

DISCLOSURE WITHIN HIV-AFFECTED FAMILIES

EDITED BY: Grace Gachanja, Gary J. Burkholder and Aimee Ferraro

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DISCLOSURE WITHIN HIV-AFFECTED FAMILIES

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While HIV/AIDS is a global public health challenge, its impact is arguably greatest in the Sub-Saharan Africa (SSA), where new infections account for approximately 66% of the total number of HIV-positive persons globally. In SSA, medical, social, and economic resources are limited, thus necessitating innovative approaches to disease prevention. One of the mechanisms of prevention that is most promising occurs through HIV disclosure to family members (e.g., adult sexual partners) generally, and to children in particular. Our emphasis in this eBook is on HIV disclosure to children because it has multiple benefits, including improved adherence to antiretroviral medication treatment and understanding at an early age of the impact of sexual activity on the spread of HIV. While there is a noticeable gap in research on HIV disclosure to younger children, some of the general reasons for non-disclosure include concerns about fear of adult partners leaving relationships, and that children are too young to comprehend the severity of the situation and may tell others outside the family. Thus, it is critical to better understand how the HIV disclosure process happens

(or does not happen) within HIV-affected families, as well as the best practices on how to disclose. In this eBook, we present a combination of empirical research studies and critical literature reviews that investigate the reasons for and for not disclosing HIV status within HIV-affected families and provide evidence-based practices that could be adopted by healthcare professionals to help HIV-positive parents facilitate disclosure activities within these families. This information can also be used by researchers, practitioners, and stakeholders who are in a position to influence policies on effective HIV disclosure practices, guidelines, and programs.

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Editorial: Disclosure Within HIV-Affected Families

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Keywords: child HIV status disclosure, parental HIV status disclosure, HIV disclosure, HIV/AIDS, Sub-Saharan Africa (SSA), resource-poor setting, HIV disclosure process

Editorial on the Research Topic

Disclosure Within HIV-Affected Families

This special issue, “Disclosure Within HIV-Affected Families,” welcomed manuscripts primarily focused on disclosure of a parent’s and/or a child’s illness to HIV-positive, negative, and untested children within HIV-affected families. Our goal was to increase the body of knowledge available on how disclosure is performed within these families; however, we did choose to include two manuscripts exploring disclosure among adults.

The majority of the original research was conducted in countries within Sub-Saharan Africa (SSA) where the HIV/AIDS epidemic continues to affect populations disproportionately and where disclosure practices are arguably most critical. The systematic reviews drew from the global published literature on HIV disclosure.

There was a noticeable gap in the literature on disclosure to younger children. In addition, there are few interventions presented that are designed to disclose to younger children. One pervasive assumption is that older adolescents can handle the emotional aspects of disclosure while younger children cannot. Researchers noted in their literature reviews that early disclosure aids in ART adherence and prepares children to protect themselves and their peers as they move into the teenage years when drug and sexual experimentation increases. The research presented suggests that disclosure interventions/practices which train caregivers/parents/partners and healthcare professionals (HCPs) on how to disclose, and then provides post-disclosure support to the persons disclosed to and to the disclosing caregivers/parents/partners, may be important. Summaries of the manuscripts are provided below.

ORIGINAL RESEARCH

Bhatia et al. found that gender inequality in South Africa contributed to fear and mistrust within adult relationships leading to infrequent and complicated partial or implied HIV disclosure. The authors called for integrated interventions aimed at reducing barriers that lead to more trustful and effective communication among HIV-affected men and women.

Chaudhury et al. analyzed the effectiveness of a randomized controlled trial comparing a family-based intervention versus usual social work care to support HIV disclosure among families in Rwanda. Qualitative findings indicated that caregivers and children reported increased stress during the time of disclosure. The authors assert that the family intervention offered structured support for improved parental-child communication which resulted in improved family trust and child mental health.

Cooper et al. documented unexpected shifts in reactions expressed by study participants to their qualitative interviewers over the course of 3 interviews in South Africa. The authors postulated that richer data can be collected with several participant interviews over time as opposed to one-time cross-sectional interviews. During data collection, the possibility of ethical dilemmas arising when participants confide in researchers thereby blurring the researcher’s versus a counselor’s role during qualitative research was revealed.

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Fair et al. found that disclosure is on the mind of HIV-positive parents who were perinatally infected, but they felt their children are still too young to understand the illness. The authors called for additional disclosure training for HCPs who provide adult HIV care because perinatally infected children will eventually transition into their care when they become adults and require future support to disclose to their HIV-positive and negative children.

Namukwaya et al. found that factors motivating disclosure by caregivers in Uganda included curiosity by HIV-positive young people, who reported harboring no resentment despite caregivers' pre-disclosure fears. The authors advocated for disclosure to young people to occur as a planned process with caregivers/parents receiving support from HCPs.

Okawa et al. examined adolescents' perspectives on the best HIV disclosure practices in Zambia, one of the highest HIV-burdened countries in SSA. Adolescents reported being emotionally impacted by disclosure but that it also improved their self-care, adherence to medication, and ability to speak about HIV with their caregivers. The authors called for adolescent post-disclosure support provided by caregivers/parents, HCPs, and peers.

Rochat et al. designed the Amagugu Intervention to enhance the capacity for HIV-infected mothers to disclose their status and educate their young primary school HIV-uninfected children about the disease. A pretest-posttest evaluation of the intervention was found to be acceptable, feasible, and adaptable in other settings. While the authors found that disclosure was not made easier, mothers reported feeling comfortable disclosing to their children and encouraging them to have healthy behaviors.

van Rooyen et al. presented a novel model of successful home-based HIV testing and counseling program with the potential to improve HIV testing, identification of infected family members, disclosure of illness, and linkage to care. The authors addressed implementation challenges that included but were not limited to cultural mores, intergenerational communication among family members, and privacy concerns especially for adolescents.

SYSTEMATIC REVIEWS

Aderomilehin et al. conducted a systematic review of SSA literature to determine the perspectives of HCPs and caregivers on disclosure practices to children and adolescents in the region. The authors found that partial disclosure was suitable for children before adolescence and full disclosure was best for adolescents with disclosure being performed by their caregivers with the support of HCPs. The authors recommended family

counseling/community education to encourage discussions on sexuality to empower children to make sexual health decisions.

Conserve et al. reviewed the global literature for interventions efficacious in assisting parents living with HIV to disclose their status to their children. Of the five articles from China, South Africa, and the USA, four interventions were found to increase HIV disclosure. Their findings suggested that these effective interventions were adaptable in different cultural contexts/settings.

Krauss et al. reviewed the global literature for reasons used to disclose or not disclose to children. They found that the top three reasons for disclosure were children's curiosity, to improve adherence, and the child's age or maturity level. The top three reasons for not disclosing included fear of the child's negative reaction, young age of the child, and the child's inability to keep the information secret.

Odiachi conducted a literature review on the association between pediatric HIV disclosure and health outcomes in SSA. Five major health outcomes were found including physical/physiological outcomes, psychosocial outcomes, adherence to HIV treatment, sexual and reproductive health, and disclosure of their status to others. The author recommended larger longitudinal studies focused on health outcomes of pediatric disclosure and the creation of policies/guidelines aimed at promoting and improving the low rates of disclosure among this population, especially in SSA.

The HIV disclosure process is known to be difficult and complex. This special topic sheds light on some of the issues that caregivers/parents/partners, children, and HCPs experience before, during, and after HIV disclosure. The manuscript authors suggest feasible interventions and recommendations for future research, in an effort to reduce the HIV disclosure burden within HIV-affected families.

AUTHOR CONTRIBUTIONS

GG, GB, and AF substantially contributed to the drafting, revising, and final approval of this editorial.

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The Role of Relationship Dynamics and Gender Inequalities As Barriers to HIV-Serostatus Disclosure: Qualitative Study among Women and Men Living with HIV in Durban, South Africa

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Background: This qualitative study investigated gender power inequalities as they contribute to relationship dynamics and HIV-serostatus disclosure among men and women living with HIV in Durban, South Africa. HIV serodiscordance among men and women within stable partnerships contributes to high HIV incidence in southern Africa, yet disclosure rates remain low. Given the emphasis on prevention for HIV-serodiscordant couples, this research supports the urgent need to explore how best to support couples to recognize that they are part of this priority population and to access appropriate prevention and treatment.

Methods: Thirty-five in-depth individual interviews were conducted with 15 HIV-positive men and 20 HIV-positive women (not couples) receiving care at public-sector clinics near Durban. A structured coding scheme was developed to investigate men's and women's attitudes toward HIV-serostatus disclosure and behaviors of sharing (or not sharing) HIV serostatus with a partner. Narratives were analyzed for barriers and facilitators of disclosure through the lens of sociocultural gender inequality, focusing on reasons for non-disclosure.

Abbreviations: ART, antiretroviral therapy; ANC, antenatal care; CHCT, couples-based HIV counseling and testing.

Results: Among 35 participants: median age was 33 years (men) and 30 years (women); average years since HIV diagnosis was 1 (men) and 1.5 (women). Four themes related to gender inequality and HIV-serostatus disclosure emerged: (1) Men and women fear disclosing to partners due to concerns about stigma and relationship dissolution, (2) suspicions and mistrust between partners underlies decisions for non-disclosure, (3) unequal, gendered power in relationships causes differential likelihood and safety of disclosure among men and women, and (4) incomplete or implicit disclosure are strategies to navigate disclosure challenges. Findings illustrate HIV-serostatus disclosure as a complex process evolving over time, rather than a one-time event.

Conclusion: Partner communication about HIV serostatus is infrequent and complicated, with gender inequalities contributing to fear, mistrust, and partial or implicit disclosure. Relationship dynamics and gender roles shape the environment within which men and women can engage successfully in the HIV-serostatus disclosure process. Integrated interventions to reduce barriers to trustful and effective communication are needed for HIV-affected men and women in partnerships in which seeking couples-based HIV counseling and testing (CHCT) is challenging or unlikely. These data offer insights to support HIV-serostatus disclosure strategies within relationships over time.

Keywords: gender inequality, partner communication, qualitative, HIV-serostatus disclosure, barriers to disclosure, couples-based HIV counseling and testing, relationships, living with HIV/AIDS

INTRODUCTION

In South Africa, young women are disproportionately at risk for HIV (1–4); HIV prevalence increases from 7% among women aged 15–19 to 17% at ages 20–24, compared to 0.7 and 5% among men in those age groups, respectively (1, 2, 5). Rates of HIV serodiscordance within couples—wherein one partner is HIV positive and the other partner is not—are estimated at 25% in South Africa (6, 7), contributing to sustained high HIV incidence (3, 4). Despite research informing and promoting public health strategies to support prevention for HIV-serodiscordant couples in this setting, rates of HIV-serostatus disclosure remain low among both men and women, hindering access to prevention (8–11).

HIV-serostatus disclosure encompasses the process and experience of sharing one's HIV infection status with others (12, 13). This process can facilitate couples' access to available HIV treatment and prevention options (14). Studies suggest that men and women who communicate with their partner about HIV-serostatus are more likely to seek out and adhere to antiretroviral therapy (ART) (15–17), cope with their diagnoses (18), seek increased social support (19), and engage in protective behaviors including condom use (20, 21). However, difficulties surrounding disclosure communication may prevent the use of HIV prevention methods or result in suboptimal adherence to HIV treatment (14, 22, 23). HIV-serostatus disclosure may be particularly stressful for women due to fear of negative reactions from one's partner upon disclosure (24–26), including violence (27–29), discrimination, abandonment, or accusations of infidelity (24, 26, 29, 30). Safer disclosure strategies are needed (31), including harm reduction approaches (32), especially

during pregnancy when women are often more vulnerable (27, 33–36). In addition, given the emphasis on prevention for HIV-serodiscordant couples (8–11), data are needed to explore how to best support couples to recognize they are part of this priority population and access prevention and treatment services.

Socially and culturally rooted gender power inequality within relationships and intimate partner violence place South African women at increased risk of HIV infection compared to men (3, 4, 33). South African gender norms are rooted in sociocultural expectations and historical contexts of violence and oppression (33), resulting in men often leveraging more power in sexual partnerships (3, 9, 33). Gendered social norms that enable male power in sexual relationships also include intergenerational relationships between younger women and older men (4, 9). Women may experience difficulty negotiating safer sex practices (33), or communicating about intimacy (37), adding to the difficulty of discussing HIV serostatus or similar topics (20, 21, 37–39). The intersection of HIV and gender power inequality within relationships has been explored and analyzed extensively as an important sociocultural determinant of HIV risk (33, 34), yet the implications for HIV-serostatus disclosure have not been comprehensively explored (24). Research from Uganda and Zimbabwe explored the process and implications of HIV-serostatus disclosure between sexual partners (12, 18, 20, 28, 39). However, the nuanced barriers and strategies to disclose have not been adequately investigated in this population of South African men and women living with HIV, and their partners (10, 14, 17), creating the need for a qualitative investigation.

We used qualitative methods to explore dynamics of HIV-serostatus disclosure, and associated barriers and promoters, to

inform strategies for safe disclosure among HIV-infected South African men and women. We investigated the process, experiences, and consequences of HIV-serostatus disclosure through the lens of gender inequality by exploring HIV-infected men's and women's narratives of non-disclosure within relationships. By exploring how gender roles and relationship dynamics influence the disclosure process, we offer insights to inform future interventions.

MATERIALS AND METHODS

Setting and Participant Recruitment

Data were collected within a study exploring reproductive decision-making and safer conception counseling experiences to safely address fertility goals among men and women living with HIV in eThekweni district, KwaZulu-Natal (40, 41). In this region, HIV prevalence among pregnant women attending antenatal services is estimated at 41% (42).

Individual in-depth interviews were conducted in June and July 2012 with HIV-infected men ($n = 15$) and women ($n = 20$) (not couples) enrolled in HIV care in one of four public-sector health clinics. Eligible participants were aged 18–40 years (women) or over 18 years (men), self-reported being HIV positive, were not pregnant (women), and spoke English or isiZulu.

Ethics and Regulatory Approvals

Ethics approvals were obtained from University of the Witwatersrand Human Research Ethics Committee (Johannesburg, South Africa) and Partners Healthcare (Boston, MA, USA). Permissions were obtained from local provincial and district Departments of Health and the individual health facilities. All participants provided written informed consent.

Data Collection

Open-ended in-depth interviews lasted approximately 1 h and explored participant experiences of reproductive goals, lived experiences of HIV, HIV-serostatus disclosure, and relationships. Interviews were conducted by research assistants fluent in English and isiZulu. Interviews were digitally recorded and transcripts were translated into English. Transcripts were reviewed for translation quality and fidelity by another study team member.

Data Analysis

The findings were compared and contrasted across participants and genders using a rigorous analytical process to establish robust qualitative results. Themes relating to promoters and barriers of HIV-serostatus disclosure were identified and explored, based on a conceptual framework developed to guide analytical decisions considering how gender inequality shapes partnership dynamics that influence HIV-serostatus disclosure behaviors. Transcripts were read to identify major themes, analyze parallels across men's and women's experiences, and inform the development of a coding scheme to categorize data. Multiple coders engaged in an iterative analytical process to ensure that codes were developed using a structured, consensus-driven process. The final coding scheme included both *a priori* themes and

those developed from preliminary readings of the transcripts (43). Data were organized using NVivo 10 (QSR International) and separated into themes and subthemes relating to barriers and promoters of HIV disclosure. Data reduction methods were employed to extract the overarching narrative from the most pertinent data (44).

Conceptual Framework

The critical analysis framework (Figure 1) contextualizes HIV-serostatus disclosure within community-level gender norms in South Africa. It examines the intersections between South Africa's HIV/AIDS epidemic and the realities of gender inequality. This framework identifies sociocultural gender inequality as the root cause of the higher rates of HIV infection among women through its influence on individual and couple-level behaviors and partnership dynamics. In turn, these gendered behavioral outcomes influence HIV-serostatus disclosure as well as decisions surrounding conception and childbearing that place women at higher risk of HIV infection than men (4). The coding scheme contextualized gender-specific data within this framework to analyze how gender inequalities influence the process of HIV-serostatus disclosure within relationships.

RESULTS

The study population ($n = 35$) had the following characteristics: median age 33 years (men) and 30 years (women); average years since HIV diagnosis 1 (men) and 1.5 (women); 60% of men and 65% of women were on ART. Although a large proportion (11/15 men and 16/20 women) reported having disclosed their HIV serostatus, almost half of women did not know their partner's HIV serostatus (Table 1).

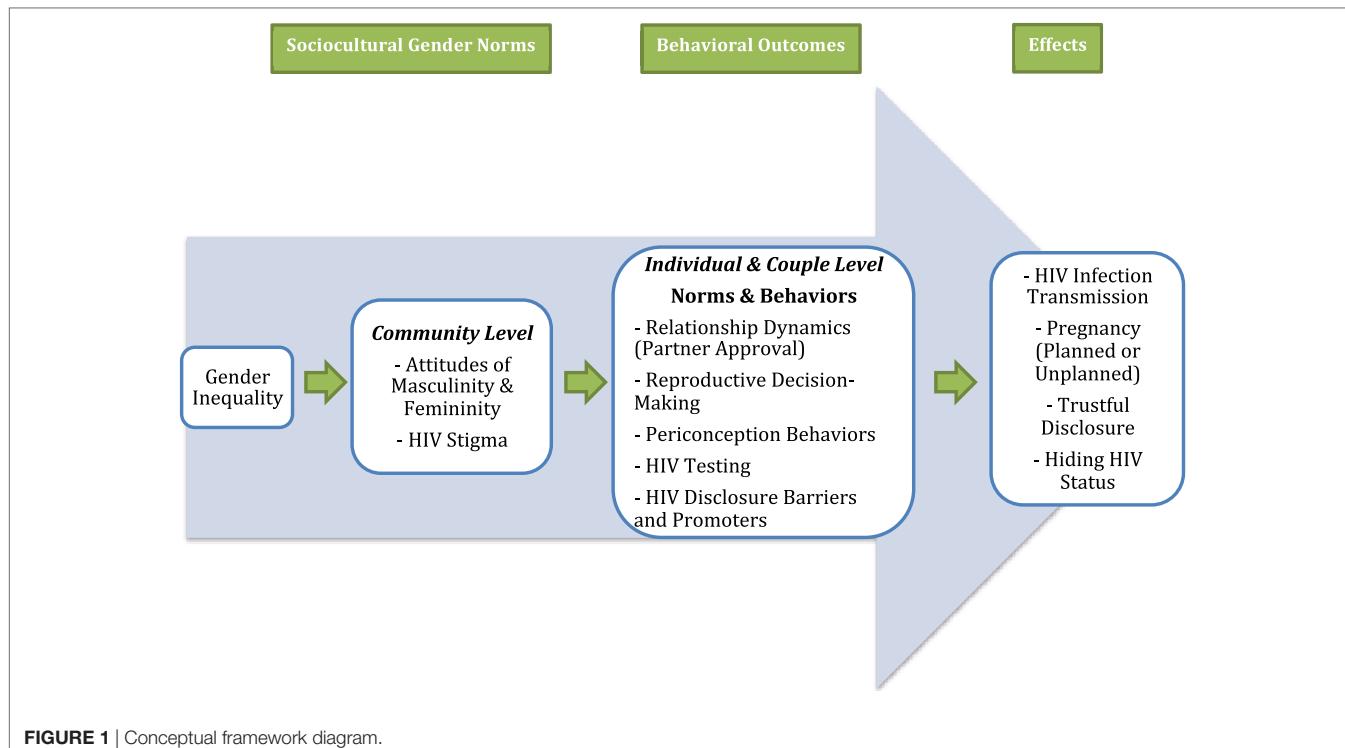
Overview

Four major themes regarding HIV-serostatus disclosure emerged. First, men and women fear HIV-serostatus disclosure to partners due to concerns about stigma and potential relationship dissolution. Second, suspicions and mistrust between partners underlie and contribute to lack of disclosure. Third, unequal power in relationships based on gender influences women's disclosure patterns, resulting in different disclosure practices for men and women. Fourth, these factors often lead to partial or incomplete disclosure. These findings reveal how men, women, and their partners experience HIV-serostatus disclosure as a complex process rather than a one-time event, and highlight important considerations for interventions.

Men and Women Fear Disclosing to Partners

HIV-serostatus disclosure was recognized as an important "first step" (30- to 34-year-old female) to caring for oneself and one's partner, although both men and women experienced tension with the process.

If a person is scared to say they are living with HIV...maybe the person she met is HIV positive...or both of them think they are negative. When one of them is positive, one might end up getting infected because

**FIGURE 1** | Conceptual framework diagram.**TABLE 1** | Sociodemographic characteristics of participants.

| | Men (n = 15) | Women (n = 20) |
|--|-------------------------|-----------------------|
| Median age (IQR) | 33 years (28.5–38.5) | 30 years (27–33.3) |
| Employment | | |
| Employed | 8 (53%) | 8 (40%) |
| Unemployed | 7 (47%) | 11 (55%) |
| Student | 0 | 1 (5%) |
| Average years since HIV diagnosis (IQR) | 1 (0.4–2.2) | 1.5 (0.9–6.0) |
| Currently on antiretroviral therapy | | |
| Yes | 9 (60%) | 13 (65%) |
| No | 5 (33%) | 7 (35%) |
| Disclosed to current sexual partner | | |
| Yes | 11 (73%) | 16 (80%) |
| No | 2 (13%) | 3 (15%) |
| N/A (no current relationship) | 2 (13%) | 1 (5%) |
| HIV status of primary partner | | |
| HIV positive (seroconcordant) | 9 (60%) | 8 (40%) |
| HIV negative (serodiscordant) | 2 (13%) | 2 (10%) |
| "Do not know" | 2 (13%) | 9 (45%) |
| N/A (no current relationship) | 2 (13%) | 1 (5%) |

they did not tell each other the truth. (30- to 34-year-old female)

Participants feared consequences of disclosure, including stigmatization, accusations of infidelity, loss of a partner, and violence. As one man described:

Being sick like this, I will date someone and disclose to her and she will just leave. (40- to 44-year-old male).

One woman's "*husband left [her] with their children*" after learning she was HIV infected (35- to 39-year-old female), while another expressed fear of "*what kind of person he [her partner] would be*" upon learning her serostatus (30- to 34-year-old female). Above all, participants feared being unable to live a normal life, inclusive of intimate relationships. Comments reflecting community stigma, such as "*most people are scared to be HIV positive*" (25- to 29-year-old female), or people think HIV "*mean[s] that, [it] is the end of your life*" (30- to 34-year-old male) were common.

Most frequently, participants who disclosed did so because they did not "*want [their partner] to get infected*" (30- to 34-year-old male), although motivations sometimes differed by gender. Pregnant women often disclosed to secure partner support to seek health care to prevent perinatal transmission and relationship dissolution.

If you didn't [disclose], you are killing your child because the child will be infected while you were scared to come forward. (35- to 39-year-old female)

In contrast, some men feared that disclosure might interfere with their reproductive goals.

To have more children...I would impregnate someone who doesn't know I'm [HIV-infected]. (40- to 44-year-old male)

These responses characterize gender differences in the approach to HIV-serostatus disclosure.

Suspicions and Mistrust within Relationships

Underlie Lack of Disclosure

Both men and women viewed trust as the foundation for HIV disclosure within a relationship, yet frequently described partners as not “trustworthy” (40- to 44-year-old male).

Men have a problem...They are scared...to come forward even if they know their status. They are ruining lives because they want to infect you without [disclosing to] you. (35- to 39-year-old female)

Some participants feared that their partner had not been truthful when disclosing:

I cannot say she was being truthful when she said she's negative. Women, especially, say they are negative, even if [they] are positive. (25- to 29-year-old male)

This man's concerns about his partner influenced his own decision not to disclose.

Male respondents' suspicions of women as untrustworthy were often linked to infidelity:

I can...tell my partner that I have the virus ...[but] at the end if she got sick she wouldn't know if she got it from me or from another person because women, they are not trustworthy sometimes. Also us men, we do not trust ourselves. (40- to 44-year-old male)

I have some doubts if it is me who made [my girlfriend] pregnant. (40- to 44-year-old male)

With women perceived as devious or subversive, conversations about condom use or HIV prevention were viewed as trickery, rather than honest attempts to disclose. Some men implied that women's non-use of condoms or other HIV prevention was willful, aimed at intentionally spreading HIV infection, such that they “deserved” to be infected (30- to 34-year-old male). At the same time, men and women both expressed concerns about infecting their partner, and also about the importance of HIV disclosure to prevent this.

Further, both men and women feared that condom use would mark them as HIV infected. Secretive behaviors were common: “*He does not know I am on family planning*” (25- to 29-year-old female). One woman's partner stated that her initiation of HIV treatment while he did not would “destroy him somehow” (35- to 39-year-old female), conveying a sense of mistrust that also precluded ARV use. Accordingly, one participant observed, “[Many women] who are taking ARVs hide that they are taking [them]” (35- to 40-year-old female). Others described how they exist in limbo concerning their own and their partner's HIV serostatus: “*I don't know [my partner's status], that's the main thing we're fighting over...me too, I felt I must not tell him [my status]*” (30- to 34-year-old female).

