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Reproductive Health Decision-Making in Perinatally HIV-Infected Adolescents and Young Adults

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Abstract

With widespread access to antiretroviral therapy in the United States, many perinatally HIV-infected (PHIV₊) children are surviving into adolescence and adulthood, becoming sexually active and making decisions about their reproductive health. The literature focusing on the reproductive decisions of individuals behaviorally infected with HIV can serve as a springboard for understanding the decision-making process of PHIV₊ youth. Yet, there are many differences that critically distinguish reproductive health and related decision-making of PHIV₊ youth. Given the potential public health implications of their reproductive decisions, better understanding of factors influencing the decision-making process is needed to help inform the development of salient treatment and prevention interventions. To begin addressing this understudied area, a “think tank” session, comprised of clinicians, medical providers, and researchers with expertise in the area of adolescent HIV, was held in Bethesda, MD, on September 21, 2011. The focus was to explore what is known about factors that influence the reproductive decision-making of PHIV₊ adolescents and young adults, determine what important data are needed in order to develop appropriate intervention for PHIV₊ youth having children, and to recommend future directions for the field in terms of designing and carrying out collaborative studies. In this report, we summarize the findings from this meeting. The paper is organized around the key themes that emerged, including utilizing a developmental perspective to create an operational definition of reproductive decision-making, integration of psychosocial services with medical management, and how to design future research studies. Case examples are presented and model program components proposed.

Keywords

HIV and reproductive health; Perinatal HIV; HIV-infected youth; Adolescent reproductive health

Introduction

Since the first reported case of perinatal HIV infection in the United States (US) in 1983 [1] the cohort of perinatally HIV-infected (PHIV₊) children in the US rose steadily until 1992 when perinatal antiretroviral therapy (ART)-based protocols were developed resulting in a dramatic drop in the rates of mother-to-child transmission (MTCT) [2]. In 2008, an estimated 9,129 PHIV₊ youth were living in the US [3]. As this unique cohort is aging into young adulthood, becoming sexually active, building intimate relationships and entering the workforce, many are beginning to make decisions about their reproductive health. Given the potential public health implications of their reproductive decisions, better understanding of factors influencing their decision-making can inform the development of salient treatment and prevention interventions. To date, very few studies have examined reproductive decision-making (RDM) among PHIV₊ youth (e.g., [4, 5]).

Between 6,000 and 7,000 HIV-infected (HIV₊) women give birth annually in the US [6]. This number is likely going to rise as 20 % of HIV₊ people in the US are women of reproductive age, [7], most men and women with HIV desire to have children [8], and the longevity and quality of life of HIV₊ people in the era of highly active antiretroviral therapy (HAART) is improving. Studies evaluating factors influencing RDM in adults suggest that HIV status alone is not a key factor [9]. Younger age, better health, and perceived partner

desire for parenthood are the most predominant factors that positively influence desire and intention to have children. Conversely, concern about infecting partners and future children, misunderstanding of MTCT risk, societal disapproval of reproductive behavior post HIV diagnosis, and concerns pertaining to leaving a child an orphan are factors that mitigate against desire and intention to have children among HIV₊ adults [10-29].

The existing body of literature focusing on the RDM of women and men who are behaviorally infected with HIV can serve as a springboard for understanding the decision-making process of PHIV₊ youth. Yet, there are many differences that critically distinguish reproductive health and related decision-making of PHIV₊ youth from that of behaviorally HIV-infected adults and research and clinical efforts aimed at understanding the decision-making process of PHIV₊ youth should include significant focus on these and other unique circumstances of PHIV₊ youth (Table 1). Although there are significant differences between the two groups, they are both comprised of young adults who are dealing with complicated reproductive considerations pertaining to short and long term decision-making.

This paper reports the findings and recommendations generated from a think tank meeting addressing the critical and understudied area of RDM in PHIV₊ youth that was held in Bethesda, MD, on September 21, 2011.

