

The Power of Knowing: Experiences of youth and caregivers with pediatric HIV disclosure

Lisa M. Butler, PhD, MPH, PHD

Division of General Pediatrics, Boston Children's Hospital
Department of Pediatrics, Harvard Medical School

Robert Inglis

Jive Media Africa

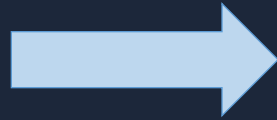
Pediatric HIV in sub-Saharan Africa: Incidence, Treatment Coverage

- **3.3 million children 0-14 years living with HIV worldwide**
 - 3.1 million in sub-Saharan Africa
- **~ 280,000 incident infections in children annually in low- and middle-income countries (LMICs)**
- **~ 630,000 children on ARVs in LMICs**
 - 544,000 in sub-Saharan Africa

Increased survival to adolescence → new challenges

- Clinical

- Chronic disease (lung, cardiac)
- Growth failure
- Neurocognitive disease
- Skin disease
- Renal and bone disease



Increased need for youth to be aware of and understand their HIV diagnosis

- Mental Health

- Depression
- Anxiety

- Behavioral

- ART adherence
- Sexual behavior

Pediatric HIV Diagnosis Disclosure

- WHO recommends HIV diagnosis disclosure by age 12 years
- Benefits of disclosure
 - Reduced rates of emotional and psychological distress
 - Improved engagement in care
 - Improved ART adherence
 - Reduced morbidity & mortality
- Prevalence of pediatric disclosure: 2% to 39.5%

Barriers to paediatric HIV diagnosis disclosure

- Age and perceived cognitive ability of child
- Illness related fears
- Belief that non-disclosure will protect the child from social rejection
- Fear of a negative emotional reaction from child
- Concern that child will not maintain secrecy leading to negative social effects
- Uncertainty regarding how to start discussion or how to answer questions

d.i.s.c.o. Kids

dialogue i nterventions to S upport C ommunication & O penness



- NICHD R01HD074261 (PI: Butler)
- Collaborators: Makerere University-Johns Hopkins University Research Collaboration & U California San Francisco
- Randomized controlled trial to test effectiveness of a cognitive-behavioral intervention on disclosure and short- and long-term psycho-social, mental health outcomes of children and ART adherence in children

Development of *The Power of Knowing*

- Purposive recruitment
 - caregivers of HIV-infected children who had previously disclosed to their child
 - HIV-infected youth age 18 and older
- Facilitator led 'memory work' with caregivers and youth
- Discussion regarding potential implications of participating in film
- Consent
- Interviews and filming
- Viewing and editing with participants
- Viewing with participants and family members/ friends

A woman and a man are standing on a rocky outcrop, looking out over a lush green valley. The woman is wearing a black top and a patterned skirt, while the man is wearing a yellow hoodie and dark pants. They are holding hands. The valley below is filled with dense green trees and a river flows through it. The background shows rolling hills under a hazy sky.

The Power of Knowing: Experiences of youth and caregivers with pediatric HIV disclosure

Available at:

World Health Organization

Adolescent HIV testing, counselling and care

http://who.int/maternal_child_adolescent/documents/hiv-testing-counselling/en/

Acknowledgements

Jive Media Africa

- Robert Inglis, Director
- Hilary Kromberg, Art Director

Sinomlando Centre for Oral History and Memory Work

- Nokhaya Makiwane, Specialist Contributor

WhizzKids United Health Academy

- Marcus McGilvray, Specialist Contributor
- Gugu Mofokeng, Specialist Contributor

Funding:

- National Institute for Child Health and Development, R01HD074261
- Boston Children's Hospital Aerosmith Endowment Fund