

The Future Wishes of Adolescents Living with HIV and Perinatal Exposure

Philip Kreniske, PhD, Julia Ettlbrick, Rehema Korich, MPH, Nadia Nguyen, PhD, Claude Ann Mellins, PhD
HIV Center for Clinical and Behavioral Studies at the New York State Psychiatric Institute and Columbia University

Background

- In the United States (US), advances in HIV prevention and treatment has converted the pediatric HIV epidemic to one of adolescents and young adults (AYA).
- Approximately **11,000 AYA**, perinatally HIV-infected (ALPHIV), now 13 years or older, live in the US.
- The majority of PHIV+ AYA in the US have faced chronic life adversities such as poverty, violence, trauma, and stigma/discrimination, resulting in potential for psychiatric illness and poor adherence to HIV treatments.

Narrative Coding

Using a **values analysis approach** (Daiute, 2014; Kreniske, 2014) wishes were coded into three overarching categories based on the intended wish beneficiary:

- *Self*: benefiting the wisher.
- *Family*: benefitting the family of the wisher.
- *Greater good*: benefitting the immediate or global community.

We compared wishes from BL to FU1, and adolescents living with perinatal HIV infection (ALPHIV) compared to adolescents who were perinatally exposed but uninfected (ALPHEU).

Participants

Participants ages **9-16 years (mean 12.5)** were recruited into a longitudinal cohort study of ALPHIV and ALPHEU, the Child and Adolescent Self-Awareness and Health (CASA) study from four NYC medical centers.

- ALPHIV ($n=206$)
- ALPHEU ($n=134$)

There were few demographic differences between the two groups (Mellins et al., 2009) overall 51% of participants were female, 65% of participants were Black and 42% were Latino. **As part of the extensive psychosocial CASA interview participants were asked: if we could grant you three wishes — what would you wish for?**

Method

Random selection of **20% of the sets of three wishes** recorded at baseline (BL) and at the **18-month-follow-up (FU)**. Using **50 participants' wish sets** (100 sets of wishes when adding BL and FU), resulting in a total of **295 individual wishes**.

- ALPHIV = **34** out of the 50 wish sets
- ALPHEU = **16** out of the 50 wish sets

Results

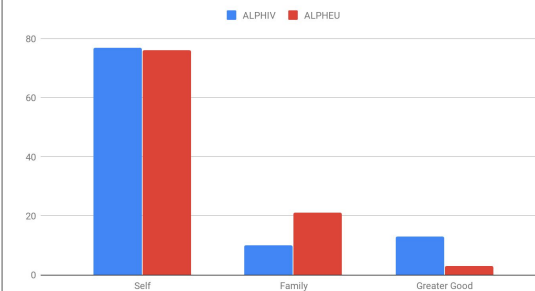
- **There were few differences between BL and FU1 wishes.**

- Note: More ALPHIV narratives focused on *greater good* (13%) than *family* (10%) as compared to ALPHEU (3% *greater good*, 21% *family*).

Combined

- **Self (77%)**
 - “My wish is to have a cat.”
 - “My wish is I wish I never had human immunodeficiency virus.”
 - “My wish is to make it to the fifth grade.”
- **Family (13%)**
 - “My wish is for a good life for me, my mom and my sister.”
 - My wish is to buy my mom a big house.”
 - “My wish is for my father to get a chance to open his own upholstery shop.”
- **Greater good (10%).**
 - “My wish is to get all homeless people houses.”
 - “My wish is to make the world a better place.”

ALPHIV and ALPHEU



Discussion

Despite the challenges associated with growing up with HIV, the ALPHIV appear to **express similar wishes** to their ALPHEU peers; both groups focused on self-wishes. However:

- **ALPHIV** expressed wishes that were more oriented toward the **greater good**
- **ALPHEU** focused more on **family**.

It is possible that part of the experience of being HIV+, as compared to peers who were uninfected, spurred these adolescents to think more about broader issues facing society. It is also possible that the increased counseling and services available to ALPHIV could have promoted this robust commitment to the greater good in ALPHIV as compared to ALPHEU.