



Received: 10 November 2017
Accepted: 06 April 2018
First Published: 19 April 2018

*Corresponding author: R. Wang'onde,
Combined Internal Medicine/Pediatrics
Residency Program, Yale School of
Medicine, New Haven, CT, USA
E-mail: ruth.wangonde@yale.edu

Reviewing editor:
Albert Sabater, University of Saint
Andrews, UK

Additional information is available at
the end of the article

SOCIOLOGY | RESEARCH ARTICLE

Desire for improved disclosure, community and bonding among young adults with perinatally acquired HIV

R. Wang'onde^{1*}, S. Samuels², W. Andiman³, E. Paintsil³, L. Barakat⁴ and A. Langs-Barlow⁵

Abstract: The increasing number of patients with PHIV transitioning into adulthood in high-income countries over the last decade or so has provided health care providers with opportunities to learn about unique obstacles and challenges faced by this population. To better understand the lived experiences of youth with PHIV, we conducted comprehensive interviews with nine patients with PHIV, between 19 and 30 years of age, at the Yale New Haven Human Immunodeficiency Virus (HIV) Program. Our interviews aimed to provide youth with PHIV a forum to share their views about: (1) what comprises a good quality of life (QoL), (2) their personal experiences with HIV disclosure, and (3) challenges they faced growing up and transitioning into adulthood. We derived supporting data on the resilience and QoL of our participants from responses to The Brief Resilience Scale and WHOQOL-HIV BREF surveys. Common themes that emerged included: desire for improved disclosure of HIV status, fear of stigma, and anger against biological mothers. Anger against biological mothers appeared to worsen feelings of isolation and adherence to medication. Our findings suggest that forums to enhance sharing of experiences and improve age-appropriate HIV knowledge are potentially important in caring for patients with PHIV.

Subjects: Social Sciences; Behavioral Sciences; Health and Social Care; Medicine, Dentistry, Nursing & Allied Health

Keywords: HIV; adolescents; youth; perinatally acquired HIV; anger; stigma; disclosure; resilience; quality of life

ABOUT THE AUTHOR

R. Wang'onde is a resident physician in the combined medicine and pediatrics residency program at Yale New Haven Hospital. She is interested in (1) chronic health conditions affecting children in the United States and in resource-limited areas, including Sub-Saharan Africa and (2) the clinical and psychosocial aspects affecting transition of patients with chronic health conditions from pediatric to adult health care systems.

PUBLIC INTEREST STATEMENT

Our study explores the experiences of adults between the ages of 19 and 30 who acquired HIV at birth, through what is termed mother-to-child transmission of HIV. These adults share powerful stories of their experiences learning about their HIV status when they were children, growing up with HIV, and transitioning from childhood to adolescence and then adulthood. Some of their experiences highlight what is already known about challenges faced by this population but this does not make their stories any less powerful or meaningful. These patients' stories also provide some new insights on the challenges faced by patients who acquired HIV at birth.

1. Introduction

Globally, approximately 3.7 million children live with Human Immunodeficiency Virus (HIV) (WHO, 2012). Historically, the clinical trajectory of patients with perinatally acquired HIV-infection (PHIV) is fraught with unique challenges compared with patients with behaviorally-acquired HIV. Not only do youth with PHIV have longer, more-complicated, treatment histories but they also face specific social, psychological, and developmental challenges (Bush-Parker, 2000; Foster & Fidler, 2011; Gadow et al., 2012; Hazra, Siberry, & Mofenson, 2010; Hoffman, Futterman, & Myerson, 1999; Koenig, Nesheim, & Abramowitz, 2011; MacDonell, Naar-King, Huszti, & Belzer, 2013; Murphy, Roberts, & Herbeck, 2013). Emerging data highlight an alarming increase in mortality for youth with PHIV, particularly during transition to adult care (Wood, Dowshen, & Lowenthal, 2015; Zandoni & Mayer, 2014). Targeted interventions that address the multi-level vulnerability of youth with PHIV are required to decrease the morbidity and mortality of this growing population around the globe.

A number of studies have explored barriers, challenges, and opportunities for the care of children and adolescents with PHIV as well as the transition of their care from pediatric to adult health care systems (Pinzón-Iregui, Ibanez, Beck-Sagué, Halpern, & Mendoza, 2017; Vijayan, Benin, Wagner, Romano, & Andiman, 2009). As children with PHIV transition beyond adolescence, an increasing number of research studies are focusing on adults with PHIV (Frederick et al., 2000; Lee et al., 2006). And, an increasing number of studies of youth with PHIV specifically highlight the personal views of these young adults on their own quality of life (QoL), recollections about their childhood, and their lived experiences, offering unique insights about their past and present lives (Silva-Suárez, Rabionet, & Zorrilla, 2017; Williams et al., 2017). By targeting youth with PHIV in the 19–30-year age-range, in this qualitative study, we aimed to identify issues which may influence their HIV-related care as adults and obtain unique insights on issues they considered important when they were children and adolescents. We elicited their views on (1) what comprises a good QoL, (2) their personal experiences with HIV disclosure, and (3) challenges they faced growing up and transitioning into adulthood. Through these interviews we endeavored to capture patients' perspectives and provide them with a unique opportunity to articulate their own opinions about factors that influenced their QoL through childhood into adulthood. We explored themes that provide insights on improving adherence to combined anti-retroviral therapy (cART) and clinical outcomes for patients with PHIV.