In contrast to these prevailing attitudes, some women and men described communication about disclosure as a way to “respect each other” (30- to 34-year-old female) and maintain a faithful, honest relationship. As two participants described:

As people who are positive, you must be faithful to your partner that you love. You have to be open about your status. You tell him and he tells you. (30- to 34-year-old female)

She knows mine [HIV-serostatus] and I am in this situation now because she...encouraged me to get tested. (30- to 34-year-old male)

Men and women who described disclosure as beneficial often viewed it as a means of communication, whereby “*no one gets discriminated between the partners*” (35- to 39-year-old male).

Unequal Power in Relationships Influences Gendered Disclosure Practices

Although women appeared more accepting of disclosure, they were generally more affected by gender inequality within relationships and more concerned about negative consequences. Because of mistrust, stigma, and the potential loss of a relationship and its social and economic security, many women lived with partners for some time without disclosing: “*I am scared to tell him [my partner] I am HIV positive*” (25- to 29-year-old female).

Often, this silence was based on fears of how a partner might react, including accusations of “bringing HIV into the relationship,” reflecting respondents’ concerns about infecting their partners as well as the negative reactions that might result:

I knew [for] ten years that I was positive. I was unable to tell him. I asked him to go and check and he came back with results showing he was negative. I was unable to tell him I am positive because I was thinking what he was going to say, from where I got this. (35- to 39-year-old female)

Another woman described a 12-year relationship, in which she did not know her partner’s status while he knew she was living with HIV (30- to 34-year-old female), and she felt that asking him might disrupt the relationship.

Participant: This is the twelfth year [we are living together]...I don't know his status.

I: Does your partner know your HIV status?

Participant: Yes he knows. (30- to 34-year-old female)

Often, women were first to test for HIV, which added further stress by making them responsible for encouraging their partner to test:

I found out [about my infection] from my wife, she was the one who came first here. She tested...and found out she was positive. I came after and found out I'm positive. I'm about to start [ARVs]. (25- to 29-year-old male)

Although both men and women described HIV disclosure as stressful, women were generally viewed as more open to it. Indeed, some women appeared more comfortable with the process, reporting that “[men] don't want to talk about things

concerning HIV" (25- to 29-year-old female). Many women described a partner's unwillingness to test:

I: Why did you not tell [your partner your status]?

Participant: If he agreed to come to clinic, we would find out together, I would tell him that I am already like this, go and check. (30- to 34-year-old female)

Whether they chose to disclose or not, both men and women expressed deep-seated concerns about a partner's reaction to learning their HIV status and the implications for their relationship.

Incomplete Disclosure As a Strategy to Navigate Disclosure Challenges

In some cases, participants thought their partner was HIV positive and encouraged them to disclose, but reported that they "kept on denying" (35- to 39-year-old female).

[My partner] was trying to tell me indirectly about his situation [HIV-positive], but he was scared. (20- to 24-year-old female)

Participants frequently learned of their partner's HIV-positive serostatus through unspoken clues, including physical signs and symptoms:

In order for me to become HIV positive, the condom burst. I went to check alone and came back with results to show him...There were some warts I saw on his private parts. I [knew] something is a problem. (30- to 34-year-old female)

Many participants believed that if their partner was HIV positive then they, too, must be positive. One woman explained how she sought assistance to explain serodiscordance to her partner:

I explained to her [the nurse] that I have this problem, I request you to [explain] so this male person could understand [serodiscordance], how [this infection] has been found in me, because it can happen that, it is a female person who is found positive and not the male. And sometimes, it happens that it is found in a male and not in a female. (35- to 39-year-old female)

Many men assumed that their partner was HIV negative without having been told directly.

Participant: I know her status. It is right.

I: ...it is negative?

Participant: Even though she never told me, I know that she has nothing. (30- to 34-year-old male)

Sometimes, disclosure was implicit rather than explicit. In the following exchange, a woman tells her partner only that she is "sick," without stating directly that she is HIV infected.

I: Does your partner know your HIV status?

Participant: No. But I told him that I am sick.

I: ...So he knows?

Participant: He knows, yes. (35- to 39-year-old female)

Avoiding conversations about HIV status or providing untruthful responses were consequences of the fear surrounding disclosure and the fear of losing one's partner.

When I ask him what were the results of your blood test he will say 'hay you know,' then I'd ask 'what do you mean...HIV or negative?' then he will say negative. (25- to 29-year-old female)

These vague discussions about HIV status frequently led to partial or incomplete disclosure, in which individuals were uncertain about their partner's serostatus.

DISCUSSION

HIV-serostatus disclosure, a critical component of HIV prevention, is a complicated and often indirect process. This research found that (1) Partner communication about HIV serostatus is infrequent, and the gendered nature of mistrust, fear, and suspicion within relationships creates multilayered barriers to disclosure, often leading to partial or implicit disclosure; (2) participants were often uncertain about partner serostatus, reflected in vague discussions about disclosure; (3) relationships and gender roles impact HIV-serostatus disclosure by influencing the environment within which discussions about HIV-serostatus disclosure occur; and (4) multistep interventions that occur over time to facilitate the disclosure process and reduce barriers to effective communication and trust are needed for HIV-affected men and women in relationships. For many men and women in this setting, seeking couples-based HIV counseling and testing (CHCT) together would be challenging or improbable.

Couples-based HIV counseling and testing, an evidence-based strategy to promote HIV-serostatus disclosure within partnerships, has been implemented with some success in South Africa, Rwanda, and Zambia (14, 21, 45–47). While CHCT is a beneficial strategy for couples who are able to undertake HIV testing together, it is not effective for many couples given the relationship distrust and fears of disclosure highlighted in this study. CHCT can be especially challenging because it requires that both partners go together for HIV counseling and testing, and thus functions under the assumption that both partners are comfortable discussing their HIV status with each other and that they have already disclosed to each other. This expectation is not feasible for many men and women living with HIV infection. Our findings suggest a need for approaches with attention to gender and relationship dynamics, with particular attention to the fear, mistrust, and misunderstandings of serodiscordance surrounding disclosure (11–13, 18, 20, 25, 36).

Gender inequalities influence disclosure by fostering general distrust between men and women and deep fears of repercussions of disclosure. In this study, both men and women worried about infidelity, and women feared male partner violence as well

as accusations about transmitting HIV, although implications of HIV disclosure differed by gender. Men feared losing their relationship and a partner with whom to have a child, while women's concerns focused on losing the relationship itself, including social and economic support. Many women feared violence as an outcome of HIV-serostatus disclosure; developing interventions to address these fears is critical. For both men and women, the level of relationship trust necessary for disclosure was often absent. Instead, suspicions, fears, and mistrust were barriers to disclosure. Importantly, men, women, and their partners experience disclosure as a complex process that evolves over time, not a one-time event. This process is complex because conversations about disclosure consider aspects of relationships beyond partners' serostatus alone. Couples-based strategies could be enhanced to include HIV counseling and testing as well as gender-based violence prevention and other intervention components to address gender inequalities and stigma, the issues identified as being of paramount importance in this study.

These findings highlight the gendered nature of mistrust and suspicion within relationships (11, 24). Consistent with research findings from other African settings, many women in this study felt obligated to disclose, yet simultaneously feared consequences of losing their partner (19, 20, 27, 29, 36, 38, 48) or accusations of infidelity and infecting the partner (27, 29). This led women to hide their HIV serostatus or even ART use (15, 16). Both men and women experienced HIV-serostatus disclosure as uncomfortable and stressful. These findings show that facilitators of the HIV-serostatus disclosure process include trustful and honest partner communication while barriers include stigma, gender inequalities, and mistrust within the relationship. In this study, more women had disclosed and appeared more comfortable with the process overall, especially when motivated to help their partner test and receive ART (18, 26). Correspondingly, men more often assumed that they knew their partner's HIV status by forming conclusions based on prior instances or interactions with their partner, even without formal disclosure. Respondents had concerns about how their partners would react to their HIV disclosure, as well as broader concerns about infecting their partners.

Other research has found that gender power inequalities powerfully shape attitudes within relationships, influencing patterns of HIV disclosure. A widespread lack of communication grounded in fear and mistrust is also common in HIV-affected partnerships (9, 12, 45), as is confusion about serodiscordance. In this study, many men and women believed that if their partner was HIV infected then they, too, must be infected, a situation known as "testing by proxy" that reflects common misconceptions about HIV serodiscordance (49–52). Partly due to such misunderstandings about HIV serodiscordance, partial disclosure is common (12, 22, 31).

Our study shows how gender inequality serves as a barrier to HIV-serostatus disclosure. We found that likely facilitators of the disclosure process would be interventions that provide support for couples to address stigma, violence, and concerns about confidentiality within their relationship. Rather than approaching disclosure as a discrete, one-time event (21, 53), disclosure interventions may be more effective if they engage participants over time, especially if they are not yet prepared to seek CHCT together.

Multisession interventions may be required to reduce stigma and support disclosure communication within relationships to have constructive conversations about HIV-serostatus disclosure and treatment. Strategies with known efficacy to increase communication between partners include community-based support groups for men and women (19, 37, 46, 47), which draw on psychosocial or peer-adherence models (47, 49, 54–56). Systematic reviews of HIV-serostatus disclosure interventions show that cognitive-behavioral group sessions, peer support groups, and voluntary partner notification may be effective in encouraging disclosure to sexual partners and can also impact morbidity and retention in care (31, 53). Combining such promising approaches to develop gender-focused interventions to teach disclosure strategies individually for HIV-affected men and women in partnerships who are unable to seek CHCT together would be a significant step. Multistep interventions conducted over time with individuals or single-sex groups of men and women in serodiscordant partnerships could focus on improving communication challenges identified as barriers to disclosure in this study. Potentially effective strategies to enable individuals to engage with disclosure prior to attending CHCT include facilitating role-playing scenarios, or home visits by community health workers. Behavioral approaches that incorporate gender-focused components, including gender equality and violence reduction, could be combined with interventions that address HIV stigma and barriers to honest communication to develop an integrated strategy that addresses gender inequality's role in HIV-serostatus disclosure (14).

This study's participants were not couples but individual heterosexual men and women discussing their relationships. There are advantages to this, however, as much can be learned about couples, with potentially greater honesty from men and women who knew their partner was not in the study. Differences in HIV disclosure among men and women, including some women's greater comfort with the process, may reflect social desirability bias and gender differences in reporting personal experiences. This may also result from women's greater participation in health care, usually through antenatal care, and greater likelihood of receiving HIV testing and treatment.

CONCLUSION

This paper investigates how relationship dynamics and gender inequalities serve as barriers to HIV-serostatus disclosure, and attitudes and behaviors that may promote it. Relationship and gender roles shape the environment within which men and women can engage productively in the HIV-serostatus disclosure process. These findings highlight the consequences of implicit or incomplete disclosure and the fact that, despite participants' concerns about disclosure, non-disclosure is equally serious. Multisession interventions focused on engaging individuals or couples and health-care providers over time may reduce barriers to effective and trustful communication for the many HIV-affected men and women in partnerships in which seeking CHCT together is challenging or unlikely. Combination interventions to strengthen women's agency, and programs to change men's attitudes toward HIV-serostatus disclosure, are interventions worthy of further testing.

ETHICS STATEMENT

Ethics and regulatory approvals. This study was carried out in accordance with the ethics recommendations of the University of the Witwatersrand Human Research Ethics Committee (Johannesburg, South Africa) and Partners Healthcare (Boston, MA, USA). All participants provided written informed consent in accordance with the Declaration of Helsinki. The protocol was approved by the local provincial and district Departments of Health and the individual health facilities.

AUTHOR CONTRIBUTIONS

LM was involved in all phases of the work. AH, AK, FB, IW, CP, SS, DRB, and JS were involved in study design, tool development,

interpretation of data, and editing and final approval of the manuscript. DSB led data analysis and interpretation and production of the manuscript. MK and CM were involved in data collection, interpretation, and editing and final approval of the manuscript. All the authors read and approved the final manuscript.

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HIV Status Disclosure through Family-Based Intervention Supports Parenting and Child Mental Health in Rwanda

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Introduction: Few evidence-based interventions exist to support parenting and child mental health during the process of caregiver HIV status disclosure in sub-Saharan Africa. A secondary analysis of a randomized-controlled trial was conducted to examine the role of family-based intervention versus usual social work care (care as usual) in supporting HIV status disclosure within families in Rwanda.

Method: Approximately 40 households were randomized to family-based intervention and 40 households to care as usual. Parenting, family unity, and child mental health during the process of disclosure were studied using quantitative and qualitative research methods.

Results: Many of the families had at least one caregiver who had not disclosed their HIV status at baseline. Immediately post-intervention, children reported lower parenting and family unity scores compared with those in the usual-care group. These changes resolved at 3-month follow-up. Qualitative reports from clinical counselor intervention sessions described supported parenting during disclosure. Overall findings suggest adjustments in parenting, family unity, and trust surrounding the disclosure process.

Conclusion: Family-based intervention may support parenting and promote child mental health during adjustment to caregiver HIV status disclosure. Further investigation is required to examine the role of family-based intervention in supporting parenting and promoting child mental health in HIV status disclosure.

Keywords: children affected by HIV AIDS, Rwanda, family-based intervention, resilience, parenting

INTRODUCTION

There is a dearth of literature examining the effects of caregiver HIV status disclosure within families in sub-Saharan Africa (1). Notably, there is limited examination of interventions that support parenting and child mental health during this process (2–4). Family-based intervention delivers psychosocial support for children through strengthening communication and parenting, resulting in enhanced disease-coping strategies in both the immediate and long term (5–10). In particular,

family-based intervention may support parenting and promote child mental health during the process of caregiver HIV status disclosure to children (9, 10). Early research in South Africa has demonstrated the feasibility of family-based intervention to support caregiver HIV status disclosure to children (11).

Family-based intervention, also known as family strengthening intervention, was adapted for use within HIV-affected families in Rwanda (FSI-HIV) (10–15). Quantitative and qualitative analysis of data from an 80-family randomized-controlled trial of FSI-HIV versus usual-care social work was undertaken to examine supported caregiver HIV status disclosure within families in Rwanda¹.

MATERIALS AND METHODS

Quantitative and qualitative data from a randomized-controlled trial of a family-based intervention (FSI-HIV) versus usual-care social work were examined. Changes in parenting skills, child resilience, and child mental health during the process of supported caregiver HIV status disclosure were assessed (10). Quantitative data were collected at pre-intervention, immediate post-intervention, and at 3 months post-intervention, from December 2012 to June 2014. The relationship between supported HIV status disclosure and family relationships during the family-based intervention was explored through mixed-methods techniques (12–14).

Study Population

Families affected by caregiver HIV were recruited through referrals from health-center social workers in rural Southern Kayonza District in Rwanda for participation within a randomized-controlled trial of the FSI-HIV. A randomization sequence was generated in Microsoft Excel to assign families to the FSI-HIV intervention or to the control group of the trial. Randomization was conducted after baseline assessments. A sample size of 80 families was calculated, assuming 2 eligible respondents per family on average and moderate intra-class (within-family) correlation (approximately 0.5), to yield power of 0.80 to detect a standardized a “medium” effect size of approximately 0.50 in study outcome measures, assuming a standard alpha level of 0.05. Inclusion criteria required at least one caregiver to be HIV-positive and at least one school-aged child (7–17 years) to be resident within participating households. Caregivers agreed to discuss their HIV status with their children. Caregivers gave informed consent to participate for themselves and for their children. Additionally, children gave oral consent. Children could elect not to participate. A community advisory board was formed to oversee conduct of the study. All study procedures were granted approval by the Rwandan National Ethics Committee and the Harvard School of Public Health’s Institutional Review Board.

Intervention

The FSI-HIV was designed, developed, and tested within families affected by caregiver HIV in Rwanda (10, 15, see footnote text 1).

Previously published findings have demonstrated the acceptability and feasibility of FSI-HIV (10). The four main aims of the FSI-HIV comprise development of resilience through family narrative, improved parenting and family communication, HIV psychoeducation, and engagement of formal and informal sources of support (10, 15). Data about demographics and HIV status of all family members were collected in introductory meetings. Then, trained bachelor-level counselors delivered a series of six core modules within each household. Counselor-led sessions with caregivers (Modules 1, 2, and 4) established the family narrative, discussed the effect of HIV on the family, and identified sources of resilience. Counselor-led sessions with children (Modules 3 and 5) established the family narrative from the children’s perspective, provided psychoeducation on HIV, and identified sources of resilience. During the sixth and final module, caregivers led a family meeting and discussed the family’s challenges, strengths, and goals (10).

Controls

Once enrolled in the study, participating households were randomized to receive the FSI-HIV intervention or care as usual social work. Control households received care as usual social work support through the locally available government-provided social services. This support generally consisted of advice concerning food insecurity and access to schooling. Study outcomes were measured in both FSI-HIV and control households at baseline, immediately post-intervention, and at 3-month follow-up.

Study Outcomes

Parenting and Family Unity

Parenting was measured using local and combined parenting scales consisting of a 32-item scale ($\alpha = 0.91$). The local parenting score contained 16 locally derived items (4), whereas the combined parenting score included an additional 16 items from the Parental Acceptance and Rejection Questionnaire, scored on four-point scale from 0 (“never”) to 4 (“every day”) (16). Family unity was assessed on a scale of 0 (never) to 3 (every day), using a 15-item scale derived from local qualitative data ($\alpha = 0.93$) (4, 10). Parenting and family unity scores were developed and validated within Rwandan families in prior mixed-methods studies (15). Questionnaire components capture varying dimensions of parent-child and family relationships (Table 1) (15).

Child Mental Health

Child depression was measured using a locally validated version of the Center for Epidemiological Studies Depression Scale for Children (CES-DC) (17). Child combined anxiety-depression was measured using a 23-item adapted youth self-report ($\alpha = 0.93$) scored as the mean of items from 0 (“not at all true”) to 3 (“often true”) (18). Child resilience was measured using an adapted Version of the Connor-Davidson Resilience Scale (CD-RISC) (19) and from local qualitative data ($\alpha = 0.92$) and scored as the sum of all items. Child prosocial behavior was measured using a 20-item scale from local qualitative data ($\alpha = 0.90$) scored as the mean (4).

¹Betancourt TS, Ng L, Kirk C, Brennan RT, Beardslee W, Stulac S, et al. Family-based promotion of mental health in children affected by HIV (2016, submitted).

TABLE 1 | Components of the parenting and family connectedness assessments.

| Good parenting | Family connectedness |
|--|--|
| Provide trainings | Interact with each other |
| Provide teachings | Converse to reach agreements |
| Provide discipline | Understand each other |
| Give advice | Unified |
| Converse with children | Do not have conflicts with each other |
| Interact with children | Being honest with each other |
| Draw close to children | Not suspicious of each other |
| Treat all children in the family equally | Cooperate with each other |
| Respect children | Respect each other |
| Being calm with children | Do not stigmatize one another |
| Express love | Love each other |
| Provide resources (food, water, clean clothes and school fees) | Share and keep secrets with each other |
| | Parents don't cheat on each other |

Data Collection

Quantitative child and caregiver self-report measures of family factors and child mental health were developed and adapted to fit the local context and underwent forward and back translation processes (4, 20). Questionnaires were administered by local research assistants in Kinyarwanda using hand-held smartphones at baseline, immediately post-intervention, and at 3-month follow-up. Qualitative data were extracted from counselors' clinical notes to capture interventionist observations during child, caregiver, and family interviews through the course of the modules of the intervention.

Data Analysis

Quantitative analyses were performed using STATA 13.0. Means of child and caregiver self-reported parenting and child resilience and mental health scores with corresponding 95% confidence intervals were calculated and plotted.

Qualitative data were analyzed using thematic content analysis to identify and analyze patterns driven by *a priori* research questions (21): (1) What, if any, are the effects of the process of HIV disclosure within FSI-HIV families on the relationship between parents and their children? (2) What, if any, are the effects of the FSI-HIV intervention on the process of HIV disclosure with respect to parenting skills and child resilience and mental health? Data were analyzed inductively to identify codes, which were then further categorized to capture main patterns within the data. Themes from families' experiences were observed and developed from these categories.

RESULTS

Baseline Characteristics

Forty-one families were randomized to the FSI-HIV intervention and 41 families to treatment as usual. Approximately half of all families were dual-caregiver households. Most caregivers within FSI-HIV families were female ($n = 42$; 68.9%), HIV-positive ($n = 52$; 85.3%), and had a mean age of 41 years. The majority of children within FSI-HIV families attended school ($n = 87$, 96.7%) and 6.5% were HIV-positive ($n = 6$) (see Table 2).

TABLE 2 | Baseline characteristics of participants enrolled in family-based preventive intervention arm of trial.

| | FSI-HIV | TAU (usual-care control families) |
|--|-------------|-----------------------------------|
| Families, no. (%) | | |
| Dual-caregiver families, no. (%) | 41 (50) | 41 (50) |
| Average no people per household, mean (SD) | 20 (48.8) | 20 (48.8) |
| Average no children per household, mean (SD) | 5.1 (1.5) | 4.8 (1.5) |
| SES, mean (SD) | 3.2 (1.3) | 3.0 (1.4) |
| | 0.11 (0.08) | 0.10 (0.07) |
| Caregivers, no. (%) | | |
| Female, no. (%) | 61 (49.6) | 62 (50.4) |
| Age, mean (SD) | 42 (68.9) | 42 (67.7) |
| HIV-positive, no. (%) | 41.1 (9.1) | 41.0 (8.5) |
| | 52 (85.3) | 51 (82.3) |
| Children, no. (%) | | |
| Female, no. (%) | 93 (54.7) | 77 (45.3) |
| Age, mean (SD) | 52 (55.9) | 31 (40.3) |
| Attends school, no. (%) | 11.8 (2.8) | 11.7 (2.9) |
| HIV-positive, no. (%) | 87 (96.7) | 64 (88.9) |
| | 6 (6.5) | 15 (19.5) |
| Non-disclosure families, no. (% of all) | 18 (43.9) | – |
| Maternal, no. (%) | 10 (55.6) | – |
| Combined maternal and paternal, no. (%) | 7 (38.9) | – |
| Paternal, no. (%) | 1 (5.6) | – |
| Prior disclosure families (% of all) | 17 (41.5) | – |
| Maternal, no. (%) | 13 (76.4) | – |
| Combined maternal and paternal, no. (%) | 4 (23.5) | – |
| Paternal, no. (%) | 2 (11.8) | – |
| Supported disclosure families, no. (% of all) | 15 (36.7) | – |

Caregiver HIV Status Disclosure

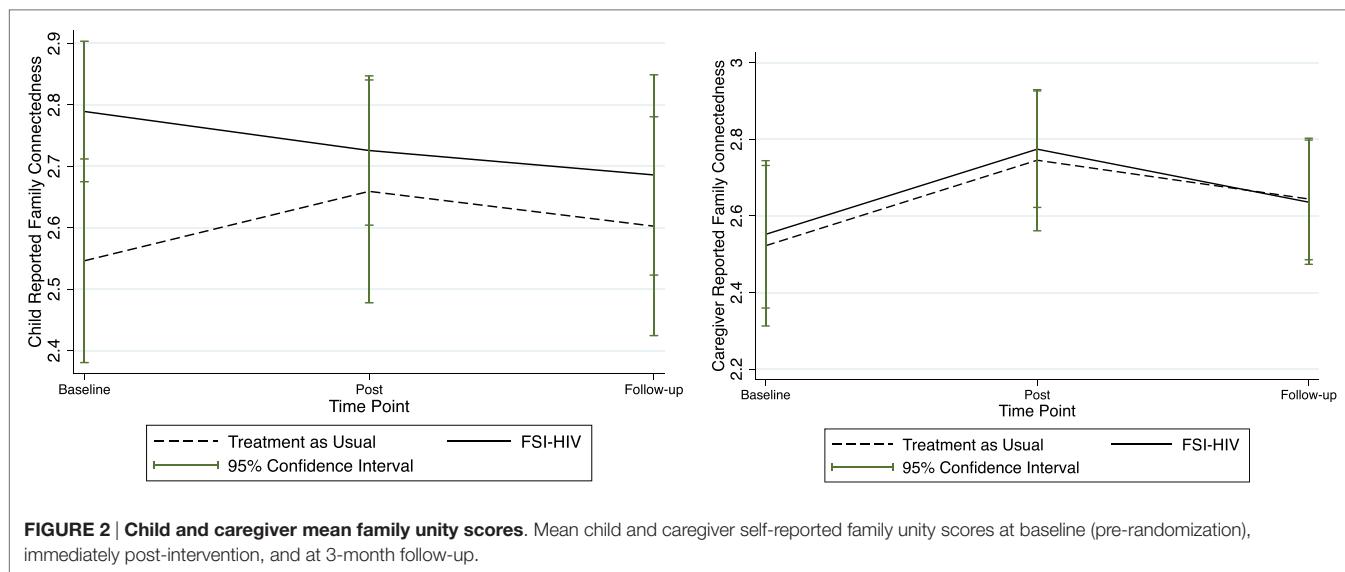
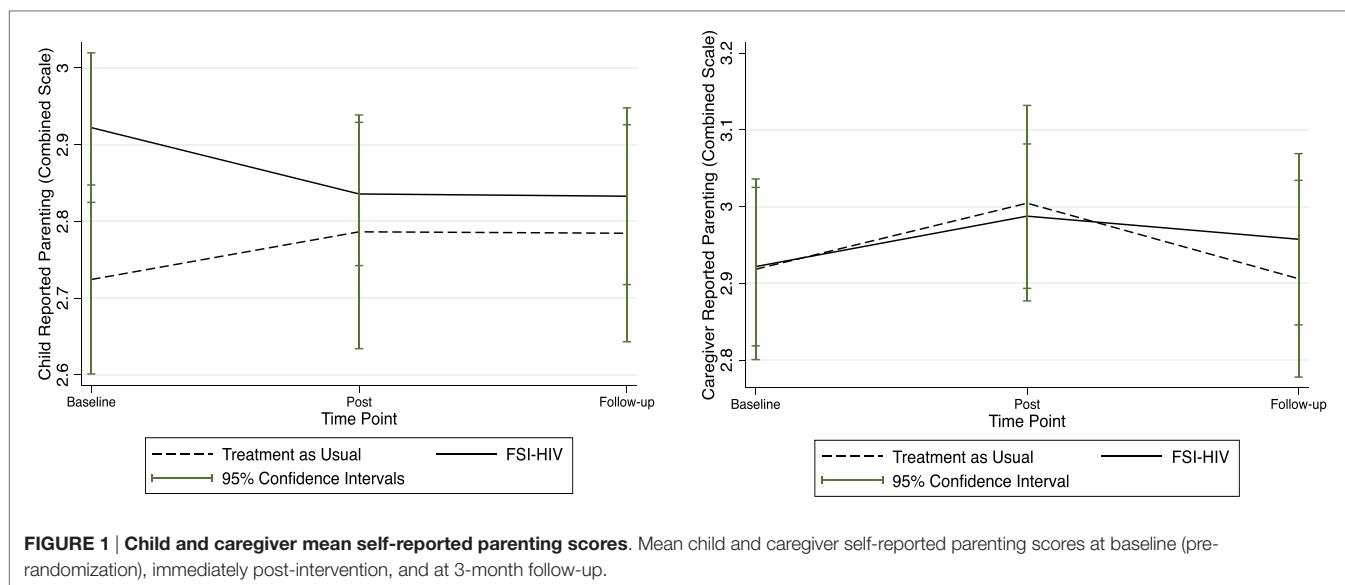
A total of 18 (43.9%) of all FSI-HIV families experienced non-disclosure of at least 1 caregiver at baseline (see Table 2). The majority of families described maternal HIV status non-disclosure, with a lesser proportion of combined maternal–paternal HIV status non-disclosure and a minority of paternal HIV status non-disclosure. Within these families with non-disclosed HIV status at baseline, 15 went through a supported disclosure process (83.3%) representing approximately 37% of all families enrolled in the FSI-HIV arm of the trial. A total of 17 further families had experienced disclosure of caregiver HIV status in the past, which again had been predominantly maternal HIV status and combined maternal–paternal HIV status disclosure events. A small number of families described unstable, partial, or presumed disclosure experiences.