Methods

Two of the authors (CF, LW) invited a panel of mental health clinicians, medical providers and researchers with expertise in the area of adolescent HIV to attend a “think tank” meeting. (The meeting format was based upon a previously successful think tank [30].) The aim was to explore what is known about factors that influence the RDM of PHIV₊ adolescents and young adults, determine what important data are needed in order to develop appropriate intervention for PHIV₊ youth having children, and to recommend the direction the field should go in terms of designing and carrying out collaborative studies. Each participant was asked to prepare a brief presentation based upon their clinical work and/or research and to conclude with recommendations of future research questions. The meeting was audio-recorded and detailed notes were taken as well. Following the conclusion of the meeting, a written summary of the meeting was sent to each participant for review and revision. The panel came to full agreement on the final version of notes, questions and recommendations. This final version is presented as the “Findings” section of this report, which is further divided into sub-sections reflecting main themes that emerged throughout the meeting. These include: An Operational Definition of Reproductive Decision-Making, Developmental View, Key Psychosocial Factors, Medical Management and Research Methodology. Case studies presented during the Think Tank are included to underscore the intricacy of and variability within the population of PHIV₊ youth regarding reproductive decisions.

Findings

Operational Definition of Reproductive Decision-Making

Reproductive-Decision Making (RDM) is a broad term. Such decision-making may be active or passive, and is characterized by varying levels of desire and intent to bear children. Previous literature includes the following aspects as part of the RDM process [31-33]:

- Sexual debut
- Continuation of sexual activity
 - Frequency

- Time in sexual union
- Use of contraception
 - Type
 - Consistency
 - Use in individual sexual encounters
- Pregnancy
 - Carry to term vs. abortion

Much of the language surrounding RDM for people living with HIV focuses on condom use, birth control and abortion, possibly due to emphasis of education on abstinence and pregnancy prevention rather than risk reduction and family planning [34, 35]. For the purposes of describing RDM in the PHIV₊ population, Think Tank participants identified a need for researchers to distinguish between outcomes of sexual risk behaviors and other aspects of reproduction for the purposes of describing RDM in the PHIV₊ population who contend with reproductive decisions within unique developmental, psychosocial, and medical contexts. The next sections provide greater detail regarding how these contexts may influence the RDM of PHIV₊ youth.

Developmental View

The primary focus of research in the field has been on medical management of pregnant PHIV₊ youth or obstetrical outcomes, particularly on preventing MTCT, rather than on in-depth evaluation of the underlying behavioral/social processes that brought the PHIV₊ youth to parenthood. However, two parallel developments will lead to increased global relevance of reproductive health and related decision-making among PHIV₊ youth: (1) improved access to HAART has increased longevity of PHIV₊ youth in the developing world leading to increased need for comprehensive approaches to their well-being as adults, including their reproductive health and (2) improved accessibility of effective perinatal ART-based protocols will likely lead to more pregnancies among PHIV₊ women due to reduced fears of MTCT.

Interventions designed to reduce the risk of sexually transmitting HIV by this population should include developmentally appropriate psychological and social approaches that target perceptions of peer influence and emotional well-being [38]. Accordingly, the participants highlighted the need for future research objectives and resulting clinical interventions to adopt the developmental view of the RDM among PHIV₊ youth, as illustrated in Fig. 1 and discussed below.

Brain Development and Mental Health Outcomes

Poor neurodevelopmental and behavioral outcomes could critically affect decision-making process of PHIV₊ youth, including their RDM. Data from US-based multi-site observational cohort studies have consistently reported high rates of neurocognitive scores well below population norms [39-42] and higher than expected rates of mental health problems [43-46] in PHIV₊ youth. There are multiple bio-psycho-social risks, starting with in utero exposure of developing brain to maternal HIV, ART, drugs, alcohol, immune dysregulation [47-52], followed by life-long immune dysregulation, vascular dysfunction, central nervous system viremia [42, 53-58] and exposure to ART [59, 60]. Significant psychosocial and/or familial risks include relatively high prevalence of substance abuse and psychiatric disorders among the biological parents [50,51, 61, 62] neighborhood disadvantage and other environmental factors: approximately 85 % of PHIV₊ youth are living in urban environments, are of ethnic

minority status, and have likely experienced disruptions of placements leading to multiple separations from parents and caregivers [63].

In addition to neurodevelopmental and mental health outcomes, it is important to consider the role of adolescent brain development within the context of RDM. For example, Casey et al. [64] noted that the cortical regions of the brain associated with problem solving continue to develop through adolescence. Older adolescents may be better able to assess risk and understand the consequences of their actions than younger youth [65].