2. Methods

2.1. Study design and sample

Participants were recruited from the Pediatric HIV and Adult HIV clinics at Yale New Haven Hospital in New Haven, Connecticut between January and December 2014. Adolescents and young adults meeting the following criteria were eligible for the study: (1) between 19 and 30 years of age; (2) history of perinatal HIV infection; and (3) English speaking and able to review and sign the consent form. Patients who were critically ill were excluded from the study. Physicians, nurse practitioners, and social workers directly involved in patient care identified eligible patients based on eligibility criteria and informed them about the study. Basic information regarding the purpose of the study and study methods was relayed to eligible individuals over the phone or during clinic visits. Providers clearly informed patients that their decision whether or not to participate would not impact their access to medical care or any of the clinic's services and obtained their permission to be contacted by study researchers. Out of approximately 15 individuals informed about the study, 12 patients agreed to participate and provided permission to be contacted by study researchers. Three of 12 patients who agreed to participate were unable to attend interviews due to schedule conflicts. The Human Investigation Committee at the Yale School of Medicine approved the study protocol.

2.2. Data collection and analysis

All study participants completed a Brief Resilience Scale (BRS) Survey and a WHOQOL-BREF survey prior to interviews. The BRS, which is reported to have good internal consistency and test-retest reliability (Smith et al., 2008), was used to measure how participants perceived their ability to bounce back from stress at the time they were interviewed. A score of less than 3 on the BRS scale is considered a marker of low resilience while a score of greater than 4.3 is considered a marker of high resilience (Smith, Epstein, Ortiz, Christopher, & Tooley, 2013). The WHOQOL-HIV-BREF scale (O'Connell & Skevington, 2012), a QoL instrument to assess wellbeing in adults with HIV, was used to measure each study participant's subjective perception of his or her QoL. The scale consists of 6 domains: physical, psychological, level of independence, social relationships, environment, and spirituality. Mean scores for each domain range from 4 to 20. Similar to prior studies that have applied the WHOQOL-HIV-BREF scale, we interpreted scores of 4–9.9, 10–14.9, and 15–20, as representing perceptions of low, intermediate, and high QoL, respectively (Cunha et al., 2016).

Nine face-to-face semi-structured interviews, lasting between 90 and 120 min, were conducted. Interviews explored views on: (1) QoL, (2) personal, familial, and social factors that subjects felt impacted their participation in HIV care, (3) disclosure of their HIV status, and (4) how the view of the above issues may have changed over the course of their adolescence. Questions probing participants' views on their QoL included "What do the words 'good quality of life' mean to you." Questions on disclosure included "Please tell me about the moment you found out you had HIV?" and "Do you wish you could have found out in a different way?" The set of questions addressing factors influencing respondents' health care included, "What influences how you care for your health?"

All interviews were conducted in strict confidentiality by study authors (RW, SS, and ALB) and conducted in designated interview rooms on the Yale New Haven Hospital campus. Interviewers were not directly involved in the clinical care of the subjects. All interviews were audiotaped and anonymously transcribed verbatim by an independent contractor.

For thematic content analysis, a unique subset of interview transcripts was independently reviewed by two of the authors (RW and ALB) to identify preliminary common codes based upon interview questions as well as new emergent codes. Based on a review of preliminary codes and code definitions the two coders generated a list of codes of common personal, familial, and social factors impacting respondents. Definitions for these common codes were then used to code all transcripts.

3. Results

3.1. Demographic, HIV disease characteristics, and family structure of study participants

We interviewed 9 participants with a mean age of 24 years (Table 1). Six participants were female. Four participants identified their race as Black, 3 were white, and 2 were Hispanic. All, except one, of the study participants had received HIV-related care at Yale New Haven Hospital since birth. The CD4 count of participants was ≥ 350 cells/mm³, for at least one year preceding the interview, and all participants were on cART with undetectable viral load or viral load less than 1,000 copies/ml.

All study participants experienced the absence of their biological mothers for the entirety of their lives or for a significant proportion of their lives. Several study participants were raised by female relatives, either an aunt or a sister. Two study participants were raised by foster or adoptive parents. Three participants were raised by at least one biological parent for a portion of their lives. Biological mothers of six participants were physically absent from their lives or unknown to study participants. Of the three participants raised by their biological mothers for a portion of their childhood; two subsequently experienced the death of their biological mother, one at age 6 and the other at age 16, the third of these participants was abandoned by his biological mother at age 15.

Table 1. Demographic characteristics of the study population

Variable	N (9)
Gender	
Male	3
Female	6
Age, mean years (Std. Dev.)	23.7 (4.2)
Race	
White	3
Black	4
Hispanic	2
Employment status	
Employed	5
Unemployed	4
Marital status	
Single	7
Married	1
Living as married	1

3.2. HIV-related QoL profile and brief resilience scale among study participants

Seven study participants (78%) had average scores of greater than 3 but less or equal to 4.3, which suggests average resilience. Mean scores for QoL perceptions in six domains of WHOQOL-HIV BREF scale were 14.9 (SD ± 4.4) in the Independence domain, 14.9 (SD ± 4.9) in the Social Relationships domain, 15.4 (SD ± 4.2) in the Physical domain, 15.5 (±3.0) in the Environment domain, 15.7 (±3.0) in the Religion domain, and 16.1 (±3.5) in the Psychological domain. Overall average WHOQOL-HIV-BREF scale scores of study participants ranged between 10 and 19.6, suggesting that study participants perceived themselves as having intermediate to high QoL. WHOQOL-HIV-BREF scale scores were categorized into two groups of high QoL versus low QoL using the median score for each domain as a cutoff point. Using this classification, a majority of participants had scores in the low QoL category (66.7–88.9%). The proportion of respondents with low QoL scores was highest in the social relationships domain (88.9%) followed by the religion domain (77.8%). The relatively low scores in the social relationships domain suggested social isolation among majority of participants.

3.3. Recollections of HIV disclosure and suggestions on improvement

Our study participants shared their recollection of the timing and nature of the initial conversations they had about HIV disclosure. They also reflected on aspects of their HIV disclosure which could be improved.