Mean scores of all study outcomes were graphically displayed with corresponding confidence intervals over the pre-intervention, post-intervention, and at 3-month follow-up after for FSI-HIV intervention and control families (Figures 1–3).

Parenting and Family Unity

Quantitative

Trends in parenting are displayed through graphical representation of mean self-report scores and corresponding 95% confidence intervals in Figure 1. Child-reported mean parenting scores appear to decrease post-intervention among the FSI-HIV participants compared with apparent increases in the treatment-as-usual arm of the trial, while caregiver-reported parenting scores



appeared to increase post-intervention (**Figure 1**). Both local and combined mean parenting scores remained stable in the FSI-HIV arm of the RCT by 3-month follow-up. Patterns in parenting score reports were closely mirrored by changes in family connectedness scores, reflecting commonalities within the measures concerning communication and trust (**Figures 1 and 2**).

Qualitative

Caregiver HIV diagnosis and disclosure were noted to have effects on the family through a number of potential mechanisms. Caregivers reported reduced coping at the time of HIV diagnosis and disclosure. Grieving processes undermined caregiver capacity to care for children. Additionally, caregivers reported increased marital stress and conflict. Children underwent adjustment responses during the disclosure process. Parental self-assessment of parenting improved during the intervention. Child assessment

of parenting also improved, following an initial period of adjustment following caregiver HIV status disclosure.

Since being informed they are HIV positive, they have lost hope and cannot work because they think they will die tomorrow. They lose confidence in their partner or the entire family, and progressively become depressed.

The parents accuse each other and the children think that their parents are going to die and worry about becoming orphans. The children have dropped out of school and are not happy at home as they only see their parents arguing. As the parents are not coping well, everyone in the family is affected.

First parents have to have hope themselves without hopelessness because when children see their parents

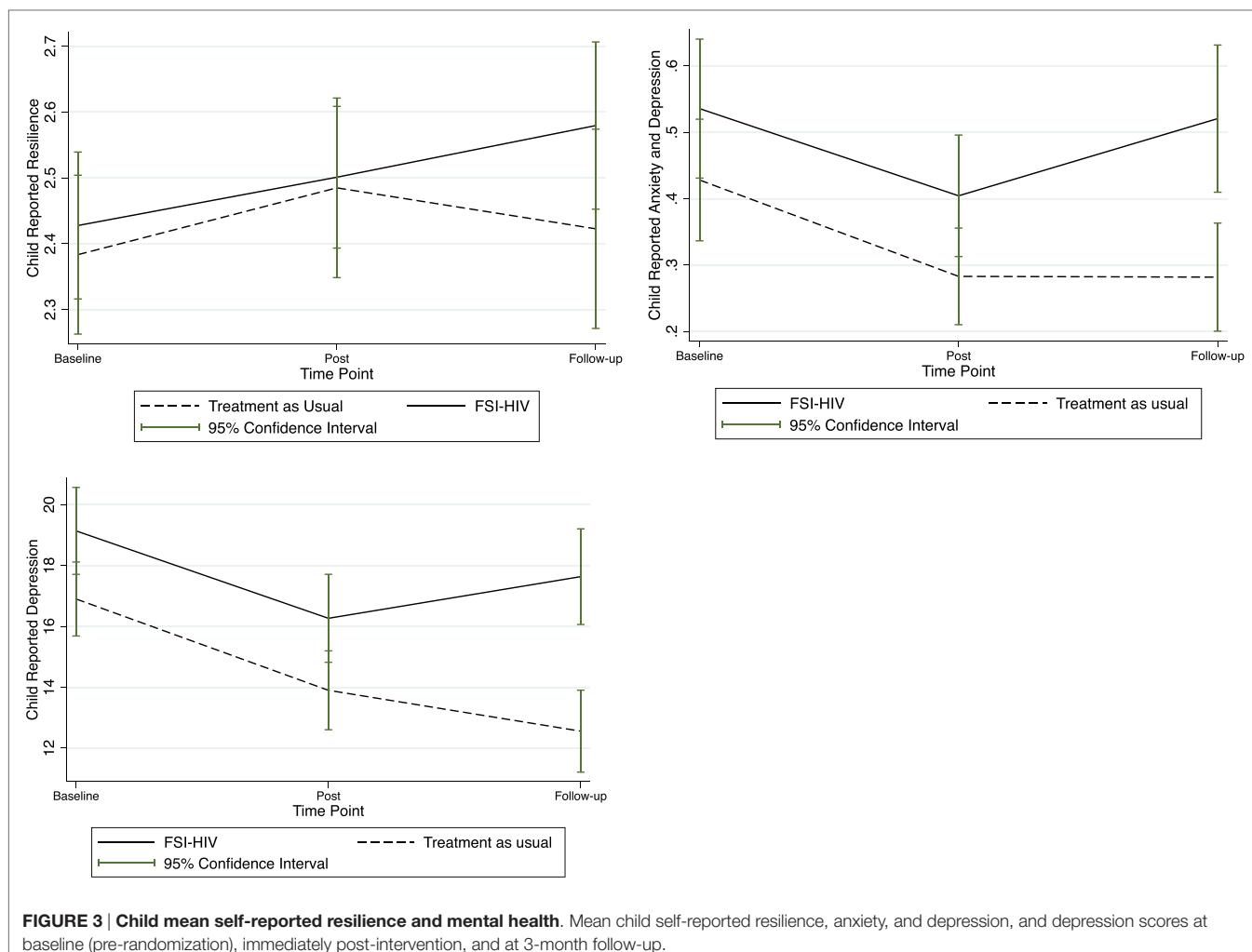


FIGURE 3 | Child mean self-reported resilience and mental health. Mean child self-reported resilience, anxiety, and depression, and depression scores at baseline (pre-randomization), immediately post-intervention, and at 3-month follow-up.

planning and caring for them, they automatically have hope. If parents have a good relationship, HIV would not be a problem for their children otherwise they think that their parents will die soon. (Counselor, Module 2)

Children described stress responses to parental HIV diagnosis and disclosure. Frequently children described assuming caregiving responsibilities for the family in response to family stress.

When she (the mother) was informed of her HIV serostatus, she became sick. Her first-born tried to help her even though he was very young. He was asking her what he could prepare for her, and he did his best to organize the house and to comfort his young brother and sister. The Holy Spirit motivated him to do so until her mother got some strength.

Overall life in the family changed, the children were depressed and had to work and look after their mother. The elder sister stopped schooling in order to take care of her mother. (Counselor, Module 2)

Partial or unstable parental disclosure was associated with worse effects on child mental health when compared with full disclosure. Children feared discovering the diagnosis from outside of the family and possible community stigmatization. This undermined trust in caregivers contributing to reduced child-reported parenting scores.

Everything is changing, children are losing trust in their parents and are looking for comfort elsewhere. It would help them to know the diagnosis from the parents and not hear it outside and also children would feel trusted. (Counselor, Module 2)

Family was arguing, quarreling, because there was no proper channel of communication and the result was poor family functioning and poor school performance for children. (Counselor, Module 2)

Family intervention offered structured support for improved parental child communication with improvements in family relationships and child mental health. The FSI-HIV provided support to parenting.

The caregiver did a great job in leading the session especially in HIV discussion. It was constructive to her children and she gave them a comforting message. The caregiver mentioned that the discussion was helpful to discuss HIV with the child and the child would ask how her mom became HIV positive, and how she can herself be prevented from HIV/AIDS. (Counselor, Module 4)

I learnt different things about HIV and I was very happy. I wish to continue the conversations. (Final Family Meeting, Child 11 years)

Child Resilience and Mental Health

Quantitative

Child-reported resilience and mental health quantitative scores increased over the course of the intervention as displayed in **Figure 3**. Further investigation of the possible mediating role of the intervention in improving child mental health through supported parenting in HIV-affected families undertaking disclosure is warranted (**Figure 4**).

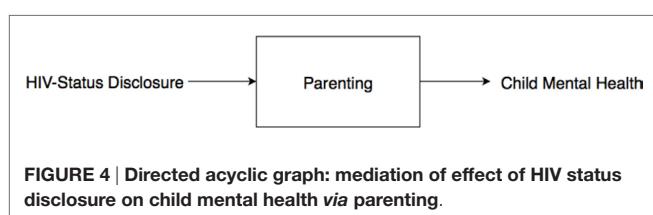
Qualitative

Child resilience and mental health improved during the process of disclosure within intervention families.

HIV status is now no longer a major problem for the family. Interventionist assured the mother, that through parenting skills and communication she will be empowered and can learn which proper channels to use in order to handle those issues. (Counselor regarding Mother, Module 2).

I learned how to tell my children about my status; I feel very relaxed about it and I hope that I will be able to do it in this week. Before when I thought about it, it was like a heavy burden and very difficult but now I think that is easier. (Counselor describing Mother's response, Module 2).

The family group sessions went well, I enjoyed being part of the family group sessions. We discussed about many things including child behavior, HIV/AIDS and how to talk to children and understand them, and be there for them in order to have time for talk. After the family meeting led by FSI-HIV interventionist we would like to go on by holding regular family meetings in order to avoid depression and not feel down. (Counselor describing Mother, Family Review)



Resilient caregivers can make their children resilient. (Counselor, Family Review)

Children described improvements in communication, trust, and honesty. Additionally, children reported greater hopefulness, resilience, and confidence in the family over the course of the intervention.

She said that he enjoyed the session because she learned more about HIV while the caregiver was satisfied because before it was hard for her to discuss with her children about HIV but then after the family meeting she felt relaxed. She was happy also because her children didn't have emotional problems while talking about HIV in the family. The family is very happy, children did well in school and the whole family is proud of it! (Follow-up Family Meeting)

DISCUSSION

Disclosure of caregiver HIV status to children can be challenging and is often an ongoing process rather than a one-time event. Disclosure within a family environment is important to facilitate communication about HIV between family members (22). However, caregivers often fear negative consequences of disclosure such as being stigmatized or causing distress to their children (23). However, evidence suggests that caregiver HIV status disclosure conveys psychosocial and clinical benefits for HIV-affected families (24, 25).

Parenting

At the end of the FSI-HIV intervention, family unity and child-reported parenting appeared to decrease in intervention families, with recovery and signs of resolution after the follow-up period (**Figures 1 and 2**). Trust was a common component to both the family unity and parenting scale scores. This suggests the possible mechanism of disrupted trust between parents and children underlying reduced parenting and family unity scores immediately surrounding the disclosure process. Discordance between caregiver and child-reported parenting may indicate differences between child and caregiver perspectives of relationships during family-based intervention and support of the disclosure process. In particular, while parents were gaining confidence in their parenting skills through the counseling sessions, children were adjusting to the disclosure of their caregivers' HIV status. Supported parenting at this time contributed to improved family trust and unity and enhanced child resilience and mental health.

Increasing numbers of children are being affected by caregiver HIV, due to expansion of ARV programs across sub-Saharan Africa. The family is an important focus for intervention for delivering psychosocial support including child protection (6, 11, 26, 27). Prior studies have investigated the impacts of the mediating role of parenting in reducing the impact of caregiver distress on child well-being in HIV-affected families (28). Stress on children surrounding the process of HIV status disclosure

may be mitigated through supporting parenting *via* family-based intervention (28). Parenting competence is defined by caregivers' self-efficacy through self-estimation of competence or ability to positively influence the development of their children in their parenting role (29). Caregivers with psychological distress lose self-esteem as caregivers or may perceive they lack knowledge and skills to provide a suitable environment in which to care for their children (30, 31). HIV-positive mothers' major concern is their perceived inability to provide adequate care to their children when they became ill (32). Parenting behaviors, such as the maintenance of daily routines, may protect children when a parent is infected with HIV (33). Hence, supporting the parental role, through recognition of its centrality within the family and empowerment of caregivers with a sense of self-efficacy, may be of critical value during HIV status disclosure. Further assisting with parental competences and parental stress management through family-based intervention could contribute toward positive parental coping and reduction of harsh parenting (34, 35). Therefore, it is likely that improvement of parenting protects the mental health of children within the family during caregiver HIV status disclosure.

Child Mental Health

Children in HIV-affected families living in situations of compound adversity are more frequently called upon to assume adult roles in response to diminished capacity of caregivers to assume responsibilities. This shift in roles is thought to contribute to a negative series of effects on child mental health (36, 37). Burdens on child mental health are exacerbated in situations where there is partial disclosure with a consequent lack of trust within-family relationships and fear of community stigmatization (37, 38).

Child resilience and mental health were shown to improve over the course of the intervention in FSI-HIV families, when compared with control families (**Figure 3**). The causal directed acyclic graph (DAG) in **Figure 4** maps assumptions about potential causal relationships between HIV status disclosure, parenting, and child mental health (39). The effects of HIV status disclosure on child mental health during the trial were potentially mediated *via* parenting, as delineated in the DAG (**Figure 4**). Hence, by stabilizing changes in parenting following disclosure through family-based intervention, the potential harmful effects of caregiver HIV status disclosure on child mental health were mitigated. Improvements in child mental health within intervention families were also potentially mediated *via* improvements in parenting (40, 41).

Limitations

Counselors were not blinded as to whether they were offering the family-based intervention or usual-care social work. Baseline measures were undertaken prior to randomization. Hence, apparent differences at baseline between intervention and control groups in **Figures 1–3** are artifacts of the randomization process. There was insufficient evidence to justify repeating the randomization, which is generally reserved for

extreme situations. There was insufficient justification to select variables for blocking (other than single- versus dual-caregiver status) prior to randomization. Qualitative data from control families were not available; hence, it was beyond the scope of this study to qualitatively compare control families' experiences of disclosure (42).

CONCLUSION

Culturally appropriate interventions are urgently called for to better support parenting during caregiver HIV status disclosure to protect and promote child mental health. Multidimensional assessments are needed when developing and testing interventions for HIV-affected families, to evaluate parenting and family trust during the disclosure process. Future longitudinal studies are called for, to discern the effects of family-based intervention on parenting and child mental health within families undertaking caregiver HIV status disclosure. Further investigation may also illuminate potential mediation of the effect of caregiver HIV status disclosure on child mental health *via* parenting.

AUTHOR CONTRIBUTIONS

SC: conception or design of the work, interpretation of data for the work, drafting the work, and agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. CK: contributions to conception and design of work, revising and drafting the work for important intellectual content approval of the version to be published. CI: revising and drafting the work for important intellectual content. SM, BN, KG, and RB: interpretation of data for the work. TB: contributions to conception and design of work, revising work critically for important intellectual content, final approval of the version to be published, and agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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Narrative Methods and Sociocultural Linguistic Approaches in Facilitating In-depth Understanding of HIV Disclosure in a Cohort of Women and Men in Cape Town, South Africa

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The South African National Department of Health has rapidly extended free public-sector antiretroviral treatment for people living with HIV from 2007. Approximately 6 million people are living with HIV in South Africa, with 3.1 million currently on treatment. HIV disclosure stigma has been reduced in high prevalence, generalized epidemic settings, but some remains, including in research interviews. This paper documents the unexpected reactions of people living with HIV to interviewers. It highlights shifts over time from discussing daily events with researchers to later expressing distress and then relief at having an uninvolved, sympathetic person with whom to discuss HIV disclosure. While there are commonalities, women and men had gendered responses to interviewers. These are apparent in men's uncharacteristic emotional responses and women's shyness in revealing gendered aspects of HIV acquisition. Both women and men expressed stress at not being allowed or able to fulfill dominant expected masculine or feminine roles. The findings underline the role of research interviewers in study participants confiding and fully expressing their feelings. This greater confidence occurred in follow-up interviews with researchers in busy health facilities, where time of health-care providers is limited. It underlines the methodological value of narrative inquiries with research cohorts. These allowed richer data than cross-sectional interviews. They shaped the questions asked and the process of interview. They revealed participants' increasing level of agency in expressing feelings that they find important. This research contributes to highlighting pivotal, relational aspects in research between empathetic, experienced researchers and study participants and how participant-researcher relationships progress over time. It highlights ethical dilemmas in roles of researchers as opposed to counselors, raising questions of possible blurring of lines between research and service roles. This requires further research exploration. It additionally underscores the importance of "care for the

carer.” Furthermore, it emphasizes that cultural sensitivity to language involves more than merely speaking the words in a language. Culture, humor, dialects, conceptual issues, wordplay, common sense, and respectful attitudes to other languages, resonates.

Keywords: HIV disclosure, researcher-participant interactions, narrative method, qualitative cohort, language and culture, South Africa

INTRODUCTION

“At its heart, public health is a conversation society has ...” [(1), p. 3].

The South African National Department of Health has rapidly extended free public-sector antiretroviral treatment for people living with HIV (PLWH) from 2007. The country has the largest ART treatment program in the world (2). Approximately 6 million people are living with HIV in South Africa, with 3.1 million currently on treatment. Those PLWH currently qualifying for free life-long treatment include PLWH whose CD4⁺ count is <500, pregnant women living with HIV (WLWH), those with a repeat episode of TB, children, or having AIDS-related symptoms (3). If South Africa transitions to free ART regardless of CD4⁺ status, as WHO now recommends (4), this number will double. As HIV has become more common in generalized high prevalence epidemics such as in South Africa, stigma has been reduced.

The pattern of HIV disclosure among adults is likely to be selective over time. Disclosure to health-care providers, intimate partners, and chosen family members and friends is most common (5). Less common is broader openness of HIV status in residential communities, except where PLWH have a high level of institutional support, HIV activism, and advocacy (6). Disclosure is conditional on a number of factors, including individuals' perceptions of their own socioeconomic status in the community. Frequently, those with lower and higher socioeconomic status are more reluctant to disclose. Disclosure in the workplace is still uncommon, despite legislation in South Africa that prohibits discrimination (7). The dynamics of HIV status disclosure and issues of stigma is a much-studied topic. However, as the terrain of availability and access to treatment changes, it warrants continued research.

This article seeks to continue the conversation on disclosure by acknowledging how this process plays out in dynamic interactions between research participants and researchers. This is specific to research methods used and is situated within broader sociocultural and language contexts. The focus of this article is on the experiences and practices of qualitative researchers in discussing HIV disclosure with a cohort of women and men living with HIV. This took place during a period when access to ART was being increased. It documents participants' unexpected reactions to interviewers captured in sometimes, gendered “distress” and “well-being” narratives and their support needs. Additionally, it underscores the importance of relations between participants and researchers (8) in a qualitative, narrative cohort study and of sociocultural linguistic understandings.

MATERIALS AND METHODS

Study Design and Procedures

The study used a qualitative narrative methodology, with data collected through in-depth interviews (IDIs) with a cohort of women and men living with HIV. This was prior to implementation of a multilevel structural intervention study integrating sexual and reproductive health issues into HIV care. These interviews assisted in analyzing participants' subjective meanings and reactions to disclosure. Qualitative methods are inductive and search for meaning rather than measuring trends, proportions, or patterns of association. They place emphasis on human discourses (9).

Three interviews were conducted between 2007 and 2012 with approximately 9-month intervals between interviews. Participants newly diagnosed with HIV were recruited for the first interview from four HIV care clinics. These clinics serve clients with a demographic profile likely to be seen in other HIV care clinics in Cape Town's public health sector.

Qualitative interviewers were experienced, same-sex, and English fluent, first-language *isiXhosa*-speaking researchers. Semi-structured interviews were conducted in participants' preferred language. Initial interviews were conducted with 30 women (age range 19–61 years) and 27 men (age range 20–53 years) living with HIV. Second interviews were conducted with 23 women and 20 men, and third interviews with 20 women and 19 men. Baseline interviews without follow-up were excluded from this analysis. Loss to follow-up was primarily due to being too ill for interview, deaths, or moving out of the study area. A small number refused a follow-up interview or were untraceable. The same female and male interviewers interviewed participants at baseline and follow-up interviews.

Interviewers were encouraged to remain emotionally neutral and suggest interventions or referrals when the interview was complete.

Interviews were approximately 1.5 h in length, audio-recorded, and subsequently transcribed by the same interviewers. In the baseline interview, we asked the following questions: “After learning you were HIV⁺, who did you feel you could talk to about your HIV status, if anyone, and how did you go about talking with them?” “How did they react to your having HIV?” In the second interview, we asked: “Since you were last interviewed, have you changed how you feel about telling (more) people about your HIV?”

At the final interview, we asked: “Since our last interview, has there been anyone new that you have talked to about your having HIV?” Most interviews took place in a public-sector health service environment, attended by 84% of the population (10). Interviewers had regular group debriefings with the Principal

Investigator to discuss their own feelings, how they had dealt with them, and strategies for addressing issues that emerged.

Ethics

The nature of the research project was explained to potential participants in writing and verbally in English and *isiXhosa*, and written informed consent obtained. Potential participants could refuse participation or withdraw at any stage without any repercussions. Participants' names and identities were protected. The Health Sciences Faculty Human Research Ethics Committee at the University of Cape Town and the Institutional Review Board at the New York State Psychiatric Institute – Columbia University Department of Psychiatry approved the study.

Analysis

In this article, we use participant IDIs, but also rely on interviewers' written field notes, experiences, practices, and minutes from meetings. All data were incorporated, managed, and coded using the Nvivo software package.

Using a coding list, thematic and narrative analysis was used to highlight how women and men reacted to HIV disclosure to researchers (11). The participants' narratives were examined in a sequence of events: (i) initial reactions to talking about disclosure experiences with interviewers, (ii) later confidences to interviewers, and (iii) disclosure-related counseling needs that arose from interviewer interactions. Reliability of interpretation of issues emerging was checked with the two researchers who conducted the interviews and another researcher. In addition, interviewer's written field notes and meeting minutes were compared with transcripts of interviews.

RESULTS

Table 1 provides a demographic profile of participants.

Participants' discussion about HIV disclosure with interviewers was a dynamic process. This changed from initially one of distance to one of trust invested in the interviewers over time. The quotations reflect key issues that emerged. All names used are pseudonyms.

First Interview – “Distance”

At first interview, many participants had not disclosed their HIV status outside of the health-care environment. The manner of

TABLE 1 | Participants' characteristics.

| | Female (aged 1–61 years) | Male (aged 20–53 years) |
|---|------------------------------------|-----------------------------------|
| # participants at baseline interview | 30 | 27 |
| # participants at interview 2 | 23 | 20 |
| # participants at interview 3 | 20 | 19 |
| Relationship status (currently has main sexual partner) | 76% (35% in casual relationships) | 84% (58% in casual relationships) |
| Mean age | 33 years | 37 years |
| Mean education | 10.4 years | 9 years |
| Time since HIV diagnosis | 2 weeks–6 months | 2 weeks–6 months |
| Dates of interviews | October 28, 2007–February 28, 2012 | November 1, 2007–July 30, 2012 |

narrating disclosure to interviewers tended to be dispassionate and distanced. They typically dealt with the daily realities of taking medication and attending services. For example, Sizwe, a 50-year-old man said

Now I just think about taking my medication to keep me well. I am glad I have told my wife about my condition as she helps me to remember.