Diagnostic Disclosure

Two aspects of disclosure may influence RDM: disclosure of the PHIV₊ youth's diagnosis to him or herself, and disclosure to potential sexual partners. The general consensus within the literature is that PHIV₊ children should be informed of their diagnosis in a developmentally sensitive manner [66] by adolescence [67]. Behavioral complications are more likely if disclosure was not conducted in a timely and developmentally appropriate manner [6-70]. Some guardians prefer to delay disclosure until the child is older, waiting until a specific milestone occurs such as the onset of puberty or when their child starts dating [71]. However, parents may be unaware of their child's sexual behavior.

Awareness of one's HIV status is critical to partner disclosure. Limited evidence in this area suggests that the majority of youth with HIV may not be informing their sexual partners of their HIV status [35, 72, 73]. Vijayan et al. [74] noted that out of their sample of 18 PHIV₊ adolescents, four reported having sexual intercourse and none shared their HIV status with their partner. A recent multi-site study found that 40 % of sexually active adolescents with HIV reported a sexual relationship with a partner to whom they did not disclose their HIV status [75]. Making decisions about sexual behavior can be a challenge for anyone, but particularly for youth who have a stigmatized, potentially fatal, sexually transmissible disease [66]. Case study #1 draws attention to the challenges of partner disclosure, particularly the usefulness of careful preparation in modulating anxiety.

Case Study #1. Steven is a 24-year-old African American male with perinatally acquired HIV. He was adherent to his medication regimen. His HIV PCR was <50 copies/mL and CD4 count in the 700's. Steven and his girlfriend were consistently using condoms during sexual intercourse, but she was unaware of his HIV status. At his clinic visit he discussed wanting to disclose his status to his girlfriend but indicated that he was feeling very anxious and uncertain. After discussing strategies for disclosure with the clinic staff, he initially decided to disclose with clinic staff and his mother present. Despite his plan to include others, Steven told her his status independently. Clinic staff and his mother met with them afterwards to clarify information and answer questions. Steven's girlfriend accompanied him to his next scheduled appointment at which she was tested and found to be HIV negative. They are still together 6 months after the disclosure.

Health Behaviors

Health behaviors, particularly sexual behaviors, substance use and treatment adherence are relevant to RDM. They may have a causal relationship with reproductive behavior and related outcomes. For example, the negative influence of alcohol and substance use on sexual behavior has been well established among adolescents (e.g. [76]), and poor medication adherence increases the risk of transmission to sexual partners and MTCT due to poor maternal viremia control [77]. Health behaviors may also serve as clinical windows into PHIV₊ youth's general judgment, decision making, priorities and planning capacity and, as such, help identify a youth who might need more assistance and education with regards to RDM regardless of mode of acquisition. In fact, an earlier study found no

differences between those who acquired their disease perinatally or via transfusion pertaining to sexual behavior [78].

Substance use patterns among PHIV₊ youth are not well understood. Studies using youth interviews found 15–20 % of reported substance abuse among PHIV₊ youth [43, 79] while the rates based upon chart review were approximately 9 % [45], both relatively low compared to the findings from the anonymous survey of US urban high-school students [80].

Some studies evaluating sexual behavior of PHIV₊ adolescents indicate that their sexual debut is slightly later, possibly as a result of delayed puberty secondary to the effects of HIV [81, 82]. However, by age 17, reported rates of sexual intercourse are similar to the general US high school population (70 and 62 % respectively) [83]. Despite relatively low knowledge of transmission risk factors, condom use was found to be more frequent among PHIV₊ youth, and youth with better understanding of transmission risk reported higher condom use self-efficacy [78].

Medication adherence among PHIV₊ youth, like youth with other chronic illnesses [84], typically declines during adolescence with adherence rates ranging from 27 to 41 % [85]. Complex medication regimens, unstable family systems, stigma, alcohol and substance use, adverse effects, and depression are commonly cited challenges to adherence [86–88]. The reported rates of all three behaviors are likely underestimates [45]. Case study #2 highlights the critical importance of adherence during pregnancy and complex interconnections between adherence and disclosure.