All study participants recalled HIV disclosure occurring before age 14. Seven out of nine study participants reported HIV disclosure between 6 and 12 years of age, within the age range for HIV disclosure recommended by the WHO (2011).

Seven participants recalled that they learned about their HIV status from foster or adoptive parents. Three participants recalled health care providers being involved in the initial disclosure or subsequent disclosure. All except one study participant distinctly remembered when they first found out their HIV status. The one study participant who did not distinctly remember the exact moment when she found out her HIV status reflected on the normalization of her HIV status, which she attributed to the fact that her mother discussed her own HIV status on public forums. She shared, “I don’t remember ... what age I was, but I just remember I always had HIV... it wasn’t like oh my god I’m HIV positive ... with my family everyone like knew about it and it was not a big secret because they knew that my mom had it”.

Several participants recalled that HIV disclosure occurred when caregivers were discussing the need to start or continue taking cART. One participant shared, “I found out my status when I was in eighth grade because they were thinking about putting me on medicine.” Another participant remembered being told, at age 10, that she had HIV after she challenged her stepmother to tell her why she had to take pills.

Several participants recalled being overwhelmed by various aspects of disclosure including the timing of the disclosure, secrets shared during their initial HIV disclosure, or the emotional turmoil of learning their status in response to rumors. For instance, one participant recalled learning about her adoptive status during the same conversation that her HIV status was disclosed, at seven years of age. She shared, “I just started crying because I was adopted; I wasn’t even crying because I had HIV. I didn’t even know what that was.” Another participant was told she was HIV-positive to dissuade her from running away. She shared, “I was with a sister, a step-sister of mine ... I was going to run away and she didn’t want me to run away and she just told me my situation, that I had HIV ... I felt destroyed.” Two study participants found out their HIV status when they confronted their caregivers as a result of rumors among their friends. One of these participants sustained a cut while playing with his friends and soon heard rumors that he was “sick”. Another participant shared that, while in eighth grade, her cousin started rumors about her HIV status which prompted a conversation with her parent during which her HIV status was confirmed.

Most study participants indicated a general lack of understanding of the implications of the information provided at disclosure. One participant who learned of her HIV status at age seven said: “I really probably didn’t understand about HIV yet.” Another participant whose mother disclosed her HIV status at age 12 shared: “It didn’t really dawn on me ... I still didn’t really understand until I got older.” Another participant who similarly learned of his HIV status at age 10 recalled that it was only later that he grasped the depth and implication of his HIV-positive status. He recalled, when he was 14 years old, asking his health care provider: “what is the term HIV?” After hearing it defined, he recounted: “Well, I was stunned speechless and just felt like I was just gonna die ... I was told that it was a—a very bad disease—And I had to take the medication in order to stay alive.” Another participant, who also did not fully comprehend the information relayed to him during disclosure at age 10, reflected on ideal aspects of HIV disclosure: “I think if someone were to be told they should be told at a young age but [also] told repeatedly ...” This participant also attributed his engagement in risky sexual behavior during early adolescence to lack of age-appropriate, timely information, about the modes of HIV transmission.

3.4. Feeling of abandonment and a desire for bonding

A sense of loss and or, abandonment was pervasive amongst our study participants. A majority of participants attributed this to not being raised by their biological parents who were absent due to death, substance abuse, or imprisonment. One participant felt that the absence of his biological parents robbed him of a sense of support that other children raised by both parents enjoy: “I didn’t have the support that a lot of kids [have]. I didn’t grow up with a mom and dad”. Another study participant shared, “I wasn’t a happy child because I wasn’t raised by my mother. My sister raised me, so as soon as I found out who my real family was it went downhill from there. The people that I thought would make me happy they’re not here”.

Several participants cited a need for community, for a common bond with other HIV-positive people. One participant cited this desire in her views on how to improve care for young adults and adolescents with HIV: “Maybe have more ... groups ...with people their age, so they can know that they’re not alone. ... and so that they can talk to each other, find community in each other, find commonality in each other. ... you know, they’re not alone, there’s other people out here that have the situation and are going through it. But they don’t know that there are other people like them, so maybe if, you know, you have groups, ... or it doesn’t even have to be groups. Like sitting around a table talking or go to arcade or sports game or something fun, and then can break the ice into developing a bond or something.” Another participant desired a common bond with other people with PHIV. She recalled

that she had been to groups for HIV positive people who got HIV “through sex or drug usage” but “they were never my age”. She added, “I don’t know anybody who got it from their parent or parents.”

Overall, citing a lack of opportunities to discuss their experiences, participants expressed appreciation for the opportunity to share their stories about living with HIV during interviews.

3.5. Anger against biological mother

Anger and blame were commonly cited directly or inferred by the responses obtained from seven participants. Several respondents were angry that their biological mothers transmitted HIV to them or that their mothers abandoned them.

One participant was unequivocal in expressing her feelings towards her biological mother: “Oh, I don’t blame anybody in the streets I don’t blame my family. I blame my mom. I will always feel this way. My biological mom is the one that messed up and I blame her for everything.” Another participant still attributed all blame of his positive HIV status to his mother despite identifying the shared responsibility of both biological parents in transmitting HIV to him. He shared, “I never was angry at my father, because he got it too. ... I mean they were on drugs, and sharing needles. That’s how they probably got it. ... but I blame her because I came from her.”

Several participants viewed their anger as a barrier to medication adherence. For one participant, the sight of her medication was a reminder that, thanks to her mother, she was being subjected to a fate that she did not deserve. She shared: “Every time I look at the medicine ... I’m like, ‘Damn. Why do I have to take the medicine ... I didn’t do anything.’ I could understand if I got it through sex. ... But I got it from my ... mother.”

