed with my experience of HYPE at ACDR. It is a model that is both innovative and impactful and one that can offer important lessons on anti-racist youth leadership development to organizations across the globe".

LaRon E. Nelson, PhD, RN, FNP, FNAP, FAAN
Scientist & OHTN Chair in HIV Implementation Science with Black Communities
Independence Foundation Professor and Associate Professor of Nursing, Yale University
Associate Dean of Global Health & Equity, Yale School of Nursing

Thank You

Adrian Betts
Executive Director
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