

“It’s all about labels” : Caregiving Experiences Amongst Guardians of Adolescents and Young Adults Living with Perinatally-Acquired HIV (PHIV)

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Introduction

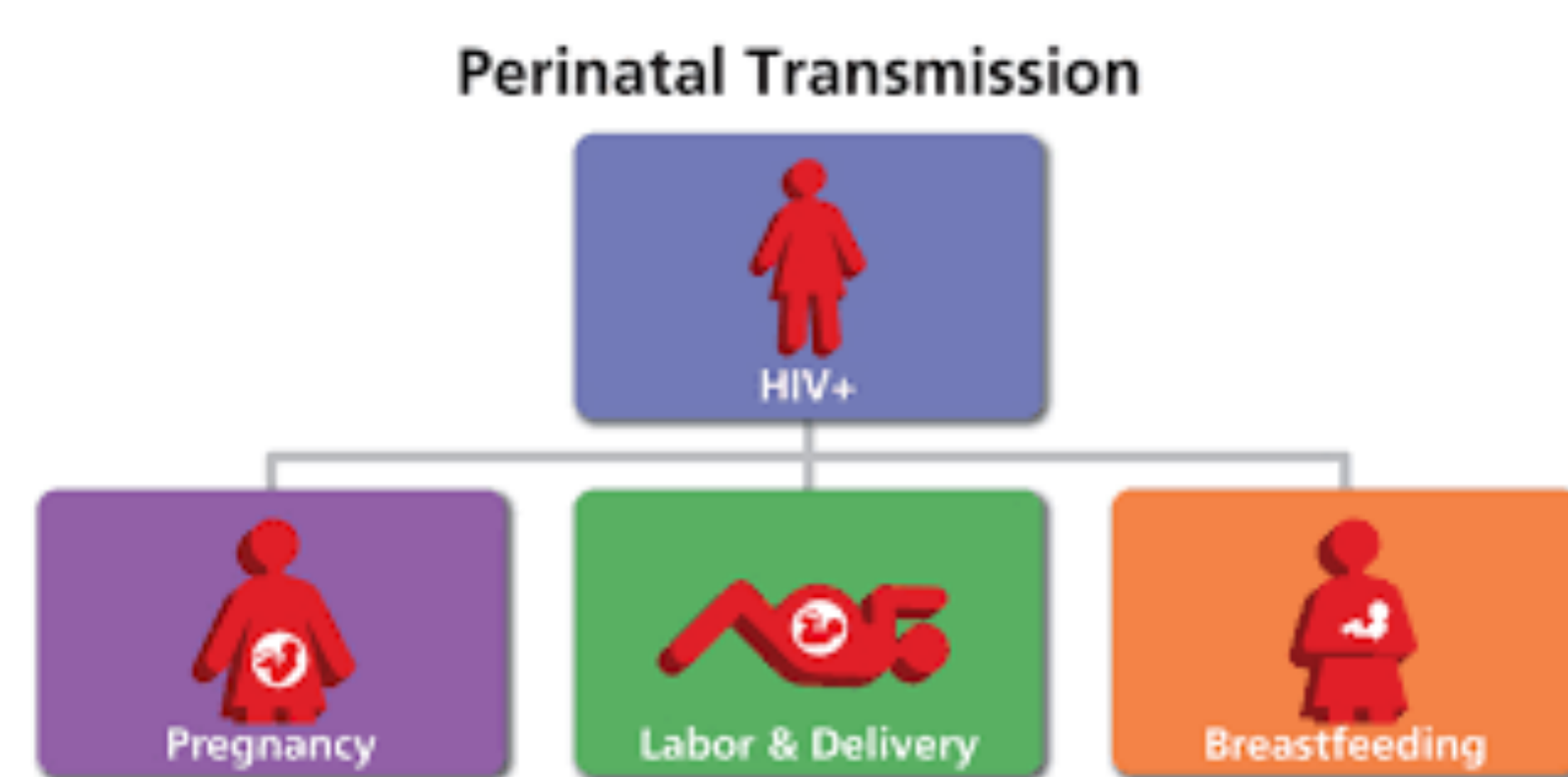
Prior to the use of antiretroviral treatment in the 1990’s:

- Approximately 30% of children born to HIV-positive mothers were also HIV-infected and many did not survive early childhood.
- Children born with HIV typically experienced upheaval in their daily lives due to parental illness and absence resulting in the need for additional caregivers.

Today the risk of mother-to-child-transmission in the US has reached a record low:

- Youth with perinatally-acquired HIV (PHIV) are living well into young adulthood.
- However, minimal research has been conducted to examine how PHIV impacts parental relationships as these children become young adults.

Because of their lived experience, caregivers of adolescents and young adults with PHIV have a unique perspective regarding the ways in which the social context surrounding PHIV has changed over time.



Methods

This qualitative project utilized semi-structured phone interviews to examine themes found in caregiver/child relationships. Participant demographics included:

- Eighteen caregivers (10 biological mothers, two caregiver relatives, four adoptive mothers, and two step parents) who cared for adolescents with PHIV over the age of 14.
- Nine identified as African American, five as white, three as African, and one as Hispanic.
- Mean age of participants was 50.5 years (range 40-75).

Participant Quotes:

Support

“[NIH has the] best doctors in the whole wide world. [They’re] helpful in every way possible. Words cant express how I feel about the doctors”

“When I don’t have medicine money [NIH] will donate. When I can’t get to the appointments they will send a cab. “

Safe Sex

“I buy my daughter a whole case of condoms...and some people say that’s encouraging your children. If it’s encouraging them, then it’s encouraging them but I’m not a dummy. I know they’re out there doing something so I always tell them to use these.”

Independence

“She don’t take her medicine on a regular basis now that she’s older and I’m not the person that’s going to shove it down her throat...when she was younger, I gave it to her all the time because I was in control of that.”

Hope/Pride

“I’m very proud of [my daughter]. I always taught my girls early, you’re not dying from HIV or AIDS. You’re not dying from it. You’re living with it.”

Reproductive Decisions

“My concerns are [my daughter] finding a life partner that’s open to her HIV status and her having children that relates to her HIV. I think with treatment, which she’s not on right now, it’s extremely low but I think any risk is too risky.”

“Aww, I want them to have children so bad I think if it’s one thing that really affects me, [tears up] and I know now that they can do it.”

Discrimination

“That’s the thing that I worry about today for people that go to the clinic is they’re not getting that same love and compassion.”

Results

Analyses revealed six primary themes:

- Strong sense of support from ID doctors and social workers (16/18)
- Safe sex rather than abstinence based sex education within the home (15/18)
- Challenges related to young adult independence in managing their HIV care (14/18)
- Continued sense of hope for change in the future (12/18)
- Guardian pride in their children’s accomplishments (12/18)
- High stress related to reproductive decisions alongside a desire to have children (9/18)
- Continued discrimination within the medical field (6/18)



Discussion

Concluding thoughts:

- Infectious disease health and social service care providers offer meaningful support to their patients.
- More must be done to address societal stigma, guidance in reproductive decisions, and familial support as adolescents with PHIV mature into adulthood and seek to form families their own.