One participant described her attitude towards her biological mother as a driving force in her self-care. She shared that the most important factor which influenced her adherence to medication was “forgiveness of my biological mother.” She added that forgiveness of her biological mother “brought a realization” that she had to take care of herself.

3.6. Fear of stigma

All participants experienced the effect of stigma. The fear of stigma prevented some participants from disclosing their HIV status to friends and others in the community. They reported expecting or experiencing unfair treatment because of their HIV status. One respondent, unable to specifically describe the difference in how people treated him after learning of his HIV status explained: “Having this illness can make you feel very isolated. Even the people that you disclose to it’s not quite the same. They can be there to support you, they can even be there to talk, or even to listen but it’s just weird. I can’t really describe it, it’s just a feeling.”

Another respondent described experiences during which people with whom she shared her HIV status stopped talking to her.

After he disclosed his HIV status to his teacher, one respondent recalled being warned to be careful sharing his HIV status “because there’s a lot of discrimination.” Another study participant was warned not to get a tattoo because “the needle goes so deep in your skin.” Asserting that her HIV status influenced her career choice, one respondent revealed that she gave up her wish to be a veterinarian or a veterinarian technician after she was turned down from a volunteer position at a veterinary facility because of her “safety and health.” Several study participants reported fear of disclosing their HIV status to others as the most common manifestation of stigma. One participant explained why she did not disclose her HIV status to her friends: “I don’t know if we’re gonna always be friends, and I would hate for something to happen and then they just go telling my business to the whole world.”

The fear of contagion was a common domain of stigma experienced by our study participants. One participant shared her fear: “I’m afraid of working in a medical field. I know you’re not supposed to tell anybody, but how do you go to work every day knowing that you have something and you work in the medical field?” This same participant’s fear of disclosure prevented her from utilizing health insurance offered through her workplace. She wondered: “Is your job going to find out that you got something and they’re like, ‘She goes to the doctor for what? We have to get her off our insurance.’” She went on to say: “... then somebody else told me ‘You should tell everybody that you interact with that you have HIV’ ... Like no way. People kill you for that still.” Another participant described incidents of romantic rejection due to her HIV status citing: “I’ve had moments where someone would like me and then I would tell them about that (her HIV status) and they wouldn’t wanna date me.”

4. Discussion

Our qualitative study of adults with PHIV revealed their sense of loss and abandonment, their attitudes towards HIV disclosure, as well as anger, and fear of stigma. The themes identified in our study support the utility of improving HIV disclosure, bolstering support for youth with PHIV while combating stigma, and helping them manage latent negative emotions such as anger towards family members, particularly biological mothers.

Overall, at the time of their interviews, our study participants perceived themselves as having intermediate to high QoL with average to high resilience scores, reflecting a general sense well-being among our respondents. Furthermore, for the entire year preceding interviews, all study participants had good to excellent immunologic status and HIV suppression with CD4 counts greater than 350 cells per mm³. Therefore, although only 2 out of 9 study participants reported adherence to ART during adolescence, the majority appear to have developed into resilient young adults with well-controlled HIV. Similar to findings of a recent study (Funk-Brentano et al., 2016), our study shows that patients with PHIV acknowledge HIV-related stressors despite good overall life satisfaction. Despite the overall well-being of our study participants at the time of their interviews, the responses of study participants to interview questions revealed various struggles that appear to have had a negative impact on their lives.

Patients with PHIV have increased rates of mental health disorders and psychiatric symptoms compared to peers without HIV (Chernoff et al., 2009; Gadow et al., 2012; Gaughan et al., 2004; Kapetanovic et al., 2011; Lam, Naar-King, & Wright, 2007; Mellins, Brackis-Cott, Dolezal, & Abrams, 2006; Mellins et al., 2009; Scharko, 2006; Wood, Shah, Steenhoff, & Rutstein, 2009). Furthermore, these patients can have psychiatric symptoms despite positive perceptions on QoL (Funk-Brentano et al., 2016). Therefore, although we did not explore psychological sequelae of HIV-related related stressors experiences by our respondents it is possible that challenges and stressors reported by our respondents may have negative impacts on their lives that are not reflected in their perception of QoL or resilience.

A majority of the participants in our studies shared vivid recollections of the initial disclosure of their HIV status. This supported the notion that initial HIV disclosure is a critical moment whose memory persists over time for patients with PHIV for many years, corroborating findings of a previous study on recollections of HIV-disclosure among adult patients with PHIV (Dorrell & Katz, 2014). Our respondents’ narratives of their disease disclosure highlighted their difficulties with the disclosure process. The acknowledgement of limited knowledge of HIV despite early initial disclosure among several of our participants echoes findings of a study on adolescents with PHIV in Spain, majority of whom experienced HIV disclosure between 10 and 15 years of age, which found that respondents demonstrated poor assimilation of disclosed information about HIV (Medin et al., 2016). In our study, we did not adequately probe the actual content of disclosure therefore we could not determine whether our respondents’ perception of poor understanding of HIV was a reflection of deficits in the disclosure process or a result of poor assimilation of disclosed content. In reporting a general lack of understanding of the ramifications of their HIV diagnosis at the time of disclosure,

the experiences of several participants point to the need for ongoing discussions about HIV that probe and augment what patients with PHIV understand about their disease.