Nompendulo aged 18 reflected:

I have to make up a reason why I go to the clinic for my ‘Beco’ [Vitamin B complex], as my family doesn't know, but I just keeping on concentrating on keeping myself well.

Second Interview – “Part Distance”

Covered and Unexpected Issues

Arise – Narratives of Distress

By the second interview, participants engaged in an emotional process of investing confidence in the interviewers. Narratives of heightened dismay, feelings of exclusion from family decision-making, stigma, and other issues emerged spontaneously.

Men, in particular, became emotional during the second interview. Tearfulness about their feelings of loss of status as men in family decision making was common. Sizwe, a 50-year-old man, wept as he said

Usually in our culture, older men like myself are included in all decisions about the larger family. Since I told them I have HIV, I am alone. I am not invited.

He expressed discomfort as a man, in crying. Nevertheless, he was comforted when the interviewer listened quietly and patiently, allowing him to express himself fully. Thabo, 35 years old, shared with the interviewer feelings of great sadness in being incapable of providing economically for his family due to illness. He was unable to share these feelings with his family.

Jonga, 28 years old, became very emotional during the second interview. He said that he wanted to go home to tend to family cattle in which men are generally involved. However, he was too sick and feared disclosing his HIV status telephonically to his family. He received comfort from the researcher. After the interview, the interviewer counseled him on preparing to disclose his status to his family.

Nompendulo, aged 18, feared adverse and judgmental reactions from her family if she disclosed her HIV status. Initially, she was reluctant to discuss this in any depth with the researcher.

A shared theme among women and men was great distress in sharing their experiences of disclosure to researchers, beyond their comfort zone. For example, 40-year-old Nomsa painfully related that her husband had divulged her HIV status to the church minister and congregation in a rural area where she resided. When she relocated to Cape Town to avoid the stigma she experienced as a result of her husband's unsolicited disclosure, she experienced further trauma. Her husband had disclosed her

status to the new urban minister who, in turn, disclosed this to the new pastoral community. During the interview, the interviewer sympathized. After the interview, she offered to talk with the church minister. Men tended to experience greater discomfort than women at first interview in sharing their feelings with researchers, but changed by the second and third interviews.

Third Interview: “Going the Full Distance” – Narratives of Relief and Gender

By the third interview, participants expressed relief in having someone who was not a family member or friend with whom to talk. Thando, a 32-year-old, gained comfort in speaking to the interviewer:

I feel there is a change because I feel right now – I can speak to you about it ... but at the beginning, I was isolated and it was painful.

By the third interview, Jonga, who was mentioned earlier, was on ART. He said he felt joyful and relief at the advice the interviewer had given him. He had disclosed to his family and was ready to return to his family's rural residence.

As mentioned, Nompendulo was reluctant to discuss her reservation about disclosure with the interviewer initially. She thawed at the third interview, admitting that she thought she may be judged by the researcher as a female, having been sexually active at 15 years. At the third interview, she responded well to the researcher's suggestion that she “test the waters” by first finding out how different family members would react to someone in the family living with HIV. Watching a TV program with her family in which HIV arose was agreed as a good way to initiate this.

Xoliswa, aged 23, who lived with her boyfriend said:

When we talked earlier I thought about my being HIV positive because I need not to keep this to my heart, I need to tell somebody. It was easy with you, I lost my stress to talk, because you saw me time and again.

Phindiwe, aged 27, currently with no boyfriend said she was reluctant to disclose her HIV status broadly:

Because people usually think, especially as a woman, that its because you misbehaved whereas sometimes its not mischief because even yourself you do not know where did you get virus, I thought a first even you might think this but I was wrong and it was good to talk with you. You listened without worrying if it took time.

Language and Culture: of Bulls, Cows, Calves and Pigs

Participants commonly used metaphors in relating feelings. Monde, a 47-year-old man, used the term “bull,” “cows,” and a disabled “pig” to denote his dismay in exclusion from family decision making:

I used to be a bull, but now I am a cow among the bulls – they don't take me with them anymore. ... those who are left [are like me] ... a castrated pig in the house [valuable livestock, but ‘impotent’ in important matters].

Thandi, 35 years old, spoke about her discomfort despite being unwell, in not being able to fulfill gendered expectations of being able to work, care for children, and complete domestic chores. She used the phrase “letting the calf go to its mother.” This term of speech indicated that it appeared she was fulfilling her roles while not doing so to avoid disclosure. However, she was willing to discuss her misgivings with respect to fulfilling gender roles and disclosure with the researcher.

DISCUSSION

At all three interview periods, participants' discussion of disclosure to researchers differed. Management of the disclosure process and style changed. This was reflected in the differences in participants' willingness to reveal thoughts and feelings.

Reflections: Disclosure Journey and Researcher Practices

As mentioned, men and women showed specific vulnerabilities in narrating their experiences of HIV disclosure. Stigma and distress were therefore sometimes gendered. This mirrored differences documented elsewhere with respect to HIV (12, 13). Men frequently feel they should not show emotions (12–14). However, male participants' uncharacteristically emotional narratives during later interviews were contrary to perceptions of normative, dominant male behavior. In contrast, men continued to identify with dominant masculine roles associated with being heads of household (15–17). Their role as decision makers in patrilineal extended families was perceived as critically important to their social and personal status. In their second interviews, men found a safe space to be very emotional about such issues as being stripped of their roles in long-term decision making in families and clans. This occurred despite shifts socially to HIV's normalization and perceived manageability. Their anxious, insecure, and sad behavior contrasted with their previously dominant male persona in an ongoing interview environment (16).

Mfecane argues that “if research is a social practice, then making friends in the field is a productive, sometimes essential strategy, the more comfortable they feel with us as researchers, the more insightful our research findings are likely to be” [(17) p125]. This was evident in our research. However, unexpected counseling tasks were frequently inadvertently “delegated” to the interviewers. The context-specific ethical dilemmas facing researchers are underscored in this study. While the researchers in our study may have been tempted to leap in and offer support as opposed to maintaining emotional neutrality during an interview, they had been trained to avoid this and leave any necessary intervention until after the interview. We had prepared a list of referral persons and organizations for researchers to offer participants, if they wished. This highlights issues raised in public health

and social science research about the “situational complexities of ethical decision making as they arise somewhat unpredictably in the field and the very personal ways in which researchers had to deal with them; in the heat of the moment and then as this cools with introspection” [(18), p. 6]. The ethical issues of maintaining a distance between researchers and participants in the field require further research exploration.

Reflections: Cultural-Linguistic Issues

Important cultural-linguistic issues influencing the narratives emerged. Thematic and narrative analysis pays attention to what participants say, the process of story telling, the impact on what emerges, and the manner of retelling. Discourse analysis focuses on language, and how this reflects cultural and social linguistics. Phrases participants used reflect sociocultural elements to capture identity, experiences, as well as categories and labels (19, 20). Without a discourse analysis, we “skimmed the surface” in how language impacts. Qualitative cohort data lend itself to future discourse analysis. Hunter (21) and Dowling (22) highlight cultural meanings and “lost in translation” misunderstandings that occur in translating *isiXhosa* to English and *vice versa*. This underscores the key role of English fluent first-language speakers in continuity in interviewing, translation, and analysis. Similar to English in which we have the expression “take the bull by the horns,” which is not literal but rather denotes confronting issues head on, in *isiXhosa*, there are different expressions about bulls with completely different meanings.

Both Dowling (22) (with respect to *isiXhosa*) and Epprecht (23) emphasize that translations or their understanding may meander far from their original meanings (22, 23). Dowling (22) singles out medical terminology, in giving an example of a medical questionnaire that needed the participant to choose the answer that “fits” where the meaning in *isiXhosa* translated to “epileptic fits.” The use of metaphors by our participants about “pigs” and “cows,” if taken literally, underscore these points. Culturally, specific references to bulls (males) being stronger and more competent than cows (females) predominated in these narratives. However, cows are also a critically important resource among *amaXhosa*, a source of wealth and bride-wealth (*lobola*). The latter can take on different meanings in “living” custom. Some men may interpret this as meaning “ownership” of a wife, while others may see this as needing to “treasure” a wife. Pigs in *isiXhosa*-speaking communities do *not* denote dirty or taboo animals. They are an appreciated economic resource. However, in this context, the addition of the term “castrated” gives them a different meaning. Our male research interviewer commented that if an analysis that misunderstood the cultural-linguistic underpinnings, the respondent would not recognize the interpretation of what he had originally said in the interview. Furthermore, the phrase of “letting the calf go to its mother” would be misunderstood unless the meaning from the *isiXhosa* translation was clear.

First-language *isiXhosa*-speaking experienced interviewers were able to understand the nuances in language and tune in to sociocultural linguistics. They uncovered hidden and spontaneous meanings. Similarly, in microbicide research, sexual violence being a reason for microbicides spontaneously emerged (24). In HIV and abortion research, the latter was perceived as much more

stigmatized than HIV (25). Experienced and trained interviewers, aware of their researcher positions and socially and culturally sensitive, elicited often otherwise hidden reactions. They were thus able to console and later counsel appropriately. This assists us in cautioning against “parachute research” in which researchers unfamiliar with Xhosa culture may sometimes conduct research or analysis without understanding language or other issues within a specific context [(26), p. 101].

Limitations

There are several limitations. Reports are necessarily retrospective and subject to recall problems. This may affect the reliability of the narratives of disclosure to others, but not their emotions in interviewer discussions, which were immediately noted. We minimized English translation bias by having bilingual, *isiXhosa* first-language speakers interviewing, transcribing, translating, and participating in analysis. The aim of qualitative research is to produce rich insights and depth rather than breadth in its findings. “Transferability” in this context means developing a theory that may determine or constitute broader social phenomena” [(27), p. 247]. Reflexivity, critical in qualitative research, involved steps to minimize and acknowledge researchers’ own views that may intrude in data collection and analysis.

CONCLUSION

HIV disclosure, when and to whom, forms an integral part of the lives of people living with HIV. Disclosure is not always a good thing and sometimes may not make logical sense rather than being a reaction to stigma. People frequently weigh up situations and make strategic decisions in this regard that have favorable outcomes for them. People take a meandering rather than a linear path in disclosure. Importantly, health-care providers, researchers, and many others they meet influence them along the way. Qualitative research interviewers are often able to spend more time with health service clients they interview than health-care providers in busy public-sector health facilities, particularly when they conduct follow-up interviews. Participants are able, as a result, to confide in them about disclosure and express their emotions fully. They can play an important role in participants’ well-being and moving forward to further disclosure, where this is the correct decision for them.

The findings underline the value of narrative inquiries with research cohorts in allowing richer data than in cross-sectional interviews. In addition, participants’ increasing level of agency in being able to discuss what they feel is important and express their feelings to researchers is highlighted (28). Individuals’ reactions on disclosure to researchers shaped the topic at hand (11) and raised questions that researchers might not have thought to ask and perhaps uncovered what participants did not initially intend to disclose (29). Issues of moving from daily concerns related to disclosure to expressing distress and later to relief are highlighted. Although there were commonalities between men and women, a pattern of gendered differences in responses is clear.

The research highlights pivotal, relational aspects in research between empathetic and experienced researchers, whose first language is the same as participants, and the manner in which

participant-researcher relationships progress over time. Male participants disclosed distressing, emotional disclosure experiences to interviewers, sometimes contrary to gendered expectations. A series of interviews with the same participants revealed modified, and shifting narratives remind us once again: "At its heart public health is a conversation society has ..." [(1), p. 3]. Furthermore, it underscores the importance of research interviewers who may need to counsel or debrief study participants at the end of an interview, having the necessarily skills, empathy, and understanding to do so. The process also continues to raises questions where lines may blur between research and service roles, and the experience needed in whether or not to counsel after the interview or refer participants to expert persons or organizations. Hekman's argument on agency captures this succinctly: "The elements of the mangle are mangled; they are mixed up with each other into a combination in which the various elements lose their clear boundaries" [(30), p. 24].

In addition, the importance of language beyond merely speaking the words in a language is highlighted. In research, Dowling's (22) call to ensure that we consider culture, humor, dialects, conceptual issues, word play, common sense, and respectful attitudes to other languages, resonates.

AUTHOR CONTRIBUTIONS

DC was South African Principal Investigator, did the primary analysis for this paper, and led this paper. JM was the Principal Investigator in the USA and contributed to the writing of this paper. NN was a key researcher involved in male interviews for study, participated in the interpretation of analysis, and contributed to the writing of the paper. NC was a key researcher involved in female interviews for study, participated in interpretation of the analysis, and contributed to the writing of the paper. KA-E

was a Master in Public Health student at the University of Cape Town. She participated in the literature review, the data analysis, and writing up as part of this study under the auspices of the Women's Health Research Unit at UCT. All authors reviewed and commented on all drafts, and ratified the final paper submitted.

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“When Should I Tell?”: Perspectives on Disclosure to Their Children among Parents with Perinatally Acquired HIV

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Adolescents and young adults (AYA) with perinatally acquired HIV (PHIV) engage in developmentally expected behaviors, such as establishing relationships and having children. Previous research has focused on pregnancy management/outcomes of AYA with PHIV. However, little research has focused on the parenting experiences of this emerging cohort and on their views of disclosure to their offspring. This article examines data from a pilot study of five AYA parents with PHIV on disclosure to their child(ren) ($n = 7$, 6 HIV-negative). Disclosure of their own HIV status to their children is on the minds of parents with PHIV. However, few currently have children old enough to understand the parent’s diagnosis. Three parents indicated they would disclose their HIV status when their child was “old enough to understand” so that their child would be knowledgeable about HIV. One father also noted that he currently had more pressing parenting responsibilities beyond disclosure. When discussing their perspectives on disclosure, many referenced their personal stories indicating a link between their decision to disclose/not disclose to their child and their own disclosure narrative. One mother cited she did not plan to reveal her diagnosis to her son because he was uninfected, while another mother explained she did not want to worry her child. The mother of the only infected child “did not want to wait like my mother did” and planned to tell her son at an earlier age than when she learned of her own diagnosis. Clinical implications related to disclosure will be discussed and future areas of research identified.

Keywords: PHIV, disclosure, parenting, adolescent and young adult, children

Historically, children with perinatally acquired HIV (PHIV) were not expected to live to reach adolescence or adulthood (1). However, in the United States, about 22% of young adults with HIV, ages 13–24, have lived with the disease all their lives (2). Similar to many adolescents and young adults (AYA), this cohort is exploring romantic relationships, engaging in sexual activity, (3) and becoming parents (4). Previous research has focused on pregnancy management/outcomes of AYA with PHIV (5). However, little research has focused on the parenting experiences of this emerging cohort and on their views of disclosure to their offspring.

Although it is not possible to know how many AYA with PHIV currently have children, there are approximately 10,688 youth with PHIV living in the United States, and research has found that this population has high fertility desires/intentions, with over 80% expressing a desire to have a child in the future (6, 7). Childbearing motivations among AYAs with PHIV are strongly linked to experiences of parental loss due to illness, the wish to leave a legacy, and the desire to receive or offer unconditional love through the experience of parenting (8–10).

Experiencing parental loss or abandonment has a significant impact on any child, regardless of HIV status (11). HIV-affected children can face significant childhood trauma, including loss of one or both parents and a lack of domestic stability (12). The experience of living with a sick or dying parent due to AIDS can have a strong effect on the overall desire to have a child (10) and is also associated with high-risk sexual behavior during adolescence (13). The parenting experiences of AYA with PHIV may greatly color how they interact with their children and perceive their future and approach to parenting.

Adolescents and young adult parents with PHIV face many of the same challenges other young parents face, including financial worries and struggles with discipline (14). However, they also face HIV-specific issues, such as health concerns and the fear their child will experience HIV-related discrimination. Another unique feature of parenting with PHIV is whether and when to disclose their HIV status to their offspring, a topic largely unaddressed in the extant literature. Disclosure to a child about his or her parent with PHIV also, by default, discloses the HIV status of the child's grandmother.

DISCLOSURE OF PARENTAL HIV STATUS TO CHILDREN

Extensive literature has explored the effects of parental HIV disclosure to children. The review of related literature by Qiao et al. (15) found that parents living with HIV frequently considered the child's age and cognitive level as well as perceived benefits of disclosure when deciding whether to share their HIV status. Additional factors included concerns over stigma and possible discrimination. While the literature on the effects of parental HIV disclosure on child functioning is mixed, the preponderance of evidence points to positive long-term outcomes for children, especially among children who were informed at younger ages (16). For example, Tompkins (17) reported that children who were informed of their mother's HIV status felt better prepared for the future and expressed pride in their ability to reduce their mother's stress. Research has also found psychological benefits to parents following HIV disclosure within a sample of HIV-affected families in rural South Africa (18).

To date, limited literature has explored disclosure to children of parents with PHIV. In a small qualitative study, Evangelista et al. (19) found that four out of seven participants discussed disclosing their HIV status to their children frequently reflecting upon their own disclosure experiences. However, it is unclear whether they were parents at the time of the study. The purpose of this pilot study was to explore views of disclosure to their offspring among a sample of parents with PHIV.

PILOT STUDY

Participants

A purposive sample of five AYA with PHIV (four females) who had children were recruited from an urban tertiary-care facility in the southeast United States (mean age = 23.4 years, range 23–24). All identified as heterosexual and African-American. Mean number of children was 1.4 ($n = 7$, range 1–3; mean age = 2.4 years, range 3 months–4 years), and one child was HIV-positive. Six patients met study eligibility and five participated. One patient was unable to participate due to scheduling conflicts.

Procedure

A staff member from the clinic introduced the study to eligible patients. Audio-recorded, semi-structured, face-to-face interviews were conducted by a trained interviewer (Hannah Allen) and later transcribed. Participants were provided a \$50 gift card in compensation for their participation. The study was approved by the hospital's IRB.

Sample questions included:

What thoughts do you have about disclosing your diagnosis to your child?

If you're going to tell your child, how are you going to tell her/him?

Data Analysis

Transcribed interviews were entered into Atlas.ti 7.0, a qualitative data analysis software program (20). The authors used a grounded theory approach to analyze the data, which employs an inductive strategy designed to identify emergent themes (21, 22). Cynthia D. Fair and Hannah Allen independently read the interview transcripts in their entirety, and following the traditions of the grounded theory method, analysis began with a process of open coding. The readers met frequently to discuss identified themes and to come to consensus on the coding.

RESULTS

At the time of the study, all of the participants had disclosed to their current significant other or the other parent of their child. However, two participants had not disclosed their HIV status to their partners at the time their children were born. All were in serodiscordant relationships. One of the participants had disclosed her status publicly and considered "the world" to know her status. None of the parents had told any friends about their illness, yet, disclosure to offspring was on their minds. However, few currently had children old enough to understand their parents' diagnosis. Findings indicated that their own disclosure experience, when and how they were told about their own HIV status, heavily influenced whether or not they planned to disclose to their child.

Yes, I'm definitely going to disclose it to him.

Three participants planned to one day tell their child(ren) about their HIV status, including the mother of the HIV-infected

child. They stressed the importance of timing, indicating that a child should not be told at a very young age, but it was also important for the child not to find out from someone else. Participants noted that their children were smart and, as a result, would be able to understand their parent's HIV diagnosis.

A 24-year-old mother, currently in school, said she wanted to tell her daughter similar to how she had been told of her own diagnosis at the hospital through a "developmental type of a program" where, she said, "I remember drawing pictures of HIV, the blood cells.... I remember learning through pictures and them explaining it to me the reason why I was coming here." She explained that she accidentally told a friend she had HIV when she was younger and was ostracized as a result. "You don't understand what it is, and you don't understand. When you hear a certain term, you think negative. I think that's what happened in that situation [with my friend]." She explained it was important that her daughter understand the risk of rejection. "I feel like I should tell her when she's in school and beginning to learn about it" because she fears her daughter might say "Mommy has it." She also noted it was important for her daughter to have accurate information about HIV, "When you're learning about it in school, they don't actually explain it ... For example, born with HIV and then being acquired with HIV like there's sex and drugs and anything. It's clearly different."

The only father in the study indicated his son would learn of his father's HIV status at some point in the future stating, "I have to tell him one day." However, his son was only 3 years old and other parenting demands took priority. When asked to speak about how he might disclose to his son, he explained that he had not disclosed his HIV diagnosis to anyone. Someone else informed his son's mother about his HIV status. He expressed remorse over his reluctance to disclose prior to engaging in sexual activity but stated, "I didn't know how to tell her, I don't know how to go about it."

The participant whose child had HIV was a 24-year-old employed mother who lived with her brother and son. She recognized that her situation was different because her child would have to learn of his HIV status. She indicated she had given disclosure a great deal of reflection stating, "I've thought about it [how to disclose to him] a lot." Referencing her own disclosure, she said, "I don't want it to be a wait, like how my mom did ... I don't want it to be like that with my son, I want him to be aware ahead of time so he can know."

I have no reason to.

Two parents indicated they would not share their HIV status with their child. One 23-year-old participant received dialysis and had a difficult pregnancy. She referenced her own experience of finding out her status stating that she "overheard [her mom and others] talking, so [she] thought it was a good thing, because ... Christmas was coming up, so I thought it was a surprise." She explained that her mom had planned on waiting longer to tell her because "I was 8 years old. She [her mom] wasn't going to tell me at that age, because I didn't understand what it was." Her disclosure experience was negative and, as a result, she did not want to tell her son about her own status.

She explained that he probably did not have HIV, based on the tests so far and that "most likely it's [the third test] going to be negative, so if he don't have it, I don't plan on telling him" that she has HIV.

The other parent who planned not to disclose her status to her children was a 24-year-old who lived in transient housing, was unemployed, and had lost custody of her three children. She was also the participant who claimed "the world" knew her status because she was very open about it. However, she said that she did not want to disclose to her children "because I don't want my kids to be worried about me."

CLINICAL IMPLICATIONS

The purpose of this study was to explore the disclosure perspectives of parents with PHIV and to draw upon the extant literature as well as the clinical experiences of the authors to highlight potential issues related to this emerging phenomena. Empirically based conclusions cannot be made from the study findings, yet they can serve as a springboard for future research and clinical considerations.

Clinical implications of disclosure to children of parents with PHIV depend upon both child- and parent-related factors. In general, timing of the disclosure should be based on the child's cognitive development and ability to understand the concept of illness (23). Furthermore, if the child is also infected then he/she will need to be told sooner as previous research indicates that children who are aware of their HIV diagnosis are more likely to be fuller partners in their care (24). Many pediatric HIV clinics have structured disclosure programs that provide a developmentally appropriate, and collaborative process involving both the caregiver and health-care provider to disclose a child's HIV status to him or her. Findings from the exploratory study highlight the importance of planned and intentional disclosure to children.

Resources addressing disclosure of HIV status to children are mostly geared to disclosure to a child with PHIV regarding his/her diagnosis and not a parent's personal diagnosis to the child (25). Therefore, if the child is uninfected there may be less support from care providers related to disclosure. Additionally, resources diminish as an adolescent ages into adult care. The social support and services that were once prevalent in the pediatric/adolescent clinics are stretched thin in the adult care setting due to the increased number of patients and different funding structures. Options for disclosure assistance and counseling for the adult with PHIV already in adult care are limited. Our findings suggested that those parents with PHIV who plan to share their HIV status with their child wish to wait until their child is older. Parents will likely be receiving care in an adult infectious diseases clinic at that time where disclosure is usually seen within the context of newly diagnosed patients or a sexual partner. HIV providers in adult clinics who are treating parents with PHIV may have limited experience with or resources for disclosure to a child. Parents may need support as they disclose to their child.

The World Health Organization and other organizations have readily available resources, which provide guidance on disclosure to children with HIV (23, 26). Cavolo et al. (25) note the cornerstones of disclosure to children with PHIV include

developmentally appropriate and truthful explanations of the illness, validation of the child's concerns about the illness, clarification of any misconceptions, and ongoing support. These principles could also be applied when a parent discloses his/her HIV diagnosis to their child.

In addition to the child's developmental and HIV status, the health of the parent and his/her disclosure history should also be taken into account (23, 25). If the parent is asymptomatic, then the parent can afford to wait to give the child insight into the parent's health. However, delayed disclosure can result in accidental disclosure, which may lead to feelings of distrust as found in several of the disclosure narratives shared by the participants (27). Previous research indicates that, over time, children and adolescents adjust well to learning their parent's HIV status (28).

Consideration should also be given to the parent's acceptance of his or her own illness and history of disclosing to others as evidenced by the young man who felt he did know how to disclose his HIV status to the mother of his child. Parents who had negative disclosure experiences, either when they learned of their own diagnosis or when they told others, may need additional support when and if they choose to tell their child, since they have not had access to models of supportive disclosure processes. Those parents with PHIV who have had limited opportunities to disclose their status to friends, family, and/or sexual partners, will likely feel less comfortable talking about their illness with others, including their offspring. Furthermore, none of the participants had disclosed to their friends highlighting the fact that, despite reduced levels of HIV-related stigma, disclosure is still difficult. Health-care providers can help young adults with HIV practice disclosure through role play, helping them think through possible questions their child might ask following disclosure (29).

