

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 nevertheless 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

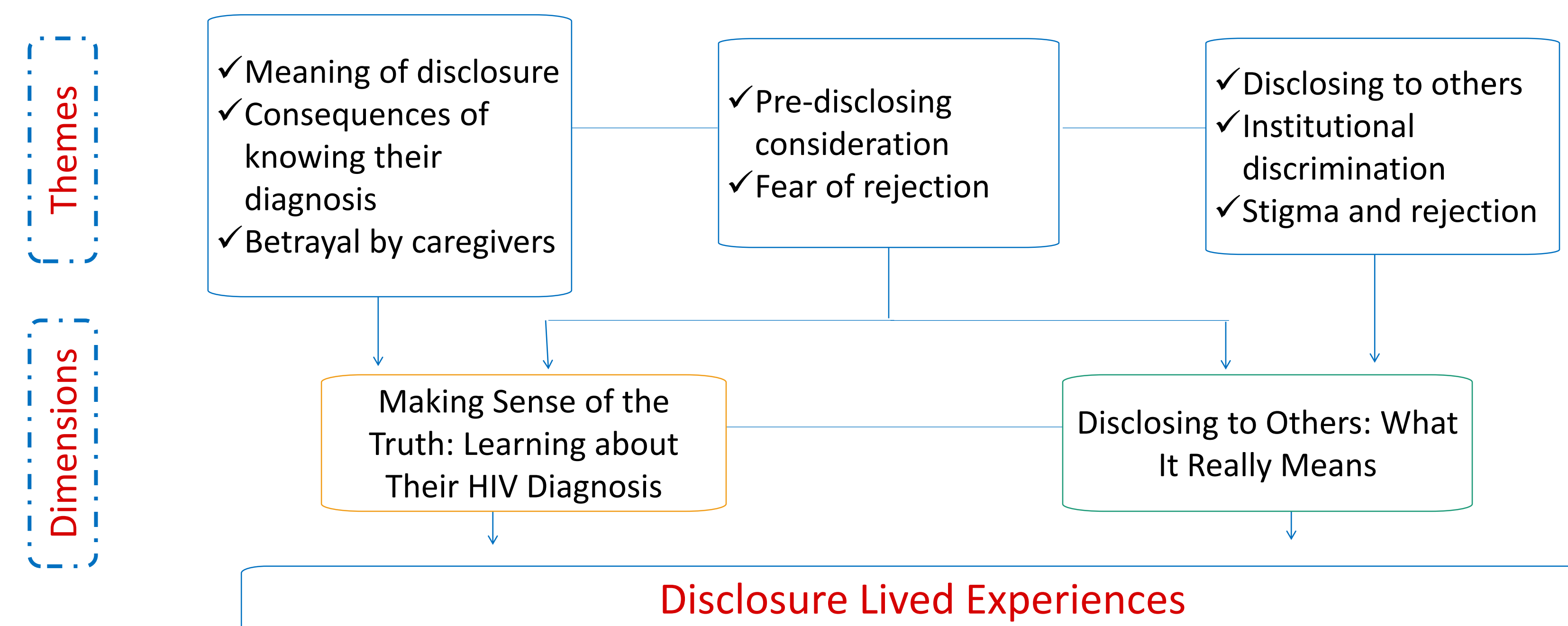
Interpretative Phenomenological Analysis (IPA) was used to explore the life experiences of pHIV-I youth in Puerto Rico. The foundation of a phenomenological research is to examine an experience or phenomenon "the way it occurs and in its own terms" (5; p. 12). The aim of IPA is to explore how people 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.

DEMOGRAPHICS

| Sample by gender | Male | Female |
|-----------------------------------|------|--------|
| n=20 | 8 | 12 |
| Age distribution | | |
| 18-21 | 5 | 6 |
| 22-25 | 2 | 5 |
| > 26 | 1 | 1 |
| Highest Academic Degree Completed | | |
| Middle School | 0 | 2 |
| High School | 8 | 10 |
| Marital Status | | |
| Single | 6 | 10 |
| Married or cohabitating | 2 | 2 |

Patterns and Connections Among Themes That Emerged During IPA Analysis



FINDINGS

Making Sense of the Truth: Learning about Their HIV Diagnosis

- 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.

Well, at the age of 9, they explained it to me with a little book. I remember, they put me there in a little room and they explained it to me with the little book. It's like there's the virus, which is bad, and the defenses are trying to fight it; and they told me. [AND WHO TOLD YOU?] Oh, I don't remember, ha ha. [BUT WAS IT IN YOUR HOUSE?] No, it was at [the UPR Pediatric HIV/AIDS Research Program]; they explained it to me with a little book, and I understood (Marina, 23 years old)

- 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 (Isabel, 22 years old).

Disclosing to Others: What It Really Means

Their Perception About Disclosing:

- Something that pertains to them and their private sphere.
- They considered it as something very difficult to do

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).

- Most felt an urge to reveal their HIV status to their partners or significant others

Responsibility to others and to themselves:

- Youth reported a strong sense of responsibility to others.

Well...is like any other illness: ...you have to treat it and you have to take care of yourself, you have to take care of others. We have to protect the people we're with. Sex is good, that isn't questioned and no one can say the contrary. But you have to be careful. [] There's no need to be selfish (Arturo, 22 years old).

Consideration Before Disclosing:

- Level of mutual trustworthiness
- That the other person is non-judgmental and understanding.

Timing of Disclosure:

- Some reveal their diagnosis almost immediately after they meet possible partners.
- Others prefer to assess their relationship before disclosing.
- In some cases the delay in disclosing to intimate partners is not on purpose.

Consequences of Disclosing:

- Discrimination, rejection, violation of confidentiality, vulnerability, and gossiping.

One time I experienced something strange, but it didn't bother me. But, it was when I had the girl because when I had the girl they did not see me until 2 o'clock and I heard the doctor when he said "...remember that she's an HIV patient, so we have to leave her for last" and it made me feel bad at the time (Fernanda, 29 years old).

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

CONCLUSION

- Participants' experiences learning about their HIV status shaped their perceptions towards disclosing to others. Delaying disclosure causes them anxiety and stress. All participants agreed that knowing the truth was best. After periods of denial and subsequently, acceptance, they reported greater adherence.
- This research supports the importance of providing management strategies not only for their health situations but also for its social implications.
- Disclosure policies and practices must take into account pHIV-I youth's needs and desires so that they can be active participants in their care.

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