Participants offered their thoughts on how HIV disclosure could be improved and, through their narratives, highlighted opportunities for improvement of the disclosure process which may be generalizable within similar sociocultural contexts. The deleterious effect of pairing HIV disclosure with sharing family secrets such as adoption or during a personal crisis that may detract from recollection or assimilation of knowledge about HIV status was illustrated in our patients' recollections. The characteristics of their disclosures echo previously reported challenges and characteristics of HIV disclosure in patients with PHIV (Dematteo et al., 2002; Lester et al., 2002; Michaud et al., 2009; Nöstlinger, Bartoli, Gordillo, Roberfroid, & Colebunders, 2006; Wiener, 1996; Wiener & Battles, 2006; Wiener, Mellins, Marhefka, & Battles, 2007). Areas for improvement in HIV disclosure which emerged in our study essentially recapitulate aspects of the WHO recommendation (WHO, 2011) and include the need for a staged process and continuum of HIV disclosure, dedicated conversations solely discussing HIV, and incorporating repetition of individualized age or developmentally appropriate information about what it means to be HIV-positive. As shown by a recent study on disclosing HIV status to HIV-positive children in Ghana, dedicated caregivers designated as adherence and disclosure specialists can be effectively mobilized to implement staged HIV disclosure (Reynolds et al., 2015). Implementation of similar approaches to staged HIV disclosure would provide opportunities to address HIV status in a focused and dedicated manner allowing better understanding of issues associated with HIV infection.

Similar to findings from previous studies of patients with PHIV, stigma and the fear of stigma played an important role in the lives of our study's participants (Rydström, Wiklander, Navér, Ygge, & Eriksson, 2016; Sayles, Ryan, Silver, Sarkisian, & Cunningham, 2007). Respondents' reports of experiencing stigmatization following disclosure of their HIV status or avoiding disclosure due to fear of stigma support findings from a recent study which revealed more profound stigma related to disclosure concerns in youth living with HIV (Rydström et al., 2016). Our findings suggest that effective strategies to augment the continuum of disclosure with HIV education could be coupled with approaches to combat stigma so as to equip youth with tools to navigate HIV-related stressors.

Study participants appeared to be in favor of developing better networking and interactions among youth with PHIV and were thankful for the opportunity to share their stories revealing a desire for bonding. To meet this need, peer support groups could provide a sense of community and boost resilience. Social networking sites and other web-based tools have been used to promote adolescent and young adult health, including in patients with cystic fibrosis where online support groups have been shown to supplement professional support (Hyden & Cohall, 2011; Kirk & Milnes, 2016). Similar platforms may be useful for promoting a sense of community among patients with PHIV, who may be able to access peer support through mobile health and online applications, popular among youth worldwide.

For several participants, anger towards biological mothers was a salient theme, which had a tremendous impact on their lives and self-care. We posit that this phenomenon of anger towards biological mothers may reflect blame which was not addressed during the disclosure process or may be a manifestation of complicated grief. A recent study of patients with perinatal HIV revealed that loss of a parent had profound effects on mental health and well-being of these patients, with grieving associated with confusion and feelings of isolation that lasted for many years after parental death (Woollett, Black, Cluver, & Brahmabhatt, 2017). Studies of the impact of parental bereavement on the offspring suggest more deleterious effects of the loss of a mother on youth (Agerbo, Nordentoft, & Mortensen, 2002; Brent, Melhem, Donohoe, & Walker, 2009; Reinherz, Giaconia, Hauf, Wasserman, & Silverman, 1999). It is therefore possible that the anger directed towards biological mothers experienced by several of our respondents may reflect an aspect of complicated grief, defined as grief that does not resolve within six months—also termed prolonged, maladaptive or pathological grief, for patients who experienced the death of their mothers (Shear et al., 2011). Our study suggests that

feelings of anger towards biological mothers can have detrimental consequences for youth with PHIV as shown by experiences of a respondent who associated reminders that HIV was transmitted to her through her mother with her reluctance to take medication.

In one study exploring the impact of grieving on patients with PHIV, losing a mother and complicated grief were amongst factors associated with depression (Woollett et al., 2017). Therefore, if indeed the anger expressed by our respondents is a manifestation of complicated grief it may be associated with mental health issues in youth with PHIV. Furthermore, identification of forgiveness of a biological mother as the most important factor which enabled one of our respondents to adhere to medications points to the possibility of a positive impact of resolving inherent anger towards biological mothers. Further studies are needed to explore the pervasiveness of these feelings in youth with PHIV and the impact that anger against biological mothers may have on self-care, and adherence to cART. This insight may inform psycho-educational and cognitive-behavioral-based interventions targeted to youth with PHIV. Additionally, since fear of a child's anger is one of the barriers to disclosure of HIV to children with PHIV by HIV-positive mothers (Waugh, 2003), identifying how this anger manifests as well as implications of harboring this anger and resolving it may point to possible opportunities for intervention.

This study has several limitations including the small number of participants and restriction to one site frequented by urban poor youth. Therefore, our findings may not be applicable in other diverse populations or different cultural contexts. Study participants generally had well-controlled HIV with either absent or mild HIV-associated immunodeficiency at the time of their interviews. Therefore, the themes identified in our study may not be readily applicable to HIV-positive patients with poorly controlled HIV. Despite these limitations, the findings of our study are instructive in the care of youth with PHIV in the United States who fit the demographic profile of the participants in our study but may also direct future inquiry into effective modalities for transition of care from pediatric to adult care, HIV disclosure, and battling stigma in youth with PHIV.

In conclusion, the findings of our study support: (1) implementation of innovative ways to facilitate peer support groups among patients with PHIV; (2) viewing HIV disclosure as an iterative process with reinforcement as patients with PHIV develop from childhood through adolescence into adulthood; and (3) recognizing that stigma, isolation, and anger persist as patients with PHIV transition to adulthood and therefore require continued psychosocial support.

Acknowledgments

We would like to thank all study participants, the Center for Interdisciplinary Research on AIDS (CIRA) and Amy Smoyer for help with qualitative research, Denise Wagner, APRN, and Anne Murphy, LCSW, for their help with recruiting participants, the Sections of Infectious Diseases in both Internal Medicine and Pediatrics Departments at Yale School of Medicine for funding and Dr George Miller and Dr Hochang Lee for their helpful discussions and support.