INTERGENERATIONAL EFFECTS OF DISCLOSURE

Parental disclosure to offspring among parents with PHIV has implications beyond their own HIV diagnosis as it also necessarily discloses a grandmother's HIV status. There are several levels of disclosure for the child to ultimately understand. The most immediate disclosure is between the parent and child, followed by the grandparent and child. A child must first learn that his/her parent has HIV, then learn that his/her parent has been infected with HIV since birth. For a young child, the story can be simple and factual, but without extensive discussions of how or why. However, older children and adolescents may have additional questions due to HIV education or their own misconceptions about HIV. They may be subject to external influences possibly leading to self-stigma with fear of discrimination by others. Indeed, Woodring et al. (30) found that adolescents who learned of their parent's HIV status were concerned about who they could talk to for fear of rejection.

Adolescents will likely realize the implication of the parent being infected since birth means a grandparent is or was also infected with HIV. The questions could quickly shift from "how did my parent become infected" to "how did my grandmother get this disease" or even "why did my grandmother give this to my parent?" This new knowledge could bring to the forefront

conversations which have been taboo for the past two generations. A culture of secrecy and silence can lead to feelings of insecurity and fears of loss for the child. Intergenerational parenting styles are not always carried through to the next generation (11). With strong relationships and social support from medical and social service providers, maladaptive communication patterns can be changed opening the way for family secrets to be discussed promoting intergenerational respect.

Findings from the pilot study confirmed previous research, which found that youth with PHIV reflected upon their own disclosure story when considering disclosure to future children (19). This underscores the importance of facilitating positive disclosure processes with those newly diagnosed with HIV. Based on these findings and the other clinical implications outlined above, it can be determined that disclosure counseling needs to be a regular part of psychosocial care for those diagnosed with HIV. In order for those services to be provided, high-quality research is needed on the process of disclosure within this unique and emerging population.

To date, many pediatric and adolescent HIV-care providers are well versed in the psychosocial considerations surrounding disclosure to children. However, adult providers will ultimately care for the vast majority of young adult parents with PHIV and, therefore, will be the point of contact for disclosure counseling for their children. Adult providers may need additional training related to disclosure support in order to promote positive disclosure experiences between parents with HIV and their children.

Disclosure to children from the perspective of parents living with PHIV is understudied. Our exploratory findings indicated disclosure is complex and linked with the parent's own disclosure experience. As more AYA with PHIV mature into adulthood, disclosure to their children will become more commonplace, especially in regions of the world with high rates of maternal HIV infection, such as sub-Saharan Africa.

CONCLUSION

It is unknown if disclosure outcomes of parents with PHIV will parallel previously published research on disclosure outcomes of parents with behaviorally acquired HIV. Longitudinal prospective studies focused on the natural history of disclosure across the lifespan of AYA with PHIV are necessary to identify ways to better support and promote optimal functioning.

AUTHOR CONTRIBUTIONS

CF was lead author on this project. She helped analyze data, write, edit, and coordinate correspondence with other coauthors. HA conducted all the interviews and analyzed the data. She also helped to write and edit the paper. CT wrote the IRB and made significant contributions to the body of the paper. JO contributed to the writing of the paper and offered clinical expertise. LD was PI on the study and made significant contributions to the body of the paper.

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“How Do We Start? And How Will They React?” Disclosing to Young People with Perinatally Acquired HIV in Uganda

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Despite great advances in pediatric HIV care, rates and the extent of full disclosure of HIV status to infected children remain low especially in resource-constrained setting. The World Health Organisation recommends that, by the age of 10–12 years old, children should be made fully aware of their HIV-positive status. However, this awareness is often delayed until much later in their adolescence. Few studies have been conducted to investigate what influences caregivers’ decision-making process in this regard in low-income settings. In this article, we present an analysis of care dyads of caregivers and HIV-positive young people in Kampala, Uganda, as part of the findings of a longitudinal qualitative study about young people’s adherence to antiretroviral therapy embedded in an international clinical trial (BREATHER). Repeat in-depth interviews were conducted with 26 young people living with HIV throughout the course of the trial, and once-off interviews with 16 of their caregivers were also carried out toward the end of the trial. In this article, we examine why and how caregivers decide to disclose a young person’s HIV status to them and explore their feelings and dilemmas toward disclosure, as well as how young people reacted and the influence it had on their relationships with and attitudes toward their caregivers. Caregivers feared the consequences of disclosing the young person’s positive status to them and disclosure commonly occurred hurriedly in response to a crisis, rather than as part of an anticipated and planned process. A key impediment to disclosure was that caregivers feared that disclosing would damage their relationships with the young people and commonly used this as a reason to continue to postpone disclosure. However, young people did not report prolonged feelings of blame or anger toward their caregivers about their own infection, but they did express frustration at the delay and obfuscation surrounding the disclosure process. Our findings can inform the ways in which mainstream HIV services support caregivers through the disclosure process. This includes providing positive encouragement to disclose fully and to be more confident in initiating and sustaining the timely process of disclosure.

Keywords: children and adolescents, young people, disclosure, caregivers, HIV

INTRODUCTION

More than two million young people below the age of 15 years are living with HIV globally with the vast majority in sub-Saharan Africa (1). Over the years, there have been remarkable improvements in providing access to pediatric HIV treatment with antiretroviral therapy (ART), which has significantly reduced mortality rates (2) and enabled perinatally HIV-infected young people to live through adolescence and into young adulthood (3). Despite great advances in pediatric HIV care, however, rates and the extent of full disclosure of HIV status to HIV-positive young people remain low especially in resource-constrained settings (4).

Young people with perinatally acquired HIV often start ART in early childhood before knowing why they are taking it (5). The need to start treatment in childhood is acute, and at that time it may be accepted that the child will be told their HIV status and the reasons for their ART when they are older. The most recent global guidelines from the World Health Organisation (WHO) (6) on the disclosure to young people living with HIV recommend that once children are of school-going age, and certainly by the age of 10–12 years old, they should be fully made aware of their condition and its consequences for them. However, this awareness is often delayed until much later in their adolescence (7–9).

In Uganda, it is estimated that of the 1.2 million people living with HIV, 13% are young people under 15 years (10). There are over 600,000 people in Uganda with access to ART and about 43,000 of these are young people below the age of 15 years (11). However, a study on disclosure of HIV status to young people between 5 and 17 years in Southwestern Uganda showed that only 31% of the young people had been informed that they had HIV (12). Sociocultural norms are likely to influence disclosure conversations. For example, in Uganda discussing the routes of HIV transmission with young people as it relates to sexuality and the sexual behavior of their parents is problematic (13, 14). Despite this, few studies have been conducted to investigate what influences caregivers' decision-making process in this regard in low-income settings.

In this article, through an analysis of care dyads of caregivers and HIV-positive young people, we examine why and how caregivers' in Kampala, Uganda, decide to disclose a young person's HIV status to them, as well as exploring their feelings and dilemmas toward disclosure.

The Importance and Challenges of Disclosure: Current Views from the Field

Young people who have been appropriately informed of their illness early, exhibit better coping skills and fewer psychosocial problems (15). Being aware of their own HIV status as they transition into adolescence is crucial for young people living with HIV to assume some responsibility for managing their own treatment (16). Most available evidence shows an association between disclosure and improved adherence to treatments (4, 17) although a recent qualitative synthesis suggests that the relationship between disclosure and the development of positive adherence habits is mixed (18). Beyond adherence, pediatric HIV

disclosure is also positively associated with safer sex behaviors in adolescents, enabling them to actively participate in making decisions about their health and sexuality (19, 20).

The HIV disclosure literature conceptualize disclosure as a process and recommend that the disclosure responsibility lies with the caregivers/guardians of the child and that it should be tailored to a child's cognitive development (21). These notions are reflected in the most recent WHO (22) and also the national guidelines from the Ministry of Health in Uganda (23). However, disclosure of perinatally acquired HIV is of course a complex and challenging process for caregivers and health-care workers. Indeed, research in African settings, including Uganda, has demonstrated that caregivers are reluctant to disclose and this is manifested in disclosure being postponed, treated as a one-off event and, when done, being partial and incomplete (8, 24, 25). Partial disclosure is the term used to describe situations in which young people are given some but not all the information about their illness or condition. They may be made aware of the fact that they have a health condition which requires them to take lifelong medication without being told that their "condition" is HIV (26).

Reasons for caregivers' non-disclosure of young people's HIV status cited in the literature include the pernicious stigma associated with HIV, which leads to caregivers being afraid that, once informed, young people may disclose their individual HIV status to others, placing them at risk of being discriminated against, for example, in schools (24). Caregivers' postponement of disclosure may also stem from their worries about their child's cognitive abilities and emotional readiness to receive the news of their (young people's) own HIV-positive status (27). Fears that young people would be emotionally affected, cry, be sad, and give up on life following disclosure have all been identified as barriers to disclosure (28, 29). A study among Ugandan caregivers has shown that not disclosing to young people is seen as a form of protection from anticipated stress for the young people (9).

Caregivers may also have doubts as to the right timing for disclosure and about how much information about HIV is meant to be shared with young people (30). Indeed, several studies have reported on caregivers' perceived lack of skills on how to disclose HIV infection to children (30, 31), for example, not knowing how to talk to the young people about HIV or how to explain mother to child transmission, which may lead them to engage in partial disclosure (32).

Furthermore, the inherited nature of the illness with perinatal acquisition means that there are direct risks for the caregivers and related household too once a young person's status becomes known (24). Thus, as Muparamoto and Chiweshe (33) have shown, caregivers' decision to disclose is affected by complex expectations in which they attempt to control the "strategic event" of disclosure to minimize the potential damage to their own identity and that of their child's. However, another recent study in Uganda with young people aged 13–17 years has shown that they may exhibit considerable resilience in response to HIV disclosure (34), so there may be a disconnect between caregivers' fears and young people's response.

When disclosure does happen, there is significant evidence to suggest that caregivers decide to disclose on the instruction from health-care workers in a bid to support young people's adherence

to HIV medication, while unintentional or forced disclosure has also been shown to be common (9, 35). Caregivers may also disclose as a result of young people's persistent questioning about why they are taking medication, if they will ever stop and when they will get better (8).

Current global and local literature thus suggests that, despite policy guidance, caregivers hesitate to disclose HIV diagnosis to the young people. With this article, we aim to compare available literature and our own qualitative study findings from Uganda, to contribute to a better understanding of local dynamics pertaining to the Ugandan context and to illuminate caregivers *as well as* young people's perspective on disclosure. We consider how these experiences impact on the disclosure process, how disclosure is received by young people themselves, and what can be done to improve support to caregivers to be more confident in initiating the timely process of disclosure. This will be important in the development of interventions to support caregivers and HIV-positive young people through a process of fuller and ongoing disclosure.

MATERIALS AND METHODS

Study Setting and Population

This was a longitudinal qualitative study, involving young people perinatally infected with HIV and their caregivers, that was conducted between 2011 and 2016 at the Pediatric clinic of the Joint Clinical Research Centre (JCRC) in Kampala, Uganda. JCRC provides comprehensive HIV/AIDS care and management to about 2,000 HIV-infected young people and over 150,000 adults. It was the first HIV/AIDS treatment center in Uganda to provide ART and is currently the country's only reference center for third-line therapy. The study was embedded within a clinical trial (36) (BREATHER) which was testing the efficacy of a treatment interruption intervention, Short Cycle Therapy on efavirenz-based regimens (5 days on, 2 days off treatment) for young people (8–24 years) living with HIV (37).

Twenty-six young people were recruited purposively to participate in repeat in-depth interviews, audio diaries, and focus group discussions. The topics covered in this article were not discussed in the focus group discussions or the audio diaries and so only the data from the in-depth interviews will be presented here. Purposive sampling was carried out to increase the likelihood of capturing various experiences. Young people were eligible to participate in the study if they were aged 10–24 years and had full knowledge of their HIV status for at least 6 months before being enrolled in the trial. The assumption is that 6 months after disclosure, through continued counseling and support, young people would have been more likely to have understood many of the implications of their HIV-positive status. A minimum age of 10 years was selected to ensure that participants had the cognitive abilities to meet the broader aim of the study. Young people who met the criteria were approached for study participation together with their caregivers (for those below 18) within the waiting area of the clinic during their scheduled clinic visit. They were then taken to a private room in the clinic where they were given a detailed explanation of the study after which they gave written informed consent for participation. For those below the age of

18 years, assent was obtained after their caregivers had provided written informed consent for them to participate in the study.

We understood consent to be a process which ran from initial recruitment through to dissemination, in which both caregivers and young people were involved. Study participants were given the opportunity to speak to a counselor, based in the clinic, at any time that they needed. The study provided additional funds to cover the counselor's time, so that this resource would always be available throughout the study. This was in line with best research practice in this context, offering an integrated and sustainable mechanism for support. All young people were offered the opportunity to speak to a counselor in case they needed to after they were interviewed, but none chose to do so. Also, each time a participant visited the clinic to engage in the qualitative study their transport costs were refunded, again in line with best local research practice.

Toward the end of the trial, all the 26 participants were asked to nominate a significant other, who was someone acting in a primary caring role for them, and that they would be comfortable for us to invite to also participate in the study. To be included in the study, the caregiver needed to be able to give all required information especially with regard to the child's illness trajectory. To manage the volume of data, we had set a predetermined sample size of 16 caregivers. Once a young person had given their specific verbal consent, 16 caregivers were purposively selected and approached through their registered phone contacts at the clinic and invited to participate in an individual in-depth interview, and there were no refusals. The purposive sampling criteria ensured maximum variation within our sample for factors such as gender, socioeconomic background, and relationship to the child among others. A detailed explanation of the study including purpose, procedure, rights of volunteering participants, and assurance of confidentiality and anonymity were given to the caregivers. They provided informed consent.

The rationale for including the caregivers in the study was the recognition that they play a significant role in young people's lives and influence their understanding and experience of living with HIV. We wanted to understand how caring for a young person living with HIV was understood and perceived, as well as learn more about whether and how the caregivers' perceptions of HIV might shape their caring and relationship with the young person.

We present the findings from these care dyads, drawing on the 16 caregiver interviews and the in-depth interview data from the related young people. We deliberately do not present matched dyad data so that the caregivers and young people are not able to identify each other from the information we present here.

Data Collection and Analysis

Audio recorded, in-depth semi-structured interviews were conducted using a topic guide, which was tailored to the circumstances of each individual. The topic guide covered the following key areas of investigation: managing children's adherence; understandings of care; relationships within the household; and disclosing HIV status to young people. The guide was adjusted according to the circumstances that the caregiver disclosed, for example, whether they told us that they were themselves HIV positive. Interviews were conducted in English or the local language (Luganda)

according to the participant's preferred language of choice to ensure confidence in their responses. Each interview session lasted between 45 and 60 min. Stella Namukwaya, a social scientist with extensive training and years of experience in qualitative research, conducted the interviews.

Recorded interviews were transcribed verbatim and translated where necessary by the first author. Discussions were held with other members of the research team (coauthors on this article) after each of the interviews to identify the emerging themes and to refine the interview guide to ensure issues arising were exhaustively explored.

Thematic analysis was carried out by all the four members of the research team (Stella Namukwaya, Sara Paparini, Janet Seeley, and Sarah Bernays). Transcripts were read and re-read to identify emerging patterns with specific focus on disclosure of HIV to young people. Themes were developed from participant's responses and categorized as shown in **Table 1**. Content theme analysis was done to ensure that all relevant information was grouped and coded appropriately. Inter-rater reliability was very high (more than 80%) and the few discrepancies that arose were discussed and reconciled during regular weekly team meetings. Pseudonyms are used in this article to protect confidentiality.

Ethical Clearance

The study received institutional and national ethical approvals from the Uganda National Council for Science and Technology, National Drug Authority and the Joint Clinical Research Centre Institutional Review Board.

RESULTS

Participant Characteristics

A total of 16 caregivers took part in this study and of those interviewed, the majority were women (13 out of 16). Four of them were biological parents while the remaining were other relatives such as aunts, an uncle, stepmothers, and grandparents. Most caregivers were reportedly HIV negative. Of the 26 young people in our study, only 3 had primary male caregivers who brought them to the clinic and whom the young people nominated to be selected to participate in the study. All three were included in this study. This reflects common gender pattern of caregivers' accompanying

TABLE 1 | Themes and subthemes.

| Theme | Subtheme |
|--|--|
| Reasons for caregivers' reluctance to disclose | Fear of mentioning HIV Fear of psychological damage to child Fear of damaging child-caregiver relations Concerns about stigma Concerns about Discretion, HIV Stigma, and Discrimination Not knowing how to talk about HIV |
| Factors that motivated disclosure | Adherence crisis/importance of drugs Young people's curiosity |
| Young people's reactions | Temporary feelings of shock. Frustration about delays in being disclosed to and partial nature of disclosure |

young people to this clinic. Discussion about the caregiver's status only occurred when initiated by the caregiver themselves. We did not ask them directly about their HIV-positive status, however, all the caregivers talked about their status during the course of the interviews. Most caregivers were making a living on irregular, small scale business initiatives such as hairdressing and selling in markets. The majority had attained primary education while the rest completed secondary or vocational education.

All of the 26 young people who participated in the qualitative study had acquired HIV vertically and many had lost one or both parents. There were 14 girls and 12 boys in the study, between the ages of 10 and 24 years, and most of them were attending or had attained secondary school education. Further details of the sample can be found in our other publications from this study (7, 36, 38).

Although in the relevant guidelines responsibility to disclose HIV diagnosis is understood to lie with caregivers, we found that caregivers were very reluctant to do so. In this article, we first look at the reasons, which prompted caregivers to disclose and their concerns in doing so. We then present findings from the young people's interviews to explore whether the concerns of the caregivers are borne out in young people's narratives around finding out about their own HIV status.

Reasons for Caregivers' Reluctance to Disclose

Caregivers faced various difficulties in initiating disclosure conversations and talking to the young people about HIV and, where relevant, AIDS-related illness, and employed strategies to postpone disclosure. In the interviews, they provided many, often interlinked explanations for their decisions to delay conversations.

Fear of Mentioning HIV

Breaking news about HIV was something caregivers wished to avoid as long as possible. They did this by fabricating alternative explanations as to why their children were taking daily drugs. Almost any condition was considered preferable to HIV, so caregivers commonly told the young people that they were taking medicines for kidney disease, malaria or tuberculosis, for example. They did not necessarily presume that this was a strategy that would work indefinitely, but caregivers reported cycling through a range of alternative explanations:

In the beginning, she didn't know what she was suffering from, they (father) first told her that she had kidney disease, then later on that it was malaria (Kitty's stepmother).

I would tell her that she had TB and even when we both started taking ART I told her that they were drugs for TB (Beth's mother).

Fear of Emotional and Psychological Damage to the Child

When asked why they were avoiding disclosure, caregivers explained their reluctance was based on their anxiety about the

unknown potential psychological outcomes of disclosure for children and young people. Caregivers' reported being worried that disclosure might result in young people withdrawing from active social and educational engagements and interactions. They feared it would deprive them of their happiness and of the opportunity to live what the caregivers considered to constitute "a normal life." As Tessa's caregiver explained:

I was so scared of how she would react. I thought that she might have regrets, feel sad, start to isolate herself from people and feel like she has a problem (Tessa's aunt).

Among our sample, the fear of the repercussions from disclosure was expressed more strongly by women than by men. Two of the male caregivers reported that even though they were concerned about the child's emotional well-being they were more confident that the young people would not be grossly affected and would instead build resilience and understanding once their illness had been disclosed to them. However, male caregivers disclosed to the young people even later than the women. Men reported that they wanted to do this once the young people had reached the age of 13 years, and justified this by saying they were waiting for the young people to "mature" because then they would cope better with the information and not be damaged by it. However, with only three male participants in our study, any gender-related significance of this finding should not be overinterpreted.

I told (disclosed) Leah when she was 13 and I knew that it would be easy because in the end she would have understood (Leah's father).

Concealment and delay strategies were additionally entwined with a desire to protect the young people from worrying about whether their caregivers or siblings were also HIV positive, and under any kind of threat:

We refused to tell them because we didn't want to scare them because they would think that we also have HIV (Amy's caregiver).

Fear of Damaging Child–Parent Relationships

For biological caregivers, disclosure carried with it more directly personal risks too. They were also concerned that young people would ask question as to how they had become HIV positive, which would lead to uncomfortable conversations about transmission, the parents' own experience of becoming HIV positive and questions of loss with regard to HIV-related deaths in the family. Mothers, in particular, were worried about being seen as "the source of infection" and blamed by the child. They were worried that disclosing would damage their relationship with their child, with young people being angry with them for "burdening" them with the virus.

For all caregivers, there was an anxiety that the young people had been failed by their parents by not being able to adequately protect them from acquiring HIV. In reality, as the caregivers were looking after young people aged 10–24 years old, there had

been significant changes in provisions to prevent mother to child transmission since most of these young people had acquired HIV at birth, with many of them not able to benefit from current preventive treatments and practices.

Nearly all of the caregivers spoke about the risks that disclosure could potentially result in conflict and also put a strain on family relationships. This highlights the concern over the wave of revelations that disclosure to their child might precipitate.

I was worried and didn't know how to tell her (Child) that I got HIV from her father, because that was what killed him (Jules's mother).

Concerns about Discretion, HIV Stigma, and Discrimination

For both biological and non-biological caregivers, their desire to protect the young people from the potential for HIV stigma and discrimination further hindered disclosure. Caregivers did not trust that, once told, their child would be able to keep their own status a secret. They rationalized that by concealing this information from the young people and thereby limiting the numbers of people who got to know about young people's HIV status, they were protecting them from negative outcomes like being a source of gossip and being rejected by friends:

The disadvantage is that if you tell them, they will also tell someone else so people might start to gossip about the child ... many people don't know that he is sick (Gucci's aunt).

This concern persisted despite the low levels of direct discrimination that the caregivers had themselves experienced or witnessed. Only one of the caregivers reported being exposed to HIV-related discrimination. But they were all aware of stories about how people living with HIV had been subjected to discrimination in the past and presumed that this prevailing attitude continued and could affect the young people.

The caregivers considered that adults were far better placed to deal with any negative fallout from their status becoming known. By contrast, they perceived that children were not competent to manage their own secrets. They stressed that stigma was a serious risk and felt that, if young people had to be subjected to it, the consequences would be too heavy for them to bear. Hence, even though they would agree that there might be benefits from disclosing one's HIV status, such as support from peers, they were quick to emphasize that these only applied to adults living with HIV.

Delaying disclosure until young people were considered competent in managing information formed an important part of a more general strategy of maintaining silence about HIV. In most cases, caregivers had kept the HIV status of the child from other household members, and biological parents had often kept their own HIV status a secret from some or all of the rest of the household, too. So not talking to young people about HIV served also as an indirect way for caregivers to control information about themselves and their household.

Not Knowing How to Talk about HIV (Inadequate Language and Understanding)

Caregivers also described feeling woefully underprepared to initiate and address disclosure conversations with the young people. They lacked confidence in how they should do it. They described not being certain about their biomedical knowledge of HIV and felt what they did know was insufficient to facilitate the disclosure process:

We used to think about it (disclosure) a lot and every time we tried to we would just postpone it (Max's Aunt).

Although common overall, this was particularly an issue for non-biological caregivers who may have had little knowledge of HIV compared with biological caregivers that had been living with HIV themselves or those who had close experience of their partners being affected. We found that biological caregivers who were themselves living with HIV had usually been able to disclose at home, while many of the non-biological caregivers had required the presence of counselors or other health-care staff because they did not know what to say.

This lack of confidence appeared to be even more problematic once the caregiver needed to move beyond naming the child's condition. They described that their lack of knowledge and skills to manage conversations about HIV treatment, transmission, and prevention severely inhibited their capacity to engage in further discussions. An example many caregivers gave was not knowing how to explain changes in prevention of mother to child transmission (PMTCT) to young people. As reported in the interviews, caregivers' explanations of transmission were commonly inaccurate and invariably brief, as exemplified by Lisa's Aunt:

I explained to her that maybe it (HIV infection) was because of the c-section so that is how she got infected (Lisa's Aunt).

Some caregivers also expressed concern about whether their child would be able to have sexual relationships and have children in the future. Although this was not an issue around the time of disclosure, but came up much later in adolescence, such concern also highlighted in caregivers' interview accounts their limited understanding of PMTCT and HIV in general. It also fueled their concerns about their capacity to respond adequately to any of the young people's questions upon being disclosed to and their anxiety about the psychosocial impact of being told.

Some non-biological caregivers also lacked biographical knowledge pertaining to the child's acquisition of HIV as they had taken on caring responsibilities after the death of the child's parent. So, as they might not have been explicitly told how the child had acquired HIV this ambiguity added an additional layer of complexity. But it was also used to justify the partial approach to disclosure which deliberately avoided moving beyond naming their condition.

Factors That Motivated Disclosure

When caregivers did disclose, it very often tended to be because circumstances necessitated it. The decision was also never taken or

planned for by the caregiver alone, but in response to the pressure of events. Thus, it was not always a decision based on what might be considered "age-appropriate" timing or the circumstances of the child.

