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The Impact of the Initial Diagnosis Disclosure Experience on Long-Term Mental Health Outcomes of the Longest-Living Survivors of Perinatal HIV

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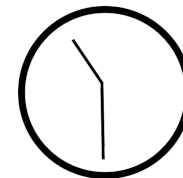
Background

>12,000

individuals in the United States were living with *perinatal HIV* in 2019.



Diagnosis disclosure is the critical point when an individual with perinatal HIV learns that they have HIV.



The context of the disclosure experience can negatively or positively impact individuals.

Background



The WHO recommends disclosure between ages 6 *and* 12. However, most disclosure occurs later.



Delayed disclosure has been associated with poor mental health.



Individuals prefer disclosure by parents alone or with a healthcare provider, but concrete guidance on *whose* role it is to disclose is lacking.

The Gap



The longest-living survivors of perinatal HIV

- Survivors' negative feelings about their experience can *re-emerge*.
- Perinatal adults may continue to be re-traumatized.
- Research with perinatal adults is scarce.
- Specifically, the impact of their age at diagnosis disclosure and the identity of their discloser *together* on their mental health status is understudied.

How would survivors' current mental health status differ if they had been disclosed to by a parent or guardian at a young age versus a healthcare provider (HCP) at an older age?

Methods



Participants: From the Beating the Odds: Living with HIV from Infancy to Adulthood (BTO) study. (Protocol 2003-001)



Eligibility: ≥ 25 years; U.S resident; acquired HIV from MTCT.

Statistical Analysis: Adjusted logistic regression to estimate the standardized contrast between poor mental health prevalence given disclosure at age six by a parent or guardian versus disclosure at age 18 by a HCP.

Standardized contrast \rightarrow **Average treatment effect (ATE)**

Average Treatment Effect (ATE)

- How would survivors' mental health *differ* if they had experienced the alternate (counterfactual) disclosure experience?
- Estimates *population-level* effect
- **Average treatment effect (ATE)**
 1. Predict all survivors' mental health outcome for each disclosure experience arm using model.
 2. Subtract means to get the mean difference.
 3. Interpret as risk difference → difference in risk of experiencing a poor mental health status between disclosure experience arms.