Case Study #2. Tamara is a 19 year old PHIV₊ African American with a history of poor medication adherence, recently gave birth to a seropositive son. She and her child live with her biological mother and are facing eviction. Tamara has expressed heightened anxiety around disclosure that was exacerbated by her mother's advice not to disclose Tamara's status to her boyfriend. Tamara's immediate family is also unaware of her and her mother's HIV status. During pregnancy her concerns worsened as she frequently stayed with her boyfriend and did not want to take her medication for fear of accidental disclosure. Tamara did not disclose her HIV status to her boyfriend until several months after the birth of their son, when follow-up tests confirmed that their child was HIV-infected. Her boyfriend remains HIV-negative. Current services include emotional support and counseling surrounding medication adherence for both her and her son's new diagnosis, housing, and post-disclosure support. Ongoing education is provided regarding safer sex practices and modes of contraception.

Transition to Adult Care

The transition of PHIV₊ youths' medical care from pediatric to adult providers is fraught with challenges. Wiener et al. [90] found that 45 % of their sample of 59 adolescents with HIV reported the transition to adult care was more difficult than anticipated. Primary concerns related to continuity and quality of care, navigating complex medical and social service agencies, and communication with providers. Vijayan et al. [74] reported the negative influence of HIV-related stigma on families' desire to meet new providers. Furthermore, adolescents' preparedness for increasing autonomy could be deficient since pediatric providers may have refrained from promoting medical independence due to the shortened lifespan of PHIV₊ youth. The typically strong relationship between pediatric providers and youth is an additional challenge to transition. Evidence suggests PHIV₊ youth and their families are reluctant to leave the comfort and familiarity of their long-standing relationships with pediatric staff [83, 89, 90]. Finally, in a recent study of adolescent

providers, several clinicians noted that young women with HIV who had been pregnant appeared to have an easier transition to adult infectious disease care. The authors suggested that the experience of receiving prenatal care in a different clinic, as well as additional social services offered to the pregnant woman, facilitated the movement from pediatric to adult care [91]. Such anecdotal observations must be further evaluated with longitudinal studies.

Reproductive Health Decision-Making

By the time PHIV₊ youths, their guardians and/or medical providers start addressing reproductive health issues, they will already have been through important developmental and clinical challenges, handling them with varying degrees of success and resulting in variable clinical outcomes. Significant new knowledge about their RDM could be gained by exploring research questions that take into account salient neurodevelopmental and behavioral vulnerabilities and the interaction between the characteristics of diagnostic disclosure, disclosure to sexual partners and overall health behaviors. Figure 1 provides graphic representation of proposed research objectives and possible clinical benefits of framing these objectives within the context of salient clinical milestones as well as neurodevelopmental and behavioral vulnerabilities of PHIV₊ youth and associated risks.

Psychosocial Factors

There was consensus amongst the participants that obtaining a psychosocial profile of PHIV₊ adolescents who have made a variety of reproductive decisions will be useful in shaping medical care as well as education and interventions. Considering the concomitant environmental factors often experienced by PHIV₊ youth, disease influences may play less prominent role in their RDM than gender, relationship issues, and family factors.

Gender

Research in RDM of HIV₊ adults has mostly focused on HIV₊ women (and their partners), and much less on HIV₊ men [8]. Gender distribution among PHIV₊ youth is more reflective of the general population, while 63 % of the HIV₊ adults are men who became infected through sex with men [92]. Young men's perspectives on fatherhood should be explored, as well as their knowledge of risk reduction strategies for childbearing.

Sexuality and Relationships

These young adults initiate their sexual lives living with HIV and must contend with the perception that HIV is an exclusively sexually transmitted disease. While disclosure issues for PHIV₊ individuals have been extensively researched with respect to disclosure of the diagnosis to the child, requirements to disclose to others may also play a role in young adults' choices of initiation of relationships as well as their reproductive decisions. The participants raised an important question that has yet to be answered: How is it different to experience first sexual encounters as a person living with HIV rather than being sexually experienced before contracting HIV₊. The potential influence of growing up with HIV on sexual identity, body image and relationships must be considered in research agendas as well as in models for sexual and reproductive health education and support.