Adherence Crisis and the Importance of Drugs

Supporting the child's adherence to their treatment was the priority for many caregivers and a child struggling with their adherence was the most common circumstance in which a caregiver disclosed to their child their HIV status. This was because health-care workers frequently stressed to the caregivers that adherence would only improve if the child was made aware of their condition and thus more likely to understand how important the drugs were for their survival and well-being. Some explained that they would have had no intention of disclosing to young people until they were much older if they had been taking their medication well: *"If he had been adhering to his drugs, I wouldn't have been bothered with that"* (Finn's caregiver).

Of note, this approach highlights that many caregivers did not consider that disclosure was necessary beyond adherence and that children had an "independent" right to know their HIV status.

Focusing the disclosure conversation on the importance of drugs, however, was not only done because adherence was the key reason for disclosure in the first place. It was seen as a way for caregivers to comfort and give hope to the young people while revealing their status, to assure them that amidst their life-threatening condition there is a known solution: taking the drugs. It appeared to give caregivers, and by extension young people, some control over what might happen in the future:

I comfort her and tell her that there are people on drugs who are now twenty years old or even thirty who are able to study and complete University (Leah's dad).

Young People's Curiosity

In some cases, disclosure was triggered by young people's persistent questions to their caregivers about why they were taking medicines every day, when or whether they would be able to stop taking them and whether they would ever be cured of whatever illness they had. Caregivers reported that as young people grew older (from the age of 10 years onward) they became increasingly dissatisfied by the explanations that they had been given. In some cases, for example, when they were the only person in the household that they knew to be taking treatment, children had to ask questions for a considerable time to push to eventually be given the answer.

In the beginning, she didn't know what she was suffering from [...] she started asking questions as she grew older because she was wondering why she was not getting better so they told her (Kitty's stepmother).

She kept asking me why she was taking drugs when other children in the home were not (Tessa's Aunt).

In households where pill taking was not such a guarded and secret activity, disclosure was also a response to questions from

other household members. Household members, especially the younger ones, became curious about why other young people were taking drugs every day unlike them or others in the home. Daisy's uncle, for example, describes how both Daisy and her siblings were all asking questions about why she was taking drugs.

I eventually told her because she asked why she took the drugs alone (Daisy's Uncle).

This curiosity put caregivers in a difficult position, and they were compelled to first disclose to the HIV-positive young people themselves, then also to the other household members. In their minds, having to tell so many people in quick succession dramatically loosened their control over the information and compounded the risks of unwanted disclosures. This highlights the tension and tussle in giving young people information about their own health, but also the prevailing reticence that imbued caregivers' attitudes toward disclosing.

However, we found that one caregiver reported telling his child their HIV status directly the first time that she asked him about it. What is unusual about this case is that we were told that Leah had not asked her father any questions about why she was taking treatment until she was 13 years old, which is much later than the rest of the young people and caregivers in our study. By the time she asked, Leah's father was confident that she understood what HIV was and what it might mean to be HIV positive. Her level of existing knowledge about the condition meant that answering her question directly by disclosing posed fewer risks to him than has been described by many of the other caregivers.

She first asked me what the drugs that she was taking every day were for so I told her that she was born with HIV (Leah's dad).

Young People's Reactions to Disclosure

As we have described when caregivers disclosed this was normally limited to naming the condition and avoiding any further discussion of the implications of their illness. As most caregivers disclosed to facilitate improved adherence, the narrow function of disclosure was why they were taking medications. Discussions, even years later, often did not encompass what impact it may have on young people's lives and how this could be managed and supported. While disclosure could give hope by emphasizing control through adherence, as shown the inherited nature of the perinatal acquisition of HIV meant that caregivers feared that disclosure could also disrupt and destroy relationships.

Critically, this was not borne out in our data. Over the course of the interviews when we asked the young people about their feelings toward being told they were HIV positive and whether and how this changed over time, they did not describe feeling resentment toward their parents.

Young people did not express anger or blame toward their parents. They had a fair grasp of the unintentional nature of the onward transmission and many understood that the prevention opportunities through treatment had not been available at the time that they had been born.

I didn't blame them (parents) that much because even when they were alive I never saw them taking any drugs, but if they had been taking them, while we were not I would have blamed them for having kept silent, but they also didn't know what was going on (Jack, 20 years old).

Most of the young people in the study could describe their "disclosure event," recounting in considerable detail. They described their reaction as being terrified, worried, confused and intensely emotional. Yet they were not angry at their parents. In the few instances that they were, they described this as being a temporary reaction, which softened or vanished quickly.

When they (counselor) told me (disclosed) I got shocked but I didn't take it as a very big issue (Amos, 20 years old—was approximately 14 years old when disclosed to).

However, some felt aggrieved by their caregivers' ambiguity, which met their initial questions and suspicions. They minded that they had been given partial or inaccurate information about their condition and their acquisition of HIV. They expressed frustration that they were not able to have more candid conversations with their caregivers and have their questions answered. It was not the facts that bothered them, but the silence about them. It was this limited access to care and support that had a psychosocial impact. With no further follow-up discussions, their experience felt lonely and isolating.

And from the moment that I heard that (HIV positive status), my heart stopped beating for a moment and I started crying and tears flowed from my eyes without even knowing I was about to cry. I felt death was next, I felt lied to; I felt that I could not have a proper life (Nelly, 18 years old).

DISCUSSION

Encouraging appropriate and timely disclosure to young people about their own HIV is a central tenet in the care and management of pediatric HIV (13). Disclosure of HIV diagnosis allows young people living with HIV to participate in making decisions they deem appropriate and to be aware of issues regarding their treatment, care, and sexuality. However, as we have illustrated in this article, as a result of the dilemmas that caregivers are faced with, the process was often condensed into a singular event, which took place either at home or at an HIV care facility in the presence of health-care workers. Our findings both echo current research (9) in this field and introduce new reflections from an analysis of caregivers and young people's accounts about disclosure.

Our inclusion of care dyads and multiple interviews with young people has enabled us to provide valuable insight into the difference between caregivers' expectations of the relational fallout of disclosure to young people and how it is experienced by young people themselves (34).

Although fear of the relational consequences of disclosing was a significant feature of caregivers' accounts, no young

people described feeling prolonged anger toward their caregivers. Instead, what appeared to negatively impact their relationships from the young people's perspectives were the caregivers' silence, refusal to answer questions or obfuscation about the acquisition, nature, and consequences of their condition (39).

Jointly, our study and current literature (33) highlight that the anticipation of negative ramifications of disclosure caused significant anxieties for caregivers, which need further consideration. Disclosure of HIV to children can be a murky process since it is about communicating about a condition that is lifelong, threatening, stigmatized and has no cure. For biological parents, it also involves bringing their own HIV-related life experiences into the picture in a way that may be unusual in their relationship with their children otherwise (40). A blunt and urgent approach to disclosure, for example, as a result of an adherence crisis, often leaves inadequate time for caregivers to feel prepared to deal with imagined or actual consequences (4, 27).

However, secrecy, concealment, and partial truths are part of the fabric of everyday relationships, and HIV disclosure is no exception (41). There is an ambiguity in caregivers' silence that relates to their desire to protect young people from worry, and to shield them and their household from the possible impact of discrimination. At the same time, caregivers are trying to avoid addressing the question of transmission, and, as other studies have found (32, 33), fear being blamed and losing status in the eyes of their children. It also reflects the difficulty in engaging in conversations, for example, about the future, which have no easy answers (8).

It is certainly important to underscore how awareness and understanding about their HIV diagnosis helps young people develop their own ways to live with the condition, something we have repeatedly found in interviews with young people linked to this study (7, 36, 38) as well as in our other work (3, 8, 42, 43). However, our other studies also point to the problems created by disclosure as a medicalized moment driven by adherence (7, 38) which does not take into consideration the social and the protective functions of silence as well as the tensions inherent to revelations and truths in the family.

Our findings illuminate the perspectives of caregivers as well as those of young people. A closer analysis of our data shows that pressuring caregivers into initiating conversation about HIV when they are not confident or ready may create long-term challenges for them and for young people because disclosure as a "forced" event will be kept to a minimum. While caregivers try to contain the potential damage of imparting information about HIV, this "bare minimum" approach leaves the young person wondering about the rest. Caregivers may be anxious to curtail the extent of disclosure, avoid follow-up questions, and restrict further discussion. The information about HIV may be imparted only as a matter of treatment adherence and onward infection. At the same time, this pivotal moment of partial revelation may signal to young people something about them is wrong, leaving little room for developing a helpful exchange about HIV as they grow up.

Therefore, the caregivers accounts in our study are an important reminder that young people's "right to know" should not be pitted against what caregivers' perceive to be their "duty of care,"

which includes but also extends beyond "improving adherence": it is a balancing act between what they see as best for their children (those with and without HIV), themselves and their households. At the same time, caregivers' desire to minimize harm to their relationship with their children by delaying disclosure might backfire if we take into consideration that young people discuss delays and silences on the matter of their HIV as frustrating and confusing omissions.

Based on our findings from this and other studies with young people, we would like to recommend that disclosure should be a supported process for all involved (6, 9, 44). Caregivers should be encouraged and supported to work toward the point of initiating a planned disclosure process, to avoid disclosure being conducted urgently in response to an adherence crisis. Even if disclosure is reactive, discussions with young people regarding the necessity of medication to sustain health need to be accompanied by a willingness to engage with young people in conversations about resilience and about the kind of present and future life they can envisage and imagine for themselves, to which medication is the means (38).

It is not sufficient to emphasize the necessity of disclosure to caregivers and expect them to be able to act without support. Short, supported disclosure courses should be offered within clinics by counselors to individual or groups of caregivers (45, 46). These should include the following elements. First, caregivers need to be persuaded by the value in the child knowing about their own diagnosis, beyond managing or containing the particular events that they are dealing with at that immediate time. Second, caregivers need to be supported in feeling confident about their own knowledge about HIV, the circumstances of their child's infection, and the realities of risks and opportunities for prevention of HIV. They also need to feel able to draw on the support of clinic staff in helping them to answer the range of questions that full disclosure may provoke. Third, and this is a point that has to date received relatively little emphasis, caregivers need reassurance that many young people, once they find out their status, do not harbor resentment toward their parents for their own infection. Fourth, caregivers and young people need support in finding strategies to manage potential discrimination. This could be delivered through follow-up meetings for groups of caregivers to offer and benefit from peer support and mentorship.

The relatively small study sample is a limitation for our study. It means that we should be cautious about interpreting gendered patterns in the different approaches of the caregivers. In addition, the data rely on the recall of many of our participants rather than exploring how disclosure was experienced in time. However, this approach provides valuable reflections and insight into the experience of disclosure over time and its effects on the relationships between caregivers and young people.

CONCLUSION

Our findings indicate that there is need to actively engage and equip parents and caregivers' of young people living with HIV with adequate knowledge, information and skills which will

prepare them to initiate and facilitate discussions around disclosure and HIV.

ETHICS STATEMENT

This study was carried out in accordance with the recommendations of the Uganda National Council for Science and Technology, National Drug Authority and the Joint Clinical Research Centre Institutional Review Board, with written informed consent from all subjects. In addition to caregivers' written consent, assent was sought from all participating young people. All subjects gave written informed consent in accordance with the Declaration of Helsinki. All young people were aware of their HIV status before taking part in the study. The protocol was approved by the Uganda National Council for Science and Technology, National Drug Authority, and the Joint Clinical Research Centre Institutional Review Board. The protocol was also approved by the London School of Hygiene and Tropical Medicine. Audio recorded data

were transcribed verbatim, anonymized, and translated into English where necessary. To ensure confidentiality of the study participants, only pseudonyms are used in this article.

AUTHOR CONTRIBUTIONS

SN conducted fieldwork and data analysis and drafted the article; SP managed fieldwork and collaborated on data analysis and manuscript writing; JS managed the research study and fieldwork and collaborated on data analysis and manuscript writing; SB managed the research study and fieldwork, and collaborated on data analysis and manuscript writing.

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Adolescents' Experiences and Their Suggestions for HIV Serostatus Disclosure in Zambia: A Mixed-Methods Study

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Background: HIV serostatus disclosure is an immense challenge for adolescents living with HIV, their caregivers, and health workers. In Zambia, however, little guidance is available from the adolescents' point of view on the HIV disclosure process.

Objective: This study aimed to examine the setting of HIV serostatus disclosure for adolescents, its impacts on them, and their suggestions on the best practice of HIV disclosure.

Methods: We conducted a mixed-methods study at the University Teaching Hospital in Zambia from April to July 2014. We recruited 200 adolescents living with HIV, aged 15–19 years. We collected data using a structured questionnaire including two open-ended questions. We excluded two adolescents due to withdrawal during the survey, and eight from the data set due to out-of-eligibility criteria in age. Eventually, we included 190 in the analysis. We performed descriptive analysis to calculate the distributions of basic characteristics of the adolescents, their experience and preference on HIV serostatus disclosure, its emotional and behavioral impacts, and health education topics they had ever learned at hospital. We performed thematic analysis with open-ended data to explain first impressions upon disclosure in detail and to determine perceived advantages of HIV serostatus disclosure.

Results: The majority of adolescents recommended the age of 12 as appropriate for adolescents to learn about their HIV serostatus and preferred disclosure by both parents. Out of 190 adolescents, 73.2% had negative or mixed feelings about HIV serostatus disclosure, while 86.2% reported that disclosure was beneficial. Thematic analyses showed that the adolescents reacted emotionally due to an unexpected disclosure and a belief of imminent death from HIV. However, they improved adherence to treatment (84.7%), limited self-disclosure of their HIV serostatus to others (81.1%), and felt more comfortable in talking about HIV with their caregivers (54.2%). Thematic analysis identified perceived benefits of disclosure as follows: better understanding of their sickness

and treatment, and improved self-care and treatment adherence. Lower percentage of the adolescents have learned about psychosocial well-being, compared to facts about HIV and treatment.

Conclusion: Despite initial emotional distress experienced after the disclosure, knowing one's own HIV serostatus was found to be a crucial turning point for adolescents to improve motivation for self-care. HIV serostatus disclosure to adolescents requires follow-up support involving parents/primary caregivers, health workers, and peers.

Keywords: HIV, disclosure, adolescent, Zambia, mixed-methods study

INTRODUCTION

Improved access to HIV testing and antiretroviral therapy (ART) has reduced the number of deaths caused by HIV (1). However, the adolescent population had not made the same progress by 2013 (2). Globally 250,000 adolescents aged 10–19 years were newly infected with HIV in 2015, and 41,000 lost their lives in the same year (3). Diagnosis of HIV infection and taking ART with good adherence are the principal means of suppressing viral load and maintaining a healthy condition (4, 5). However, adherence to ART is a great challenge among adolescents. A meta-analysis of 53 countries reported that only 60.1% of adolescents were adherent to ART in various measurements of adherence (6).

Adherence to ART among adolescents is affected by multiple factors including family structure, psychosocial and socioeconomic characteristics, treatment regimen, and access to healthcare services (7, 8). Even after initiating ART, adolescents do not necessarily know their HIV serostatus and the actual reasons for taking medicines daily, and such knowledge gaps are critical barriers to ART adherence (8, 9). After adolescents learn their HIV serostatus, they commonly improve adherence to ART (10, 11), which could contribute to delayed disease progression and death (12). This highlights the importance of disclosing HIV serostatus to adolescents.

Disclosing HIV serostatus to adolescents impacts on self-care behavior and psychosocial well-being. For example, adolescents who were told about their HIV serostatus were more likely to retain in care (13) and were able to receive social support (11, 14–16). On the other hand, disclosing HIV serostatus to adolescents could generate complex feelings. Commonly, they are strongly distressed when they are informed about their HIV serostatus, while some get a feeling of relief (17). Acceptance of HIV serostatus would not be an easy process. However, adolescents desire to be given correct information on their HIV serostatus, and the purpose of taking medicine and having regular check-ups at the hospital (11, 18), and caregivers believe that adolescents should be told about their status (19, 20).

Disclosing HIV serostatus to adolescents is a difficult task for caregivers and health workers. Perceived barriers of disclosure for the caregivers and health workers are inadequate maturity and coping skills of adolescents; fear of inflicting emotional distress on them; fear of being blamed by them; potential risk of the HIV serostatus disclosed outside of their households with subsequent risk of social exclusion (19, 21, 22). In addition, caregivers and health workers do not have sufficient skills to disclose as they

rarely have opportunities for learning and training about how to disclose HIV serostatus to adolescents (22–24).

Several studies have examined how serostatus disclosure is practiced (15, 25, 26), and in 2011, the World Health Organization published “Guideline on HIV disclosure counselling for children up to 12 years of age” (27). The guideline recommends that those aged 12 years or younger should be informed about their HIV serostatus, taking into account their maturity and capacity to understand (27). It would be beneficial to update the guidelines and include recommendations for adolescents reflecting more of their experiences and preferences. However, the majority of previous studies targeted caregivers and health workers as study participants; adolescents were less involved. It would also be important to reflect socio-cultural specificity, so that the guidelines could be adopted effectively in clinical practice.

Zambia is one of the highest HIV-burdened countries, with an estimated prevalence of 12.9% among adults in 2015 (3). About 68,000 adolescents were living with HIV, and 10% of them were newly infected (3). Coverage of ART expanded its reach to 63% of people in need in 2015 (3). However, adolescents' HIV-related knowledge is still limited. The Demographic and Health Survey 2013–2014 reported only 42.3% of male adolescents (aged 15–19 years) and 38.9% of female adolescents had correct knowledge about transmission and prevention of HIV (28). This implies that adolescents living with HIV would be vulnerable to stigma and discrimination in an environment where people have inaccurate knowledge and negative views about HIV (29). Using qualitative methods, previous studies examined caregivers' motivations and concerns as well as the process and impacts of HIV serostatus disclosure to adolescents (14, 22, 30). Two quantitative studies assessed mental health issues (31) and adherence to ART (32) and reported that serostatus disclosure was one of the factors associated with these outcomes.

However, no study has yet to quantitatively assess HIV serostatus disclosure to adolescents in Zambia. This study aimed to examine the actual setting and impact of HIV serostatus disclosure to adolescents, and their suggestions on the best practice of HIV disclosure.

MATERIALS AND METHODS

Study Setting

We conducted a mixed-methods study at the Pediatric Centre of Excellence (PCOE), and Adult HIV Centre of Excellence

(ACOE), University Teaching Hospital in Lusaka from April to July 2014. PCOE and ACOE are the national referral centers for HIV treatment and the national model institutions for the adolescent HIV care and treatment program. PCOE provides services to children and adolescents below 16 years, while ACOE is in charge of older patients including those transferred from PCOE.

Participants

We recruited a non-randomized sample of adolescents living with HIV. The eligibility criteria for the study participation were as follows: the age of 15–19 years, regularly attending treatment at PCOE or ACOE every 3 months, and awareness of their HIV-positive status before the survey. At PCOE, parents/caregivers and health workers are encouraged to disclose HIV serostatus to adolescents beginning at the age of 10, according to their maturity and cognitive development. Thus, it was very rare for someone in the target group not to be aware of his/her HIV serostatus at the time of recruitment. Adolescents visit the centers for clinical review every 3 months. Thus, we had a 3-month survey period to recruit maximum number of participants. Recruitment was done during their waiting time for clinical review at the PCOE or ACOE premises. Before recruiting an adolescent into the study, we confirmed the adolescent's eligibility for study participation with health workers or parents/primary caregivers who accompanied the adolescent.

Data Collection

We developed a self-administered questionnaire based on the Zambia Demographic and Health Survey 2007 (33), WHO's "HIV testing, treatment and prevention: generic tools for operational research" (34), and previous literature (14, 30, 35, 36). We collected information on background characteristics of the adolescents, the settings in which serostatus disclosures were performed, settings they preferred for serostatus disclosure, and the impacts of disclosure on their emotions and behaviors (e.g., improved/maintained adherence to ART, putting the blame on parents) (14, 30, 35). We also collected data on health education topics that the adolescents had ever learned at the hospital (e.g., benefit of adherence to ART, how to deal with emotions) (36).

Regarding the setting where disclosure took place, we asked each adolescent about his/her age at that time, the venue at which the disclosure took place, the person who disclosed HIV serostatus to him/her, whether he/she had already suspected infection with HIV, and emotional reaction upon knowing HIV serostatus. We also asked an open-ended question about why they had a particular reaction upon disclosure. We solicited their suggestions on how HIV should be disclosed, including the appropriate age, venue for disclosure, the best person to conduct the disclosure, and whether it is beneficial for adolescents to know their HIV serostatus. Furthermore, we asked an open-ended question on the perceived advantages or disadvantages of knowing HIV serostatus.

We developed the self-administered questionnaire using simple English, conducted a pre-test to assess the English literacy of the study participants, and finalized it. During the survey, trained research assistants guided or interviewed adolescents through

verbal translation into local language if they had insufficient English literacy.

Data Analysis

Out of 200 adolescents recruited, 200 were admitted to the study, 198 completed the questionnaire, and 2 withdrew during the survey. Out of 198, we included 190 in the analysis and excluded 8 as the data on their age did not meet the eligibility criteria (i.e., <15 or >19 years old) although we had asked the age of each potential participant at recruitment. We performed descriptive analysis to show the basic characteristics of the adolescents, actual settings in which they were informed about their HIV serostatus, their suggestions on how HIV disclosure should be done, emotional and behavioral impacts of disclosure, and the health education that they had ever received at the hospital.

Adolescents answered the open-ended questions with a single sentence. Based on the existing literature on qualitative data analysis (37, 38), we analyzed the open-ended answers using thematic analysis. Two authors (Sumiyo Okawa and Kimiyo Kikuchi) read and coded the textual data, and categorized all codes independently. Sumiyo Okawa and Kimiyo Kikuchi categorized the codes into sub-themes and developed main themes built on the sub-themes. Sumiyo Okawa and Kimiyo Kikuchi made a consistency check on the codes and emerging categories. This process continued until the two authors reached an agreement. All authors reviewed and finalized the emerging themes.

Ethical Considerations

We obtained ethical approval from the Research Ethics Committee of the University of Zambia, and the Institutional Ethics Committee of the National Center for Global Health and Medicine, Japan. All adolescents provided assent to participate in the study, and parents/primary caregivers of the adolescents aged 15–17 years also offered informed consent. We collected all data anonymously.

RESULTS

Table 1 shows basic characteristics of the adolescents ($n = 190$). Out of them, 80 (42.1%) were boys, and 110 (57.9%) were girls. Thirty-four adolescents (17.9%) never attended school or completed basic school education; 42.1% of their primary caregivers were mothers; and at least 41.6% of the primary caregivers were living with HIV.

Table 2 presents the adolescents' actual experience and suggestions for disclosure of HIV serostatus. Median age at HIV serostatus disclosure was age 12 (interquartile range 11–15)—close to the survey participants' common suggestion on the appropriate age for disclosure 12 (interquartile range 10–14). They reported that their status was disclosed at a health facility (55.3%) or at home (37.9%). Their HIV serostatus was disclosed to them by their mothers (29.5%), health workers (27.4%), their father (7.9%), and both parents (6.3%). Majority (62.6%) suggested that having both parents disclose to their adolescent would be preferable. Over 31% had already suspected they had HIV before disclosure of their status. Upon disclosure, 45.3% had negative feelings, 27.9% had mixed feelings, while only 7.9% had positive

TABLE 1 | Basic characteristics of the adolescents (*n* = 190).

| Characteristics | <i>n</i> (%) |
|--|--------------|
| Gender | |
| Boy | 80 (42.1) |
| Girl | 110 (57.9) |
| Age | |
| 15 | 28 (14.7) |
| 16 | 47 (24.7) |
| 17 | 39 (20.5) |
| 18 | 45 (23.7) |
| 19 | 31 (16.3) |
| Education | |
| Never educated/did not complete school | 34 (17.9) |
| Completed basic school | 93 (49.0) |
| Competed secondary school or higher | 63 (33.2) |
| Type of primary caregiver | |
| Mother | 80 (42.1) |
| Father | 27 (14.2) |
| Grandmother | 26 (13.7) |
| Aunt | 25 (13.2) |
| Sister | 14 (7.4) |
| Other (e.g., uncle, brother, cousin) | 18 (9.5) |
| Educational experience of primary caregiver | |
| Never educated/did not complete basic school | 20 (10.5) |
| Completed basic school | 23 (12.1) |
| Competed secondary school or higher | 128 (67.4) |
| Don't know | 19 (10.0) |
| HIV status of primary caregiver | |
| Positive | 79 (41.6) |
| Negative | 85 (44.7) |
| Don't know | 26 (13.7) |

feelings. However, 86.2% of adolescents perceived self-awareness of HIV serostatus as beneficial.

Table 3 shows the six emerging themes regarding the adolescents' first impressions upon disclosure of their HIV serostatus: (1) awareness/readiness (2), emotional reaction (3), existential perspective, (4) self-image, (5) perception of HIV and medication, and (6) stigma. A majority of the adolescents had negative impressions, as they never expected to be infected with HIV. One adolescent expressed, "*I never suspected I could have HIV and the worst part was that it came from my mother*" (Girl, age 19). They were emotionally shocked, and some desired to commit suicide. Moreover, they were anxious about dying soon, had a sense of isolation as if being the only person living with HIV, and had fear of being stigmatized: "*I felt as though my life has crumbled and that I now have a burden to carry, and eventually leading to death*" (Boy, age 19). They perceived HIV as an incurable disease and felt difficulty in daily medication for the rest of their life: "*I felt low because I would have to take my medicine for life*" (Boy, age 16).