Funding

The authors received no direct funding for this research.

Author details

R. Wang'onde¹
E-mail: ruth.wangonde@yale.edu
S. Samuels²
E-mail: slsamuels@gmail.com
W. Andiman³
E-mail: warren.andiman@yale.edu
E. Paintsil³
E-mail: elijah.paintsil@yale.edu
L. Barakat⁴
E-mail: lydia.barakat@yale.edu

A. Langs-Barlow⁵

E-mail: Allison.Langs@gmail.com

¹ Combined Internal Medicine/Pediatrics Residency Program, Yale School of Medicine, New Haven, CT, USA.

² The Children's Hospital of Philadelphia, Section of Endocrinology and Diabetes, Philadelphia, PA, USA.

³ Department of Pediatrics, Section of Infectious Disease, Yale University, New Haven, CT, USA.

⁴ Department of Medicine, Section of Infectious Disease, Yale University, New Haven, CT, USA.

⁵ Mary Bridge Children's Hospital, Tacoma, WA, USA.

Citation information

Cite this article as: Desire for improved disclosure, community and bonding among young adults with perinatally acquired HIV, R. Wang'onde, S. Samuels, W. Andiman, E. Paintsil, L. Barakat & A. Langs-Barlow, *Cogent Social Sciences* (2018), 4: 1463816.

References

Agerbo, E., Nordentoft, M., & Mortensen, P. B. (2002). Familial, psychiatric, and socioeconomic risk factors for suicide in young people: Nested case-control study. *BMJ*, 325(7355), 74.
<https://doi.org/10.1136/bmj.325.7355.74>