Family Factors

Many PHIV₊ youth were born to young mothers and fathers and grew up in single-headed family households [93]. Young maternal age at pregnancy is a predictor for early parenthood among youth, and may similarly predict early parenthood among PHIV₊ adolescents. Think Tank participants noted that in their clinical work, PHIV₊ youth sometimes question whether their own mother would have chosen to give birth to them if they had known they were HIV₊ at the time of pregnancy. Moreover, those who have lost a parent and/or a sibling

to the disease may be influenced by this experience in their own RDM as they wish to create their own family. These issues add considerable complexity to PHIV₊ youth as they reach reproductive age. Below are some examples of possible research questions focused on psychosocial factors.

- Which psychosocial characteristics influence RDM?
- Does gender affect RDM?
- How do PHIV₊ young men perceive fatherhood?
- Does a perception of intimacy impact RDM?
- What role does self-efficacy play in sex/intimacy, assertiveness, confidence/self-esteem?
- Does early/perceived maternal loss/rejection play a role in RDM?
- Are intergenerational factors influential in RDM? (e.g. teen-age parenthood)
- Do young PHIV₊ women seek pregnancy, or is pregnancy perceived as outside of one's control?
- Do HIV₊ people prefer to have relationships with others with HIV?
- What role does sexual altruism/ethics play in sex and RDM?
- What influence, if any, does a history of sexual violence or abuse have on intimacy, sexuality and RDM?
- What is the role of disclosure in RDM?
- What is the role of perceived rejection (either from parents, family or others) in RDM?

Medical Management

Clinical challenges, adherence and the provider-patient relationship were assessed by the participants as three critical areas that deserve consideration in future planning. Programs that address the medical and psychosocial challenges in a developmentally sensitive manner are critically needed. Case study #3 highlights many of the challenges experienced by PHIV₊ youth living with advanced illness.

Case Study #3. On a quarterly clinic visit, Claudia, a 20 year old PHIV₊ Caucasian woman with a history of inconsistent adherence and poorly controlled HIV, presented with abdominal pain, 10 kg weight loss, oral candidiasis and severe cellulitis. CD4 count was 45 and viral load 67,000. Pregnancy was confirmed by serum beta-HCG. Claudia “didn’t know” she was pregnant, reported that she was afraid to tell her mother since her mother hates her boyfriend (he was not allowed in their home) but that she very much wanted to “have his baby”. Social worker and Claudia called Claudia’s mother, Claudia was referred to a high risk Obstetric team. She was encouraged to quit smoking and her ART therapy was changed. Claudia remained adherent during pregnancy and her baby was born at 29 weeks, HIV-negative. Family counseling was initiated, new housing was obtained, parenting classes offered and services initiated to address the baby’s developmental needs.

Clinical Challenges

Matthews and Mukherjee identify three major clinical challenges in the reproductive health of HIV₊ individuals: (1) maintaining maternal health, (2) preventing MTCT, and (3)

preventing transmission within a sero-discordant couple [94]. Pregnancy-related sleep deprivation, pain and pro-inflammatory milieu make HIV₊ pregnant women highly vulnerable to perinatal depression (PND) [95-97] which, when occurs, poses significant challenges to achieving objectives of medical care. Indeed, the incidence of PND among HIV₊ women over a 10 year period in one study was 31 % (N = 273), despite access to ART and 100 % prevention of MTCT; the correlates of PND were substance use during pregnancy, adherence problems, past psychiatric diagnosis, social stress during pregnancy and CD4₊ nadir 200 cells/mm³ [50].

The literature has not identified any programs that systematically identify pregnant HIV₊ women (regardless of the mode of transmission) at risk for PND and/or other mental health-related complications of pregnancy. While the risk of PND among PHIV₊ women is unknown, given the reported correlates of PND among behaviorally infected HIV₊ women, research that would establish the risk and its correlates, followed by prevention and treatment interventions is vital.

Further complicating the medical management of PHIV₊ pregnant youth is the possibility that unprotected sex with another HIV₊ person may lead to a superinfection with another, possibly treatment-resistant, HIV strain [98, 99].