Participant Characteristics



$N = 70$

56



Mean age at disclosure

12 years

Over half told by a parent or guardian



identified as female

Age 25-30



Age 31-40



Age 41-49



two-thirds experienced poor mental health



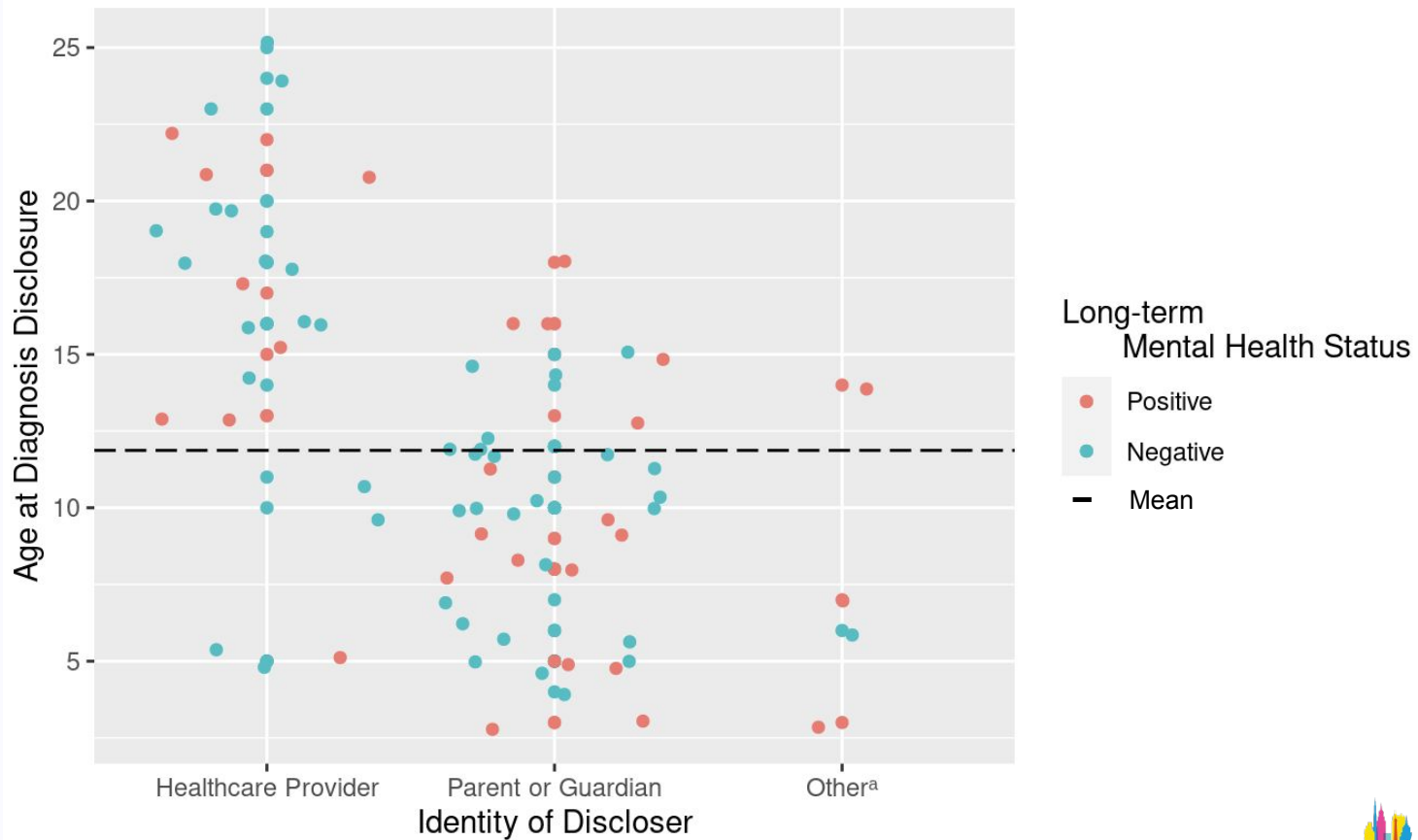
74% identified as Black or African American descent

Age at disclosure significantly differed by discloser identity group (Chi-square $p < .001$)

- Those disclosed to by a parent or guardian were, on average, *younger*, than those disclosed to by a HCP.

Figure 1

Age at Diagnosis
Disclosure by Discloser Identity Among BTO Survey Participants (N=70)



^aParticipant refused to answer (n=1), Participant learned from their brother (n=1), Participant overheard parents discussing their serostatus (n=1), Participant figured it out themselves (n=1).



Results

Table 3. Under the assumption that groups are comparable, the average treatment effect (ATE) on long-term mental health status had all survivors learned of their serostatus from a parent or guardian at the age of six versus had all survivors learned of their serostatus from a healthcare provider at the age of 18 using adjusted regression standardization (n=70).

	Estimate
ATE (ref=learned from healthcare provider at age 18)	-0.1031
Bootstrap Std. Err.	0.1186
95% Confidence Interval	-0.3355-0.1293

*The overall risk of experiencing a negative long-term mental health status would be **10% lower**...*

Discussion: Main Findings

1

Age at diagnosis disclosure differed by discloser identity group (Chi-square $p < .001$).

2

Survivors risk of experiencing a poor mental health status during adulthood could be reduced by *approximately 10%* if they are disclosed to by a parent or guardian at the age of six.*

Discussion: Previous Research



Previous studies found:

- Average age at disclosure was 12.
- Disclosure to survivors did not worsen their mental health.

However, most previous studies:

- Pertain to youth (≤ 25 years)
- Do not measure impact of discloser

The *most* similar study:

- Found that young adult survivors felt neutral or reported a good QOL regardless of disclosure experience.
- But, was qualitative and had systematically different participants

To my knowledge, this is the first study to examine the impact of age at diagnosis disclosure and discloser identity on long-term mental health status of *adult* survivors.

Recommendations

Increase sample size and representativeness

Control for social support and loss of or abandonment by parents

Cohort study with frequent follow up periods

Conclusion

- Disclosure by parents or guardians at a young age could protect survivors' mental health later in life.
- The point estimate invites the opportunity for future research.
- We must diminish the ambiguity around diagnosis disclosure in order to:
 - Protect youth
 - Foster positive development across the lifespan

Thank You

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