- Brent, D., Melhem, N., Donohoe, M. B., & Walker, M. (2009). The incidence and course of depression in bereaved youth 21 months after the loss of a parent to suicide, accident, or sudden natural death. *American Journal of Psychiatry*, 166(7), 786–794. doi:10.1176/Appi.Ajp.2009.08081244
- Bush-Parker, T. (2000). Perinatal HIV: Children with HIV grow up. *Focus (San Francisco, Calif.)*, 15(2), 1–4.
- Chernoff, M., Nachman, S., Williams, P., Brouwers, P., Heston, J., Hodge, J., ... Team, I. P. S. (2009). Mental health treatment patterns in perinatally HIV-infected youth and controls. *Pediatrics*, 124(2), 627–636. doi:10.1542/Peds.2008-2441
- Cunha, G. H., Galvão, M. T. G., Fiuza, M. L. T., Lima, M. A. C., Pedrosa, S. C., Mota, R. M. S., & Gir, E. (2016). Effect of social support on quality of life, Cd4+ T-cell count and viral load of people living with HIV/aids. *International Archives of Medicine*, 9, doi:10.3823/2082
- Dematteo, D., Harrison, C., Arneson, C., Goldie, R., Lefebvre, A., Read, S. E., & King, S. M. (2002). Disclosing HIV/AIDS to children: The paths families take to truth-telling. *Psychology, Health and Medicine*, 7(3), 339–356. doi:10.1080/13548500220139395
- Dorrell, J., & Katz, J. (2014). 'You're HIV positive': Perinatally infected young people's accounts of the critical moment of finding out their diagnosis. *AIDS Care*, 26(4), 454–458. doi:10.1080/09540121.2013.841833
- Foster, C., & Fidler, S. (2011). Adolescents with perinatally acquired HIV-1 infection. *European Infectious Disease*, 5(1), 10–16.
- Frederick, T., Thomas, P., Mascola, L., Hsu, H. W., Rakusan, T., Mapson, C., ... Bertolli, J. (2000). Human immunodeficiency virus-infected adolescents: A descriptive study of older children in New York City, Los Angeles County, Massachusetts and Washington, DC. *The Pediatric Infectious Disease Journal*, 19(6), 551–555. <https://doi.org/10.1097/00006454-200006000-00012>
- Funck-Brentano, I., Assoumou, L., Veber, F., Moshous, D., Frange, P., & Blanche, S. (2016). Resilience and life expectations of perinatally HIV-1 infected adolescents in France. *The Open AIDS Journal*, 10, 209–224. doi:10.2174/1874613601610010209
- Gadow, K. D., Angelidou, K., Chernoff, M., Williams, P. L., Heston, J., Hodge, J., & Nachman, S. (2012). Longitudinal study of emerging mental health concerns in youth perinatally infected with HIV and peer comparisons. *Journal of Developmental & Behavioral Pediatrics*, 33(6), 456–468. <https://doi.org/10.1097/DBP.0b013e31825b8482>
- Gaughan, D. M., Hughes, M. D., Oleske, J. M., Malee, K., Gore, C. A., Nachman, S., & Pediatric, A. C. T. G. C. T. (2004). Psychiatric hospitalizations among children and youths with human immunodeficiency virus infection. *Pediatrics*, 113(6), e544–e551. <https://doi.org/10.1542/peds.113.6.e544>
- Hazra, R., Siberry, G. K., & Mofenson, L. M. (2010). Growing up with HIV: Children, adolescents, and young adults with perinatally acquired HIV infection. *Annual Review of Medicine*, 61, 169–185. <https://doi.org/10.1146/annurev.med.050108.151127>
- Hoffman, N. D., Futterman, D., & Myerson, A. (1999). Treatment issues for HIV-positive adolescents. *Aids Clinical Care*, 11(3), 17–19, 21, 23.
- Hyden, C., & Cohall, A. (2011). Innovative approaches to using new media and technology in health promotion for adolescents and young adults. *Adolescent Medicine: State Of The Art Reviews*, 22(3), 498–520, Xi–Xii.
- Kapetanovic, S., Wiegand, R. E., Dominguez, K., Blumberg, D., Bohannon, B., Wheeling, J., ... Consortium, L. (2011). Associations of medically documented psychiatric diagnoses and risky health behaviors in highly active antiretroviral therapy-experienced perinatally HIV-infected youth. *AIDS Patient Care STDs*, 25(8), 493–501. doi:10.1089/Apc.2011.0107
- Kirk, S., & Milnes, L. (2016). An exploration of how young people and parents use online support in the context of living with cystic fibrosis. *Health Expectations*, 19(2), 309–321. doi:10.1111/Hex.12352
- Koenig, L. J., Nesheim, S., & Abramowitz, S. (2011). Adolescents with perinatally acquired HIV. *Current Opinion in Obstetrics and Gynecology*, 23(5), 321–327. <https://doi.org/10.1097/GCO.0b013e32834a581b>
- Lam, P. K., Naar-King, S., & Wright, K. (2007). Social support and disclosure as predictors of mental health in HIV-positive youth. *AIDS Patient Care and STDs*, 21(1), 20–29. doi:10.1089/Apc.2006.005
- Lee, G. M., Gortmaker, S. L., McIntosh, K., Hughes, M. D., Oleske, J. M., Palumbo, P., ... Klipner, K. (2006). Quality of life for children and adolescents: Impact of HIV infection and antiretroviral treatment. *Pediatrics*, 117(2), 273–283. doi:10.1542/Peds.2005-0323
- Lester, P., Chesney, M., Cooke, M., Whalley, P., Perez, B., Petru, A., ... Wara, D. (2002). Diagnostic disclosure to HIV-infected children: How parents decide when and what to tell. *Clinical Child Psychology and Psychiatry*, 7(1), 85–99. doi:10.1177/1359104502007001007
- MacDonell, K., Naar-King, S., Huszti, H., & Belzer, M. (2013). Barriers to medication adherence in behaviorally and perinatally infected youth living with HIV. *AIDS and Behavior*, 17(1), 86–93. <https://doi.org/10.1007/s10461-012-0364-1>
- Medin, G., García-Navarro, C., Navarro Gomez, M., Ramos Amador, J. T., Mellado, M. J., Jimenez, S., ... González-Tomé, M. I. (2016). Disease disclosure, treatment adherence, and behavioural profile in a cohort of vertically acquired HIV-infected adolescents. NeuroCoRISpeS study. *AIDS Care*, 28(1), 124–130. doi:10.1080/09540121.2015.1071768
- Mellins, C. A., Brackis-Cott, E., Dolezal, C., & Abrams, E. J. (2006). Psychiatric disorders in youth with perinatally acquired human immunodeficiency virus infection. *The Pediatric Infectious Disease Journal*, 25(5), 432–437. doi:10.1097/01.Inf.0000217372.10385.2a
- Mellins, C. A., Brackis-Cott, E., Leu, C. S., Elkington, K. S., Dolezal, C., Wiznia, A., ... McKay, Mary (2009). Rates and types of psychiatric disorders in perinatally human immunodeficiency virus-infected youth and seroreverters. *Journal of Child Psychology and Psychiatry*, 50(9), 1131–1138. doi:10.1111/J.1469-7610.2009.02069.X
- Michaud, P. A., Suris, J. C., Thomas, L. R., Kahlert, C., Rudin, C., & Cheseaux, J. J. (2009). To say or not to say: A qualitative study on the disclosure of their condition by human immunodeficiency virus-positive adolescents. *Journal of Adolescent Health*, 44(4), 356–362. doi:10.1016/J.Jadohealth.2008.08.004
- Murphy, D. A., Roberts, K. J., & Herbeck, D. M. (2013). Adolescent response to having an HIV-infected mother. *AIDS Care*, 25(6), 715–720. <https://doi.org/10.1080/09540121.2013.769495>
- Nöstlinger, C., Bartoli, G., Gordillo, V., Roberfröid, D., & Colebunders, R. (2006). Children and adolescents living with HIV positive parents: Emotional and behavioural problems. *Vulnerable Children and Youth Studies*, 1(1), 29–43. doi:10.1080/17450120600659036
- O'Connell, K. A., & Skevington, S. M. (2012). An international quality of life instrument to assess wellbeing in adults who are HIV-positive: A short form of the WHOQOL-HIV (31 items). *AIDS and Behavior*, 16(2), 452–460. doi:10.1007/S10461-010-9863-0
- Pinzón-Iregui, M. C., Ibanez, G., Beck-Sagué, C., Halpern, M., & Mendoza, R. M. (2017). "...like because you are a grownup, you do not need help": Experiences of transition from pediatric to adult care among youth with perinatal HIV infection, their caregivers, and health care providers in the Dominican Republic. *Journal of the International*