Adherence

Positive effects on adherence have been observed for HIV₊ women who become pregnant, though they are most apparent for ART-naïve patients [100]. For PHIV₊ youth, medication adherence can be both positively and negatively influenced by disclosure [101, 102], and has implications for reproduction in that transmission risk decreases among those with favorable viral profiles. Extended ART experience, often coupled with a history of suboptimal adherence, puts PHIV₊ youth at higher risk for developing resistance to medications, including perinatal ART regimens prescribed to help prevent MTCT.

Provider-Patient Relationship

Despite changes in transmission rates, providers who are more accustomed to working with PHIV₊ children who had a shortened lifespan may hold a residual attitude in considering their reproductive and sexual development. This residual attitude may affect contemporary clinical care, limiting discussions of reproductive health to information related to pregnancy prevention, rather than options for safe conception and decision-making. Medical providers are faced with the dual challenge of addressing developmentally appropriate sexual health needs as well as preparing adolescent patients for transition to adult care [103]. No studies to date have examined how much attention reproductive counseling is given to PHIV₊ youth during medical care visits.

Below are possible research questions related to the medical management of PHIV₊ youth.

- What role does delayed sexual maturation play in RDM?
- What medical histories, disease profiles, or biomedical characteristics, (if any), are associated with particular reproductive choices and/or outcomes?
- Does pregnancy play a role in adherence? Conversely, what is the relationship between varying levels of adherence and reproductive decisions?
- Does the presence of a learning disorder, low IQ, or psychiatric disorder affect RDM?
- What information do PHIV₊ youth receive from providers about RDM, in what format, and by which types of providers?

- How much education focuses on preventing transmission versus becoming a parent?
- What are the best models for introducing PHIV₊ youth to RDM-related matters?
- Are messages from providers about RDM different for youth with PHIV₊ versus BHIV?
- What interventions have patients who experience or attempt intentional pregnancies received?

Model Programs

Participants agreed that key components of a model program would consist of reproductive-aged girls consistently being provided access and information about reproductive health and choices by participants of the multi-disciplinary clinical team. After confirmed pregnancy and the young woman's decision to continue their pregnancy, the young women transitions to an integrated high risk obstetric program where HIV and prenatal care are provided throughout her pregnancy. The obstetric clinic includes a case manager who addresses barriers to care such as transportation, insurance, housing, reminders for appointments and perinatal ART adherence support. Following the birth of the baby, continuity with the medical team is maintained and follow up of exposed infants is continued at the same program. Services are tailored clients' needs and are responsive to consumer feedback and emerging needs in the local epidemic.

Research Methodology

After addressing gaps in existing literature and outlining specific areas for future research related to the reproductive decisions of maturing PHIV₊ youth, the Think Tank concluded by identifying methodological challenges related to studying PHIV₊ youth and ways to address the identified challenges.

Study Design

Prior research with HIV₊ adults illustrates the need for a multidisciplinary approach to gaining a better understanding of the decision-making and reproductive health needs of the emerging population of PHIV₊ youth. Existing longitudinal cohort study data may provide a starting point for obtaining a bio-psycho-social profile of PHIV₊ reproductive-age adolescents and their reproductive health. However, Think Tank participants noted selection bias and overlapping participants in the existing cohorts. In order to understand influences on RDM, large sample cross-sectional data as well as smaller, qualitative studies are needed. Moreover, as the population of adolescents growing up with HIV typically come from high risk backgrounds [93], it is important to include an appropriate control group when seeking to measure significant influences on RDM.

Selection bias may occur as a result of patients' varying levels of engagement in medical care services. It is necessary to find ways to reach out to adolescents not already engaged in care or enrolled in research in order to acquire data that will be representative of this underserved and under-studied population. Possible ways to improve enrollment rates include utilizing texting and other mobile health technologies as a mode of communication, e-mailing participants, providing phone cards if phone access is inconsistent and recruiting PHIV₊ peers as researchers or interviewers. Other social media methods should be considered while recognizing that additional protections for privacy are needed [104].

Outcomes

Think tank participants identified self-efficacy as an important construct to consider. While difficult to measure, applying the concept of self-efficacy to a specific skill or behavior, such as condom use or obtaining medical support for reproductive health issues, may be most useful. Additionally, loss, particularly early maternal loss, may influence reproductive decision-making. For this population, many of whom have experienced many losses in their lives, a consistent measurement of (perceived) loss and its impact needs to be determined.

