Reconstructing the truth: Life experiences of Puerto Rican perinatally HIV-infected youth with disclosure

Georgina Silva-Suárez, PhD 1, Consuelo Beck-Sagué, MD 2, Silvia Rabionet, EdD1,4, Irma Febo, MD 3, Carmen Zorrilla, MD 3

1 Nova Southeastern University, College of Pharmacy; 2 Robert Stempel College of Public Health and Social Work, Florida International University;
3 School of Medicine, University of Puerto Rico, Medical Sciences Campus; 4 School of Public Health, University of Puerto Rico Medical Sciences Campus

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BACKGROUND
The lives of perinatally HIV-infected (PHIV-I) youth have been cloaked in silence and secrecy. Unlike children with other chronic diseases, PHIV-I children are less likely to be told about their illness (1). Revealing the diagnosis to them requires disclosing family secrets as well as revealing other HIV diagnoses among family members. Disclosure events happen in several moments during their lifetime.

PHIV-I youth are affected by others’ lack of knowledge of HIV, and may express fear of rejection and discrimination when they disclose their HIV status (2, 3). When, why, and to whom to disclose, are among the questions adolescents living with HIV ask themselves. Public health professionals work diligently to encourage judicious disclosure to prevent risky sexual behavior, and transmission of the virus and drug resistance (4). PHIV-I youth who may be willing to disclose their HIV status may face a number of difficulties, including the uncertainty of others’ reactions, fear of rejection, stigma, and fear of losing control of their personal information (3). These youths are more likely to reveal their diagnosis in specific circumstances such as a being in a romantic relationship, getting married, having a child, and getting a job (3).

METHODS
Interpretative Phenomenological Analysis (IPA) was used to explore the life experiences of PHIV-I youth in Puerto Rico. The foundation of a phenomenological research is to examine an experience or phenomenon “the way it occurs and in its own terms” (5, p. 12). The aim of IPA is to explore how people make sense of their everyday life experiences (5).

Twenty in-depth interviews with 12 women and 8 men aged 18-30 years were conducted and audio-recorded. Their experiences as young persons living with HIV were explored and questions exploring their experience with disclosure were asked. Data were analyzed using NVIVO. Interrelationships, connections and patterns were assessed.

FINDINGS
Sixteen of the 20 participants recalled the age when their HIV diagnosis was revealed.
- The youngest at 4 years old
- The oldest at 18 years old

Thirteen participants learned about their diagnosis through the UPR Pediatric HIV/AIDS Research Program, from a multidisciplinary team.

The remaining participants did not recall how they learned their diagnosis, or found out through a parent or caregiver.

What Knowing Their HIV Diagnosis Meant:
- A greater understanding.
- They became aware of the social implications of having HIV, which they have to bear as they transition to adulthood.

Now, when I started to understand what it really was and what the diagnosis is and everything, it was very tough and I won’t deny it. I went really crazy, I started thinking that no man was going to want me; umm, that I would disgust him or cause disgust in someone that I liked (Isabella, 22 years old).

DISCLOSING TO OTHERS: WHAT IT REALLY MEANS

Some felt an urge to reveal their HIV status to their partners or significant others.

It was very hard, it was the most difficult thing I’ve done in my life. It was very hard, I cried like I’ve never cried… I didn’t know how to start, I didn’t know how to finish (Emma, 20 years old).

Responsibility to others and to themselves:
- Youth reported a strong sense of responsibility to others.

CONCLUSION
- Positive consequences = acceptance
- Participants agreed that acceptance had been a positive experience for them. They felt empowered and loved.

REFERENCES