On the other hand, some adolescents showed a positive impression as they had already suspected being infected with HIV, or they believed that the medicine should work well and that they could live as long as or even longer than other people: "*I felt good because I knew my status and I was able to live positive life*" (Girl, age 17), and "*I felt sicker when I knew about my status, so I started taking ARVs. I became healthier than ever and happy*" (Girl, age 19).

TABLE 2 | Actual experience and suggestions for HIV serostatus disclosure to adolescents.

| | Actual experience | Suggestion |
|---|-------------------|--------------|
| | <i>n</i> (%) | <i>n</i> (%) |
| Place of first knowing your HIV serostatus | | |
| Clinic/hospital | 105 (55.3) | 102 (53.7) |
| Home | 72 (37.9) | 78 (41.1) |
| Other | 13 (6.8) | 10 (5.3) |
| Person who disclosed your HIV serostatus | | |
| Both parents | 12 (6.3) | 119 (62.6) |
| Mother only | 56 (29.5) | 21 (11.1) |
| Father only | 15 (7.9) | 2 (1.1) |
| Health workers | 52 (27.4) | 32 (16.8) |
| Other (e.g., grandparents, aunt, uncle, sibling) | 50 (26.3) | 15 (7.9) |
| Don't remember | 5 (2.6) | 1 (0.5) |
| Suspected HIV-positive status before disclosure | | |
| Yes | 60 (31.6) | |
| No | 117 (61.6) | |
| Don't remember | 13 (6.8) | |
| Emotional reaction at first knowing HIV serostatus | | |
| Positive feeling | 15 (7.9) | |
| Negative feeling | 86 (45.3) | |
| Mixed feeling | 53 (27.9) | |
| No feeling | 17 (9.0) | |
| Don't remember | 19 (10.0) | |
| Perception of self-awareness of HIV serostatus at the time of survey^a | | |
| Beneficial | | 163 (86.2) |
| Not beneficial | | 19 (10.1) |
| Don't know | | 7 (3.7) |

^a189 included, and 1 declined to answer.

Table 4 shows the impact of disclosure of HIV serostatus on the emotions and behaviors of adolescents. Majority (84.7%) improved or did not change adherence to ART. Regarding relationships with parents or primary caregivers, as a consequence of disclosure 54.2% felt more comfortable talking about HIV with their parents or caregivers, while 32.1% blamed their parents. Eighty-one percent limited self-disclosure of their HIV serostatus to others, and 31.1% felt stressed about keeping the status a secret. In relationships with friends or intimate partners, 42.5% became scared of developing intimate relationships, and 12.1% isolated themselves from friends.

Table 5 shows perceived advantages and disadvantages of HIV serostatus disclosure. Majority believed that it is important to know the reasons for being sick and purpose of taking medicine. Some adolescents regarded knowing one's own HIV serostatus as their basic right. Being aware of their HIV serostatus also helps adolescents to enhance self-care behavior, including adherence to ART, improvement in their quality of life, and prevention of HIV transmission to others. For example, an adolescent mentioned that "*Knowing HIV status helps them to move to another level in life*" (Boy, age 16). On the other hand, they were concerned that some adolescents might not be mature enough to accept their HIV serostatus, become emotionally distressed, unnecessarily disclose their HIV serostatus to other people, and be discouraged about taking medicine.

TABLE 3 | First impression upon disclosure of HIV serostatus.

| Major themes | Sub-themes | |
|----------------------------------|--|---|
| | Positive impression | Negative impression |
| Awareness/readiness | Already aware of HIV serostatus | Never expected Not ready to accept HIV serostatus |
| Emotional reaction | Happy to know HIV serostatus | Shocked Desire to commit suicide |
| Existential perspective | Able to live as normal Able to live positively Able to live longer | Anxious about dying soon Unable to have a normal life anymore |
| Self-image | I am not the only person living with HIV | I am the only person living with HIV |
| Perception of HIV and medication | Trust in effectiveness of medicine | HIV is incurable or a bad disease Don't want to take medicine daily/for rest of life Concern about dependency on medicine |
| Stigma | - | Anticipated stigma |

TABLE 4 | Impact of disclosure of HIV serostatus on adolescents' emotion and behavior (*n* = 190).

| Impacts | <i>n</i> (%) |
|--|--------------|
| Physical health | |
| Improved/kept adherence to antiretroviral therapy (ART) ^a | 149 (84.7) |
| Worried about my health | 136 (71.6) |
| Relationship with parents/caregivers | |
| Felt comfortable to talk about HIV with caregiver | 103 (54.2) |
| Blamed my parents | 61 (32.1) |
| Disclosing HIV status to other | |
| Limited self-disclosure to others | 154 (81.1) |
| Felt stressed to keep my HIV status secret | 59 (31.1) |
| Relationship with friends and intimate partners | |
| Felt scared to develop an intimate relationship ^b | 59 (42.5) |
| Stopped sexual relationship ^c | 21 (32.3) |
| Ever felt bad because someone talked about my HIV status to others | 34 (17.9) |
| Isolated myself from my friends | 23 (12.1) |

^aAmong those who have initiated ART (*n* = 176).^bAmong those who have had an intimate partner (*n* = 139).^cAmong those who have engaged in sexual relationship (*n* = 65).**TABLE 5** | Perceived advantages and disadvantages of disclosing HIV serostatus to adolescents.

| Perception | Detail |
|---------------|---|
| Advantages | Improve self-care Improve adherence to medicine Improve quality of life Knowing HIV status is beneficial/human right Knowing the objective for taking medicine is beneficial Able to accept HIV status Prevent HIV transmission to others |
| Disadvantages | Cause emotional distress Disclose HIV status to others unnecessarily Not mature to accept HIV status Discourage to take medicine |
| Neutral | Depends on one's personality or characteristics |

An adolescent expressed, "Some would feel as though it is the end of the world, and some would not know how to handle their feelings" (Boy, age 19).

TABLE 6 | Health education topics that adolescents had ever learned at hospital (*n* = 190).

| Topics | <i>n</i> (%) |
|--|--------------|
| HIV and treatment | |
| Benefit of adherence to antiretroviral therapy (ART) | 169 (89.0) |
| Risk of non-adherence to ART | 147 (77.4) |
| General mode of HIV transmission | 145 (76.3) |
| Duration of taking ART once it starts | 144 (75.8) |
| How I got HIV infection | 132 (69.5) |
| Psychosocial well-being | |
| How to develop hope for the future | 151 (79.5) |
| How to develop self-esteem | 131 (69.0) |
| How to deal with emotions | 120 (63.2) |

Table 6 shows health education topics that adolescents had ever learned at the hospital. Regarding the topics about HIV and treatment, 89.0% had learned about the benefits of adherence to ART, 77.4% had learned about the risks of non-adherence to ART, and 75.8% had learned about the duration of taking ART once it begins. Seventy-six percent had learned about general modes of HIV transmission, while 69.5% had heard about how they got HIV infection. Regarding the topics about psychosocial well-being, a lower proportion of adolescents had learned about how to deal with their emotions (63.2%), compared with those who had learned about how to develop hope for the future (79.5%) and how to develop self-esteem (69.0%).

DISCUSSION

This study examined disclosure of HIV serostatus to adolescents living with HIV in Zambia using quantitative data and developing triangulate evidence from existing qualitative findings (14, 22, 30). Particularly, we probed whether parents and caregivers' concerns before disclosing HIV serostatus to adolescents such as psychologically traumatizing adolescents, being blamed for HIV transmission, and risk of exposing adolescents to stigma in community (22) eventually materialized. We also identified the appropriate setting for disclosing HIV serostatus based on the adolescents' reported experiences.

High proportion of the adolescents developed negative feelings (45.3%) or mixed feelings (27.9%) when they were informed of their HIV serostatus, and 71.6% became worried about their health. This is because HIV infection was unexpected and perceived to be an incurable and fatal disease. However, majority of the adolescents (86.2%) reported that knowing their HIV serostatus is beneficial. Over 84% of the adolescents reported improved adherence to ART after serostatus disclosure. Disclosure helped them to understand the reasons for being sick and the purpose for taking medicine, enhanced motivation to care for one's own health, and improved quality of life. Similarly, in Zimbabwe and South Africa, adolescents showed extreme shock immediately after their HIV-positive status was disclosed, but they understood that knowing one's own HIV status is important for adherence to ARVs and to stay alive (10, 18). This implies that despite initial distress, they had resilience to accept and live with HIV. However, fear of inflicting emotional distress is a major barrier for parents and primary caregivers to disclose HIV serostatus to adolescents (22). Therefore, the important strategy will be to arrange both pre- and post-disclosure care and support for adolescents and their parents/caregivers until the adolescents can accept their HIV serostatus sufficiently.

The study also showed adolescents' reactions upon serostatus disclosure that usually pose concerns among parents/primary caregivers. In previous studies, parents were reluctant to disclose HIV serostatus to their adolescents due to fears of losing reputation and being blamed by them for transmitting the virus (14, 22). However, more than half of the adolescents in this study (54.2%) reported better communication with their parents/caregivers when discussing HIV; with a lower percentage of those blaming their parents (32.1%). Similarly, in Kenya, parents/caregivers of HIV-positive adolescents experienced improved relationships with their adolescents (39).

Parents/primary caregivers were also concerned about exposing their adolescents to stigma if their HIV serostatus was disclosed to others (22). However, 81.1% of the adolescents in this study did not self-disclose to others; 31.1% felt stressed about keeping HIV serostatus in secret; and only 17.9% had ever felt bad about disclosure by someone without their permission. Similarly, in South Africa, adolescents understood the secret nature of their HIV serostatus to avoid gossip and stigma, particularly when their parents/caregivers instructed them not to disclose to others (10). This indicated that parents/caregivers benefit from disclosing HIV serostatus to adolescents. They need to talk to their adolescents about positive and negative consequences of self-disclosing their HIV serostatus, and trust their ability to keep matters private. In addition, health workers should take care of psychological well-being of adolescents and provide counseling to parents/caregivers when they encounter difficult relationships with their adolescents after disclosure.

To improve the practice of disclosure of HIV serostatus, it is worth comparing adolescents' actual experiences with what they perceive as appropriate. The adolescents were disclosed their HIV serostatus at median age of 12 years; they regarded such age as appropriate for other adolescents too. This corresponds with the WHO recommendation (27). Although caregivers considered maturity of an adolescent as an important criterion for disclosure

in Zambia (22), our study finding encourages parents/primary caregivers to prepare for disclosure of HIV serostatus to their adolescents before they turn 12 years old.

Disclosure was usually done at the hospital or adolescent's home, which was similar to the adolescents' suggestions. However, only 6% of the adolescents were actually informed by both parents, while over 60% preferred disclosure by both parents. Existing literature shows that adolescents and their parents/caregivers preferred disclosure by caregivers with assistance from health-care workers as they have accurate knowledge about HIV (25). Thus, disclosure by both parents is the preferred setting for Zambian adolescents, and additional assistance of health workers would be helpful to facilitate emotional and intellectual acceptance of HIV serostatus, although most adolescents have lost one or both parents due to HIV/AIDS.

Learning about HIV and its implications for adolescents' daily life is a critical part of care associated with disclosing HIV serostatus. At the hospital, adolescents acquired basic knowledge about HIV (e.g., mode of HIV transmission, benefits of adherence, and risk of non-adherence to ART). On the other hand, they did not learn much about psychosocial well-being (i.e., self-esteem development and emotional adjustment). They need support for developing self-esteem and mitigating emotional distress. This is because, even though they do not disclose their HIV serostatus to others, their serostatus could be spread out, and they may encounter social exclusion. Professional care and counseling are essential to respond to their psychosocial needs (30). In addition, peer support can also provide knowledge about HIV, mitigate emotional distress, and empower each other (14, 18). About 8% of the adolescents in this study reported a positive acceptance of their HIV serostatus immediately after disclosure. A recommendation for a future study is to investigate factors that enabled these adolescents to accept their HIV serostatus with minimal distress, as this information could be adopted in the pre- and post-disclosure counseling and peer support activity.

Recommendations to health workers are to provide information on benefits and potential risks of disclosure to caregivers, including the study finding that their concerns before disclosure do not necessarily materialize. The information will mitigate caregivers' anxiety and facilitate their preparation for disclosure. Disclosing HIV status is a significant life event for majority of the adolescents. Health workers should pay attention to emotional impact of adolescents upon disclosure. Moreover, health workers need to perform counseling and educating adolescents on a wider range of topics including psychosocial well-being, involving trained peer supporters.

This study has several limitations. The study design may limit generalizability of the results as the study was conducted in one tertiary hospital in the capital city of Zambia. Recruiting adolescents at their regular clinical reviews may also limit generalizability of the findings as those who were not compliant with care instructions or had no access to care were excluded from the study; those adolescents may have different views or different impacts of disclosure. A recommendation for the future study is to conduct a longitudinal study design to assess process, and emotional and behavioral impacts of serostatus disclosure to adolescents, including rural settings where local norms and HIV care and treatment

services for adolescents would be different from an urban setting. Another limitation is that adolescents may have felt obligated to participate in the study as the study site was the place where they were receiving the care, and the participants may not have been mature enough to decline to participate. We carefully explained to each adolescent at recruitment about voluntary participation and freedom of withdrawal, with no negative implications for health-care they would receive. Moreover, the accuracy of the study results might be affected by recall bias because of the time gap between the disclosure event and participation in the survey.

CONCLUSION

This study strengthens existing evidence on HIV serostatus disclosure to adolescents in Zambia. Disclosing HIV serostatus to adolescents has a strong impact on their emotions. However, it improved self-care and adherence to ART. In contrast to parents/primary caregivers' concerns, disclosing HIV serostatus to adolescents also promoted better communication, while it was not a trigger for unnecessary self-disclosure to others. They prefer to be informed of their HIV serostatus by their parents at the age of 12. Serostatus disclosure to adolescents requires continuous care with the commitment of parents/primary caregivers, health workers, and peer adolescents.

ETHICS STATEMENT

We obtained ethical approval from the Research Ethics Committee of the University of Zambia, and the Institutional

Ethics Committee of the National Center for Global Health and Medicine, Japan. All adolescents provided assent to participate in the study, and parents/primary caregivers of the adolescents aged 15–17 years also offered informed consent. We collected all data anonymously.

AUTHOR CONTRIBUTIONS

SO, NI, SM-K, MM, and CK substantially contributed to the conception and design of the work, and the acquisition. SO, NI, SM-K, and KK contributed to the analysis and interpretation of data for the work. SO, NI, SM-K, and MJ drafted the work. All authors revised it critically for important intellectual content, made final approval of the version to be published, and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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The Amagugu Intervention: A Conceptual Framework for Increasing HIV Disclosure and Parent-Led Communication about Health among HIV-Infected Parents with HIV-Uninfected Primary School-Aged Children

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Advances in access to HIV prevention and treatment have reduced vertical transmission of HIV, with most children born to HIV-infected parents being HIV-uninfected themselves. A major challenge that HIV-infected parents face is disclosure of their HIV status to their predominantly HIV-uninfected children. Their children enter middle childhood and early adolescence facing many challenges associated with parental illness and hospitalization, often exacerbated by stigma and a lack of access to health education and support. Increasingly, evidence suggests that primary school-aged children have the developmental capacity to grasp concepts of health and illness, including HIV, and that in the absence of parent-led communication and education about these issues, HIV-exposed children may be at increased risk of psychological and social problems. The Amagugu intervention is a six-session home-based intervention, delivered by lay counselors, which aims to increase parenting capacity to disclose their HIV status and offer health education to their primary school-aged children. The intervention includes information and activities on disclosure, health care engagement, and custody planning. An uncontrolled pre-post-evaluation study with 281 families showed that the intervention was feasible, acceptable, and effective in increasing maternal disclosure. The aim of this paper is to describe the conceptual model of the Amagugu intervention, as developed post-evaluation, showing the proposed pathways of risk that Amagugu aims to disrupt through its intervention targets, mechanisms, and activities; and to present a summary of results from the large-scale evaluation study of Amagugu to demonstrate the acceptability and feasibility of the intervention model. This relatively low-intensity

home-based intervention led to: increased HIV disclosure to children, improvements in mental health for mother and child, and improved health care engagement and custody planning for the child. The intervention model demonstrates the potential for disclosure interventions to include pre-adolescent HIV education and prevention for primary school-aged children.

Keywords: HIV disclosure, South Africa, children, intervention, conceptual framework

INTRODUCTION

Children living in Southern Africa are rarely left unaffected by the HIV epidemic (1). Recent estimates (2003–2011) using Demographic and Health Surveys from 23 countries in Africa found the largest numbers of children (ranging from 14 to 36%) living with an HIV-infected adult were in Southern African countries (2). This HIV-infected adult was commonly one of their parents, most frequently their mother. Given the high prevalence of HIV in South Africa, the exposure to parental, familial, and household HIV is likely to be much higher than other countries in Southern Africa (3), with a greater number of children in the care of an HIV-infected parent.

Significant improvements in access to antiretroviral therapy (ART) in women of child-bearing age have substantially reduced vertical HIV transmission to children (4, 5). However, a growing body of evidence suggests that HIV-exposed children face a range of risk factors (parental ill health, hospitalization, and ultimately possible death and loss), which impact negatively on their psychological well-being (6, 7). This presents longer-term challenges for the ongoing care and support of HIV-infected parents and their largely HIV-uninfected children over the family lifespan (8–10). A major challenge this growing population of parents will face is when and how to disclose their HIV status to their predominantly HIV-uninfected children (11–14). However, an important opportunity exists to provide and empower HIV-infected parents with the skills and capacity to educate their children about health (including HIV); to teach their children about HIV prevention and the health services available to them; and to actively plan for their child's future, all of which have been shown to improve children's outcomes in the literature outside the context of HIV.

Research to date has focused on maternal, rather than paternal HIV disclosure, finding that disclosure of HIV status has been found to be beneficial for mothers, children, and families (12). Much research has focused on rates of disclosure, with a recent systematic review (13) on maternal HIV disclosure reporting rates varying from as low as 10% in some studies to 82% in others, with most finding disclosure rates between 30 and 45%. Although the largest population of HIV-infected parents live in Africa, only a handful of disclosure studies focused on parent disclosure to HIV-uninfected children have taken place in Africa (13, 15, 16). In comparison, international literature shows a rapidly growing body of evidence, including emerging work from China (17–19). Despite this, the literature remains limited overall, with most studies being descriptive and in resource-rich settings, with few interventions in low- and middle-income countries (LMICs)

(16) and with most focused on HIV disclosure, without much attention to the broader health education and prevention needs of children.

Interventions facilitating disclosure of either maternal or paternal HIV status to children have a broader potential to mitigate risk factors facing HIV-exposed children. Support for this can be drawn from conceptual models of familial resilience (20), which provide insight into resilient adaptation (21, 22) for children and families, emphasizing the importance of families' abilities to make meaning of a difficult situation (23) and to create a coherent narrative for children (24). While many parents may be willing to disclose their HIV status, they may not feel confident about how to clearly construct this narrative in a developmentally sensitive manner (8, 25). Thus, a key gap in the literature in sub-Saharan Africa is how parental HIV disclosure should be undertaken and how best to help HIV-infected parents to do this.

Most existing interventions, developed in high-income countries (HIC), take disclosure as an endpoint, and assume that the benefits of this are predominantly in the realm of improving parent and child mental health. In HIV-endemic communities, disclosure may better be conceptualized as a starting point, rather than an end point, with potential to use the disclosure to facilitate parenting capacity to educate children on HIV prevention or to initiate parent-led sex education or custody planning, both of which are known to improve the child's immediate outcomes and later adolescent outcomes in LMICs. The Amagugu intervention has this aim; it is a family-centered disclosure intervention providing support to HIV-infected mothers to disclose their status to their HIV-uninfected primary school-aged children and to educate them about health and HIV. This paper has two aims: (i) to describe the proposed pathways of risk that Amagugu aims to disrupt through its intervention targets, mechanisms, and activities and (ii) to present a summary of results from the large-scale evaluation study of Amagugu (25, 26).

MATERIALS AND METHODS

In the early stages of the development of this intervention, we used the UK Medical Research Council guidelines for developing complex interventions (27) and undertook phased research work to fully develop and test our intervention model. The design was informed by an extensive review of existing evidence and this was followed by piloting and refinement of the intervention with community consultations.

Our review on maternal HIV disclosure to HIV-uninfected children is published elsewhere (28) and summarizes 58 studies, including two literature reviews (11, 12) and a recent systematic

review (13). In addition, we reviewed the recent guidelines from the World Health Organization on HIV disclosure to children (29), which included the available evidence on maternal disclosure to HIV-uninfected children of primary school-age, and highlighted the lack of studies in this area. Following this review of the evidence, and given the lack of intervention models available for adaptation, we undertook the development of a clear conceptual framework that would guide intervention design. First, we identified the risk pathways outlined in the literature and formative work; second, we identified potential modifiable intervention targets to establish an intervention pathway that could disrupt these risks. Finally, we designed sessional content that we hypothesized would result in the changes sought through maternal HIV disclosure.

Importantly, the conceptual framework has been informed not only by what we know about how HIV impacts on parenting behavior and child outcomes but also our understanding of parenting capacities and stressors in the context of other parental terminal illnesses. The development of the model has been influenced by family resilience literature and the socio-cultural context within which the intervention was to be tested and delivered. Our intervention targets HIV-infected mothers (as opposed to fathers or other caregivers) for pragmatic reasons, as the vast majority of children are resident with, and cared for, by their biological mothers in our context (30). The intervention is, however, highly adaptable to use with fathers and other caregivers, as outlined in the section on the intervention principles.

RESULTS

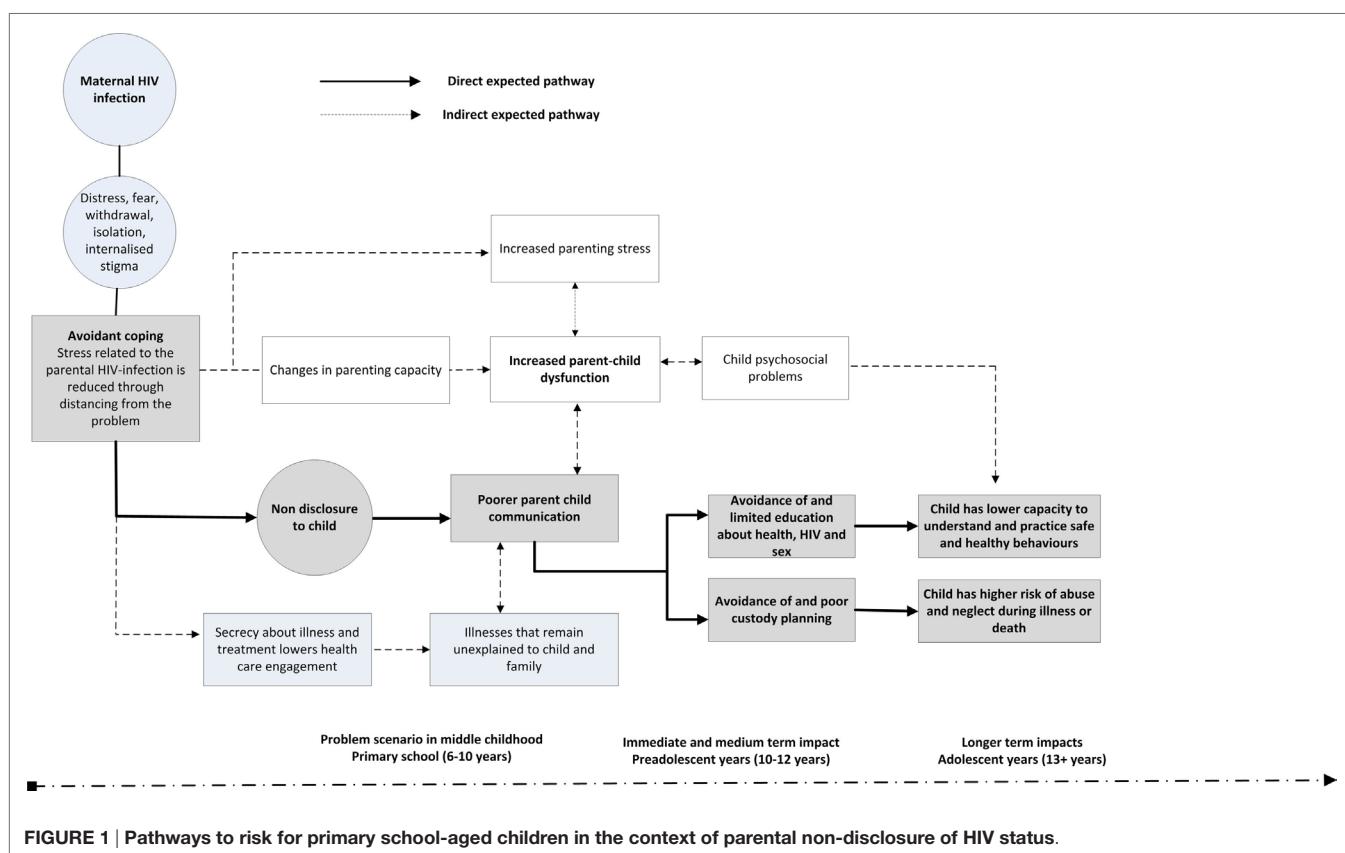
Results are presented in two sections: the first includes the design of the intervention, outlining the conceptual model, intervention targets, and principles; and the second, a summary of the results of the evaluation study.