- Association of Providers of AIDS Care (JIAPAC)*, 16(6), 579–587. doi:10.1177/2325957417729749
- Reinherz, H. Z., Giaconia, R. M., Hauf, A. M., Wasserman, M. S., & Silverman, A. B. (1999). Major depression in the transition to adulthood: Risks and impairments. *Journal of Abnormal Psychology*, 108(3), 500–510. <https://doi.org/10.1037/0021-843X.108.3.500>
- Reynolds, N. R., Ofori-Atta, A., Lartey, M., Renner, L., Antwi, S., Enimil, A., ... Paintsil, E. (2015). Sankofa: A multisite collaboration on paediatric hiv disclosure in Ghana. *AIDS*, 29, S35–S45. doi:10.1097/Qad.0000000000000725
- Rydström, L. L., Wiklander, M., Navér, L., Ygge, B. M., & Eriksson, L. E. (2016). HIV-related stigma and health-related quality of life among children living with HIV in Sweden. *AIDS Care*, 28(5), 665–671. doi:10.1080/09540121.2015.1120267
- Sayles, J. N., Ryan, G. W., Silver, J. S., Sarkisian, C. A., & Cunningham, W. E. (2007). Experiences of social stigma and implications for healthcare among a diverse population of HIV positive adults. *Journal of Urban Health*, 84(6), 814–828. doi:10.1007/s11524-007-9220-4
- Scharko, A. M. (2006). Dsm psychiatric disorders in the context of pediatric HIV/AIDS. *Aids Care—Psychological and Socio-Medical Aspects of Aids/HIV*, 18(5), 441–445. doi:10.1080/09540120500213487
- Shear, M. K., Simon, N., Wall, M., Zisook, S., Neimeyer, R., Duan, N., ... Keshaviah, A. (2011). Complicated grief and related bereavement issues for DSM-5. *Depression and Anxiety*, 28(2), 103–117. doi:10.1002/Da.20780
- Silva-Suárez, G., Rabionet, S. E., & Zorrilla, C. D. (2017). HIV normalization message and its implication on the lives of perinatally HIV-infected youth in Puerto Rico. *Journal of Pharmaceutical Health Services Research*, 8(4), 241–246. doi:10.1111/Jphs.12194
- Smith, B., Epstein, E., Ortiz, J., Christopher, P., & Tooley, E. (2013). The foundations of resilience: What are the critical resources for bouncing back from stress? In S. Prince-Embury (Ed.), *Resilience in children, adolescents, and adults: Translating research into practice* (pp. 167–187). New York, NY: Oxford. <https://doi.org/10.1007/978-1-4614-4939-3>
- Smith, B. W., Dalen, J., Wiggins, K., Tooley, E., Christopher, P., & Bernard, J. (2008). The brief resilience scale: Assessing the ability to bounce back. *International Journal of Behavioral Medicine*, 15(3), 194–200. doi:10.1080/10705500802222972
- Vijayan, T., Benin, A. L., Wagner, K., Romano, S., & Andiman, W. A. (2009). We never thought this would happen: Transitioning care of adolescents with perinatally acquired HIV infection from pediatrics to internal medicine. *AIDS Care*, 21(10), 1222–1229. doi:10.1080/09540120902730054
- Waugh, S. (2003). Parental views on disclosure of diagnosis to their HIV-positive children. *Aids Care—Psychological and Socio-Medical Aspects of Aids/HIV*, 15(2), 169–176. doi:10.1080/0954012031000068317
- WHO. (2011). *Guideline on HIV disclosure counselling for children up to 12 years of age*. Geneva.
- WHO. (2012). *The strategic use of antiretrovirals to help end the HIV epidemic*. Geneva.
- Wiener, L., Mellins, C. A., Marhefka, S., & Battles, H. B. (2007). Disclosure of an HIV diagnosis to children: History, current research, and future directions. *Journal of Developmental & Behavioral Pediatrics*, 28(2), 155–166. doi:10.1097/01.Dbp.0000267570.87564.Cd
- Wiener, L. S. (1996). Factors associated with disclosure of diagnosis to children with HIV/AIDS. *Pediatric Aids and HIV Infection*, 7(5), 310–324.
- Wiener, L. S., & Battles, H. B. (2006). Untangling the web: A close look at diagnosis disclosure among HIV-infected adolescents. *Journal of Adolescent Health*, 38(3), 307–309. doi:10.1016/J.jadohealth.2005.03.024
- Williams, E. F., Ferrer, K., Lee, M. A., Bright, K., Williams, K., & Rakhmanina, N. Y. (2017). Growing up with perinatal human immunodeficiency virus—A life not expected. *Journal of Clinical Nursing*, 26(23–24), 4734–4744. doi:10.1111/Jocn.13826
- Wood, S. M., Dowshen, N., & Lowenthal, E. (2015). Time to improve the global human immunodeficiency virus/AIDS care continuum for adolescents. *JAMA Pediatrics*, 169(7), 619–620. doi:10.1001/Jamapediatrics.2015.58
- Wood, S. M., Shah, S. S., Steenhoff, A. P., & Rutstein, R. M. (2009). The impact of AIDS diagnoses on long-term neurocognitive and psychiatric outcomes of surviving adolescents with perinatally acquired HIV. *AIDS*, 23(14), 1859–1865. doi:10.1097/Qad.0b013e32832d924f
- Woollett, N., Black, V., Cluver, L., & Brahmabhatt, H. (2017). Reticence in disclosure of HIV infection and reasons for bereavement: Impact on perinatally infected adolescents' mental health and understanding of HIV treatment and prevention in Johannesburg, South Africa. *African Journal of AIDS Research*, 16(2), 175–184. doi:10.2989/16085906.2017.1337646
- Zanoni, B. C., & Mayer, K. H. (2014). The adolescent and young adult HIV cascade of care in the United States: Exaggerated health disparities. *AIDS Patient Care and STDs*, 28(3), 128–135. doi:10.1089/Apc.2013.0345



© 2018 The Author(s). This open access article is distributed under a Creative Commons Attribution (CC-BY) 4.0 license.

You are free to:

Share — copy and redistribute the material in any medium or format

Adapt — remix, transform, and build upon the material for any purpose, even commercially.

The licensor cannot revoke these freedoms as long as you follow the license terms.

Under the following terms:

Attribution — You must give appropriate credit, provide a link to the license, and indicate if changes were made.

You may do so in any reasonable manner, but not in any way that suggests the licensor endorses you or your use.

No additional restrictions

You may not apply legal terms or technological measures that legally restrict others from doing anything the license permits.