Validity

Many other factors, such as unplanned versus planned pregnancy, family and social influences, physician-patient relationship or disease-related factors (e.g., cognitive functioning) may potentially influence understanding and reporting of information on reproduction. It will therefore be necessary not only to measure these influences, but also to identify to what extent these and other contextual factors affect data validity and develop appropriate validation methodology.

Conclusions

The findings of this think-tank suggest that youth growing up with HIV in the US typically come from high-risk backgrounds with associated mental health problems but also that they share many commonalities with their typically developing peers. They are future-oriented and many have a strong desire for having children. The findings of this think-tank must be considered within the context of several limitations. First, due to funding constraints, we were limited to those clinicians and researchers from the east coast located in close proximity to the National Institutes of Health. Additionally, our focus was exclusively on the RDM among PHIV₊ youth within the US context and thus the findings are applicable mainly to high-resource countries. A number of experts have international experience, but our primary focus was on domestic issues related to RDM, which has not yet come to the forefront in low-resource countries. Finally, lack of representative data in some areas made drawing conclusions difficult yet highlighted the need for consensus-based expert opinions to guide the field.

Thus, while it was not possible to address all the questions and suggestions for future research, this is the first report on the complexity of issues facing maturing PHIV₊ youth. It is our hope that researchers, clinicians, and systems of care will keep pace with the needs of this special population as their life spans continue to lengthen. Future research addressing objectives outlined in the report will likely have implications for policy and service delivery particularly in the developed world.

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Abbreviations

ART	Antiretroviral therapy
HAART	Highly active antiretroviral therapy
HIV₊	HIV-infected

MTCT	Mother-to-child-transmission
PND	Perinatal depression
PHIV₊	Perinatally HIV-infected
RDM	Reproductive decision making

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Fig. 1.

Panel-proposed developmental objectives and goals. The developmental view, illustrated in this picture, places reproductive health decision-making of PHIV₊ youth on the continuum which includes other age- and development-dependent bio-psycho-social milestones. In this view, although reproductive health naturally comes into focus during adolescence and (young) adulthood, the stage for it is being set from birth. The panel strongly endorsed this view as the framework for formulating research objectives and potential future clinical approaches designed to optimize reproductive decision-making and reproductive health outcomes among PHIV₊ individuals. PHIV₊ perinatally HIV-infected, RDM reproductive decision-making

Table 1

Key distinguishing features between perinatally and behaviorally HIV-infected pregnant women

Mode of transmission	Perinatal	Behavioral
Time of infection/ diagnosis	Birth/infancy or (rarely) childhood	Adolescence/adulthood; infection often acquired from the father of the baby and/or during the same sex act as the conception
ART experience	Extensive, often life-long	Often ART-naïve (either because they were recently diagnosed, or because not clinically indicated until pregnancy)
ART resistance risk	High (due to long history of treatment and frequent past history of non-adherence)	Low risk of resistance, but adherence may be affected by psychosocial and structural factors (stigma, confidentiality, etc.)
ART discontinuation after pregnancy	Rare (Anecdotal evidence suggests adherence may decline following birth of the baby)	Common (either per prescriber's directions or by the mother's choice) [105]
Adherence during pregnancy	Unknown. However, clinically good based on infant outcomes	Generally good or improved [101] but may be affected by psychosocial and structural factors (e.g., stigma, secrecy, access to care)
HIV first diagnosed during pregnancy (females only)	Extremely rare/no documented cases	Very common [106]
Social stigma	Often perceived as "innocent victims" as children, but this changes as they enter into adolescence	Infection due to "morally suspect" behavior [107]
Salient stressors	<p>Pregnancy may trigger unresolved psychological conflicts related to the experience of being born with HIV</p> <p>Support system relatively stable, may be less need for secrecy though limited disclosure within a household not uncommon. Concerns about partner disclosure are likely comparable to those among behaviorally infected women</p>	<p>Often still accepting the recent diagnosis of HIV, initiating ART for the first time, learning about HIV, guilt and concern about transmitting HIV to fetus/baby</p> <p>Cultural stigma leading to secrecy, erosion of support system</p> <p>Concerns about confidentiality, safety, decisions about diagnostic disclosure to the partner</p>