Design of the Intervention

Conceptual Model

In **Figure 1**, we outline a developmental framework for the hypothesized risk pathways leading to poorer outcomes among children of HIV-infected mothers. The proposed direct pathway of risk is illustrated in gray boxes; the intervention aims to disrupt this pathway. We hypothesize that maternal HIV-infection, and a lack of openness with the child about it, could lead to psychological stressors for both the parent and child, resulting in negative health outcomes for the child, potentially spanning into the late adolescent years. This conceptual model is described in detail below.

Literature has shown that, following diagnosis, HIV-infected women are known to experience a range of emotions and utilize various coping mechanisms, including what is termed active and avoidance coping strategies (31). Avoidant coping strategies include distraction, denial, escape, distancing, and self-blame, with mothers commonly coping with HIV by distancing themselves from it (32). By not disclosing, which is commonly reported in the HIV literature (18, 33, 34), the mother is



practicing a form of avoidant coping, which is often motivated by a desire to safeguard children from psychological distress (26), or concerns about stigma and fear that the child may disclose to others (13, 35).

However, from the broader parental illness literature (36, 37), it is established that even if children are not explicitly informed, they are often aware from their parents' mood or behavior that something is wrong, or that their parents have concerns which they are not conveying (36, 38–40). Children may blame themselves, internalize their emotions, or exhibit behavioral difficulties (36). This, in turn, increases pressure on the parenting role (41), at a time when HIV-illness and other disease-related stressors are common. This pressure on the parenting role may cause a breakdown in parent-child communication, which negatively affects the mental health of the mother (41, 42) and child (7, 13, 35).

A lack of parent-child communication could result in a lack of health education (43) and lowered care and custody planning for the child (7, 9, 11, 22, 33, 35). It is reasonable to hypothesize that at least some of the risks conferred to HIV-exposed children may be linked to the broader care and custody environment in which the child finds themselves following their parents' death (6, 44). HIV-infected parents and their families face multiple stressors, including strained family relationships which could complicate care planning for the child (45). Children may be shifted from temporary homes, separated from siblings, or be left with inadequate or inconsistent care (45–48). These happenings may result in children being more vulnerable to abuse and neglect during these periods of illness or death (7, 49, 50).

Literature has also shown that, in the long term, HIV-exposed children may engage in harmful behaviors impacting their sexual health, including earlier sexual debut and risk of transactional sex (50), particularly where children face multiple cumulative risks (51). A lack of good quality parent-child communication may

contribute to this, illustrating that the effects of parental HIV in the childhood years have potential to be long lasting and may even increase the risks of the child becoming infected with HIV themselves (50). Therefore, parental HIV disclosure provides an important opportunity for parents to educate their children about their own health and sexual issues.

We propose that through these risk pathways children enter adolescence ill-equipped to manage the risks placed upon them growing up in an HIV epidemic community.

Intervention Model

Figure 2 shows the intervention model, including the stages of the intervention, and how they aim to address and disrupt the pathways of risk outlined in the conceptual model.

The intervention targets parental HIV disclosure as a way to foster active coping, improve parent-child communication and to increase parenting capacity to educate and plan for the child's future. The intervention directly tries to reduce secrecy and stigma associated with HIV, which may lead to poorer family communication (52), with negative consequences for children (13, 53). Importantly, in contexts where HIV is less prevalent, parents and families may make a choice to keep HIV a secret, and this may have fewer negative consequences for children in particular if it is plausible that they remain unaware, and parents and families remain high functioning (15). However, in an epidemic context, where up to 50% of households have at least one adult living with HIV and taking ART medication (3), it is plausible to assume that parents and families are not able to protect children from the effects of HIV within their family or community (54). Developmental literature from other chronic diseases (37) would, on balance, suggest that developmentally sensitive disclosure of illness is better than non-disclosure, particularly for primary school-aged children. The Amagugu intervention makes use of

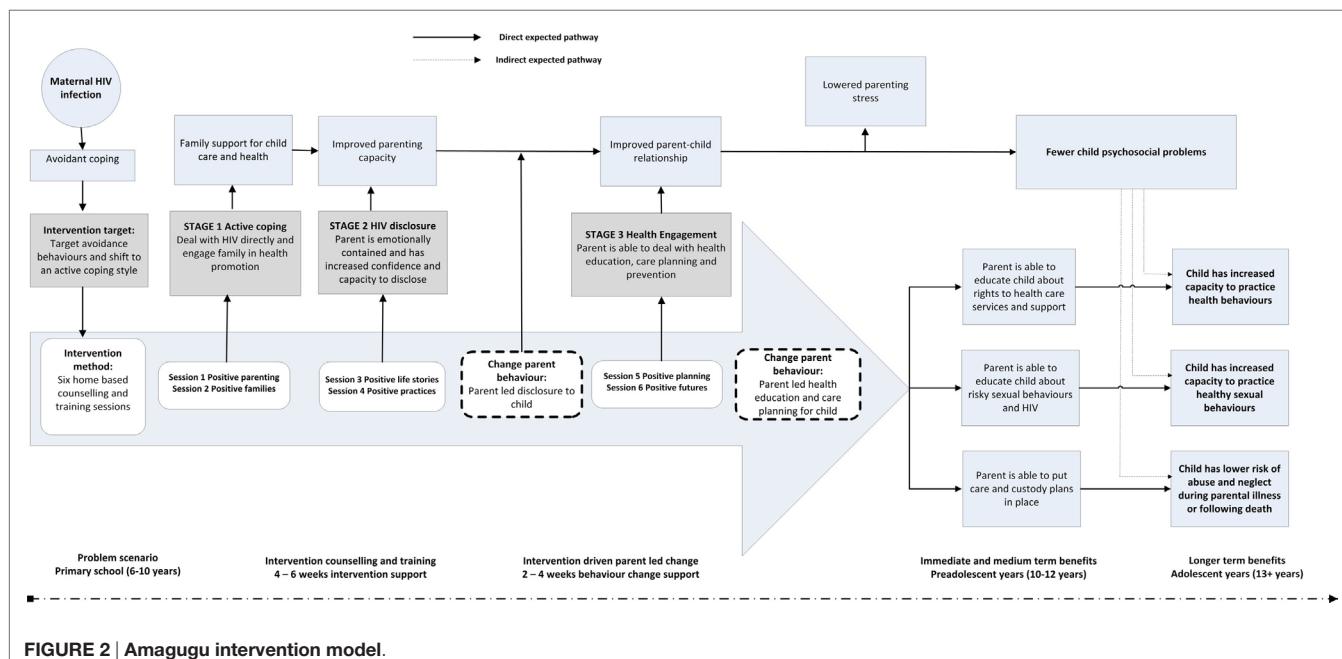


FIGURE 2 | Amagugu intervention model.

a variety of psychological approaches, packaged in activities that are accessible and user-friendly for lay professionals. It has five intervention targets that are summarized below, with supporting evidence, and has been specifically developed for high prevalence, low resource, settings.

Intervention Target One: Parenting Capacity

Research has suggested that maternal coping strategies are strongly associated with parenting styles and capacities (33). Active coping has been strongly associated with positive parenting, while avoidant coping was linked to poorer quality parenting, and higher externalizing and internalizing behaviors among children (33, 41). Drawing on the parenting literature, we hypothesized that compromised parenting and childcare practices contribute to negative outcomes for HIV-exposed children (38). This process is preceded by HIV stressors impacting negatively on the mental health of mothers, which in turn may negatively affect her parenting capacity (41). Specifically, poor parental mental health is associated with negative child behavior, low perceived parenting capacity, coercive parenting, and low attention to child emotional expression (55, 56). The Amagugu intervention attempts to address avoidant parenting behaviors and increase parenting capacity and skills, which will improve parent-child communication and the quality of the parent-child relationship.

Intervention Target Two: HIV Disclosure

Research suggests that disclosure has benefits for mothers in terms of mental health (41, 57, 58), health care behaviors (12), including ART adherence (59), and family relationships (15, 16). While it has been reported that children have an initial emotional reaction following disclosure, in general this is short lived (29), with mothers rarely reporting regrets post-disclosure (13, 18, 60). Furthermore, case-control studies have shown that children who have not been disclosed to show poorer emotional and social functioning (7, 11). Several studies have shown improvements in children's emotional and social functioning post-disclosure (11, 13), with children reporting feeling better prepared for the future and more involved in decision making. Mothers (14, 61) and children (60, 62) have reported experiencing a closer relationship following disclosure (13, 29); however, there are some studies that do report negative effects (60, 63).

Literature shows that mothers frequently express the desire to disclose to their children themselves (13, 18) but report feeling unsure about how to approach the issue, what is age-appropriate, and often have concerns that disclosure may cause emotional difficulties for their children (28, 64, 65). In most research, mothers emphasized the need for assistance in planning and preparing toward disclosure (2, 13, 18, 34). Ensuring timely, age-appropriate, disclosure of parental HIV status to HIV-uninfected children has been shown to increase the quality of custody and emergency care planning (44, 66).

We hypothesized that intervention support that directly facilitates parental HIV disclosure (whether targeting the mother, father, or caregiver with HIV) has a broader potential to disrupt a variety of parent-child relationship risk pathways. In the Amagugu conceptual framework, HIV disclosure is seen

as a key modifiable risk factor that may have both immediate and longer-term benefits.

Intervention Target Three: Parent-Child Communication

Research on family resilience suggests that family communication, organization, and belief structures are protective (20, 23, 49). This is particularly important in the context of parental HIV, as one of the negative impacts on children and families relates to repeated illnesses that may lead to hospitalizations and separation of the HIV-infected parent from the child and their family (7, 67). Presently, little is understood about children's developmental capacity to understand HIV and its health consequences (68). The limited available evidence originates predominantly from high income contexts (28) and suggests that primary school-aged children have few preconceived ideas about the meaning of HIV infection (15), and its potential to cause parental death (69). It is not known how generalizable this is in HIV-endemic settings, but some qualitative evidence suggests that high exposure to illness and death may increase the need for children to develop an understanding of how HIV make affect the human body and cause illness (54, 70). In the absence of an HIV-specific evidence base, it is possible to draw from evidence on the disclosure of other life-threatening illnesses by parents, which highlights that a child's capacity to cope with parental terminal illness is strongly mediated by developmentally appropriate parental communication about the illness and previous exposures to death (37, 54, 71). Given the high levels of exposure to HIV in South Africa, clear communication about HIV with children is essential.

Parent-child communication about maternal HIV is a highly modifiable risk pathway (72). Thus, we hypothesize that improving parent-child communication, specifically about parental HIV, will likely lead to improvements in the quality of the parent-child relationship, which is known to foster resilience in children (38) and result in lowered parenting stress and fewer child psychological problems.

Intervention Target Four: Health Education

Several studies have reported that it is more effective to begin parent-child communication about sex in the pre-teen years or before children reach puberty (73), and before they have developed established patterns of behavior (74–76). Children whose parents talk with them about sexual matters or provide sex education or contraceptive information at home are more likely than others to postpone sexual activity, and earlier education has been shown to improve later sexual health outcomes (77). However, a systematic review on parent-child communication about sex in sub-Saharan Africa (78) reported many barriers to sex education for younger children, in particular a lack of knowledge, skills, and confidence among parents and cultural taboos about discussing sex with children. Parents have a significant opportunity to impact on children's future sexual risk taking, however, few report doing so. There is strong support in the literature to illustrate that a strong parent-child relationship increases parents' willingness and ease in talking about sex and that supportive interventions that help parents understand what is developmentally appropriate are beneficial (76, 77). Although Amagugu targets younger children, parental HIV disclosure

presents an opportunity for a parent to proactively engage in health education and establish a strong parent-child relationship, which in turn increases the opportunities for parent-led communication about sex as the child matures.

Intervention Target Five: Custody Planning

The HIV literature has illustrated that children with custody or guardianship plans in place tend to have better outcomes (79). A custody plan could give children a sense of continuity and predictability after a parent's death, and some research has shown that proactively engaging with HIV-infected parents makes discussing custody planning more feasible (48, 49). Importantly, care and custody planning should be socially sensitive and culturally appropriate if it is to improve outcomes for children (80). Developing a clear plan for the child's future care may be a useful adaptive activity that could foster greater family resilience (23) in the context of parental HIV. Research also suggests that increased HIV disclosure is associated with increased custody planning (13). Given these known benefits for children in the longer term, Amagugu targets improving parenting capacity for custody planning, following parental HIV disclosure.

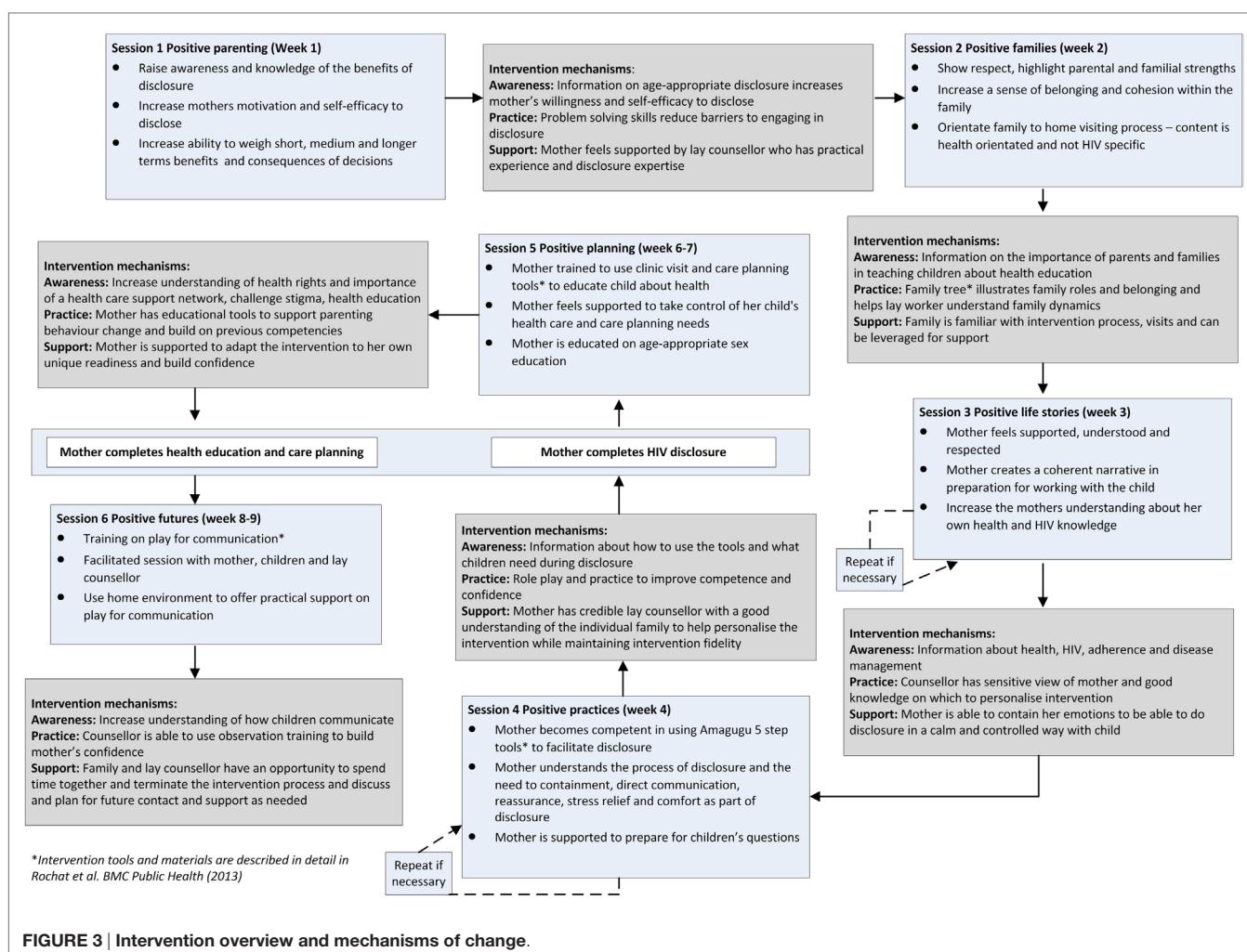
Intervention Package

The Amagugu intervention includes an intervention materials package, with session content and activities directly linked to the conceptual framework. These activities draw on evidence from both the family resilience (20, 22) and child development (37, 71) literature.

Figure 3 illustrates each session, its content, and the mechanisms by which the intervention aims to bring about change. The content of the intervention is described in detail elsewhere (81). Each intervention session aims to change parenting capacity and behavior through three processes: increasing parental *awareness and knowledge*; increasing parenting *capacity and skill*; and offering *support* in the parenting behavior change process.

During the formative and evaluative work, we developed several key principles that underpinned the approach to be taken in delivering Amagugu:

1. Enhancing parenting capacity is key to change and prevention.
2. Maternal capacity to contain emotions is a precursor to successful disclosure.
3. Parental HIV disclosure of any level is acceptable.



4. Education, care planning, and communication are a pathway to prevention.
5. Flexibility to engage other parental or family figures enhances the intervention.
6. The family is the best context for HIV disclosure.
7. Provision of intervention materials is important to support families.
8. An intervention design that supports a task shifting approach has more potential to be scaled-up.
9. Minimum standards, under which Amagugu is an appropriate and safe intervention, are defined.

Parenting Capacity Is the Central Mechanism for Change and Prevention

The intervention targets the parent, with a specific focus on building awareness and knowledge, providing training to increase parenting capacity, and providing support to the parent to undertake disclosure, health education, and care planning with their child. Parenting capacity is fostered through a series of carefully designed preparatory sessions where, after HIV disclosure, education, and planning are led by the parent themselves, and take place independently of intervention counselors, in order to ensure increased skills transference and self-efficacy in parenting capacity.

Maternal Capacity to Contain Emotions Is a Precursor to Successful Disclosure

One of the key aspects of the Amagugu intervention is that the mother is supported and enabled to disclose at a time that is suitable for her (without the counselor). It is critical that she is sufficiently prepared and able to contain her own emotions before she would be able to undertake the disclosure with her child. Not only will she need to be able to talk through the diagnosis with her child, but is likely to have to deal with a range of questions, some of which will be difficult, and potentially upsetting, to answer. Thus, the sessions that form Stage 2 (**Figure 2**) focus on the mother's feelings about her HIV diagnosis and helping her to come to terms with it and to reach some level of emotional equilibrium. If the mother is still struggling with her feelings at the end of the session, and it appears she may have difficulty disclosing her diagnosis to her child without becoming upset, the session can be repeated.

Parental HIV Disclosure of Any Level as the Primary Intervention Target

In Amagugu, parental HIV disclosure is the primary target of the intervention. As the intervention targets children aged from 6 to 10 years, we considered that the intervention would be framed developmentally to ensure scalability and reach. Taking guidance from the literature, Amagugu allows flexibility of parental disclosure level that can be partial (using the word "virus" and not naming HIV) or full (naming "HIV"). Importantly, the level of disclosure is determined by the parent, taking into consideration their child's developmental needs, their judgment on their child's level of readiness, and their own level of readiness as a parent.

Education, Care Planning, and Communication as a Pathway to Prevention

Parental HIV disclosure is not the only intervention target. We hypothesize that the communication about parental HIV provides an opportunity to increase health education among children and to encourage planning for the child's future. The intervention, thus, focuses on strengthening parenting capacity to increase health education, care, and custody planning; using activities that support improved communication and quality of the parent-child relationship to confer positive effects beyond the disclosure itself. The intervention, thus, adopts a preventative approach to risks that have been documented to emerge in the context of parental HIV at later developmental stages.

Flexibility to Engage Other Parental or Family Figures

The intervention targets mothers specifically, as the vast majority of children are cared for by their mothers in Africa (2). However, the intervention design accommodates involvement of fathers, the mothers' parents or siblings, the child's adult siblings, and other family members, alongside the mother (81). In family situations where the mother is not the primary caregiver, the intervention is highly adaptable to alternative primary caregivers.

The Family as Context for HIV Disclosure

It is well-established that families can play an important role in resilience in the face of stressful events (20, 82, 83). Families cope by making meaning of the crisis or difficult situation, by developing shared hopes for the future, and by helping children feel connected and problem-solving together (23, 39). Amagugu is developed to take place in the context of the family and includes family activities that foster a sense of belonging and connectedness, and also serve to orientate the family to intervention visits. Family activities are not HIV specific, so they allow mothers to adapt the family activities to suit their family composition and the level of disclosure within the family. Therefore, a key principle of Amagugu is to actively engage family support for the mother as a parent and for her children, regardless of the degree to which family level disclosure has been undertaken.

Provision of Intervention Materials

Taking guidance from a successful intervention in the United States (42), and understanding that parents have limited resources in our setting, the intervention provides a set of low-cost materials that are user-friendly and age-appropriate to support disclosure, health education (including sex education), and custody and care planning. The Amagugu intervention materials include storybooks, educational games, and activity cards. Mothers in the pilot study reported finding that the materials increased their confidence to disclose by providing a structure, and being understandable and appropriate for the child (81).

Intervention Design which Supports a Task Shifting Approach

In South Africa, and other poorly resourced contexts across Africa, psychosocial interventions at the primary health care level are restricted by critical shortages in health care professionals (84), and the absence of counseling or intervention guidelines (85–87). Task shifting of primary care and prevention functions

to community healthcare workers or lay counselors is showing promise in improving health outcomes at reasonable cost (88–90), including examples of cognitive behavioral interventions for postnatal depression (91) and complex treatment regimens, such as ART (92). In the setting where Amagugu was developed, community health care workers and lay counselors are responsible for psychoeducation within HIV treatment programs, including HIV counseling and testing, health promotion, and training of HIV-infected people to take ART. Throughout its development, Amagugu has utilized staff at an equivalent skills level to an HIV counselor to implement this intervention, particularly important for later scale-up given the time constraints on professional health staff within HIV programs (93–95). The package includes a train-the-trainer manual with intervention content, but also offers implementation guidance, minimum standards and community preparation for Amagugu. For larger scale roll-out, the package includes a supervisor's/implementer's guide and training video.

Minimum Standards under which Amagugu is an Appropriate Intervention

A set of minimum standards were developed to guide when Amagugu would be an appropriate intervention, as opposed to other public health interventions. These include: (i) that the mother or the disclosing parent/caregiver is in reasonable physical health to be able to undertake disclosure in an emotionally contained manner; (ii) that the mother has access to HIV treatment and health care services; if not then these should be prioritized over disclosure support; (iii) that children have access to the parent prior to, and following, disclosure; the Amagugu package offers particular guidance for migrating and working parents; and (iv) that family disclosure and support is feasible and does not introduce risks for the safety of the mother and child.

Evaluation of Amagugu Intervention

A pre-post-evaluation design study of the Amagugu intervention was conducted (2010–2012) with 281 HIV-infected women and their HIV-uninfected children, aged 6–10 years. This study aimed to evaluate rates of disclosure, and mental health outcomes of mothers and children, following the Amagugu intervention. The study was conducted from the Africa Centre for Population Health in rural KwaZulu-Natal, South Africa. The methodology and results are described in two open access papers in the journal AIDS (25, 26), and a brief summary of the results are given below. Written informed consent was obtained from mothers/caregivers and assent from children, and ethical approval was obtained from the Biomedical Ethics Committee of the University of KwaZulu-Natal (Ref: BF 144/010).

Amagugu was found to be effective in supporting maternal disclosure. Prior to the intervention, the majority of mothers 234/281 (83%) had not disclosed to any of their children under the age of 18 years, highlighting the need for disclosure support in this age group. Among the 47 mothers who had made a previous disclosure to a child, 21 (45%) had disclosed to an older child aged 10–18 years, while 26 (9%) had disclosed to a younger child aged 6–10 years. Encouragingly, post-intervention, all mothers undertook some level of disclosure, with 61% of mothers fully

disclosing their HIV status and 39% undertaking partial disclosure (using the word "virus" as opposed to "HIV").

In the evaluation, we also demonstrated improvements in maternal and child mental health, with the intervention significantly reducing parenting stress, and children showing less emotional and behavioral difficulties post-intervention (25, 26).

The mean age of children in the sample was 7 years (range from 5 to 10 years); we found age not to be significantly associated with level of disclosure. The majority of children's reactions to disclosure were reported by the mother to be "calm," regardless of whether disclosure was partial or full.

An examination of data on the questions that children asked following disclosure (while limited to maternal report) revealed that children have the capacity to understand and engage with the concept of HIV as a disease from a young age. Post-disclosure, children asked questions about the nature of HIV, how it was transmitted, how treatment worked, and how they could prevent themselves from getting infected (25). The evaluation results support the hypothesis that HIV disclosure can be a starting point for health and sex education with younger pre-adolescent children. While sex education was not directly addressed in Amagugu, at baseline 126 (45%), mothers reported having discussed the risks of sexual abuse with the child; post-intervention, this increased to 247 (88%). Sex education tools, including a storybook, have been incorporated in the post-evaluation revised materials package.

Post-intervention, mothers were asked what aspects of the intervention they found most enjoyable, and the results are shown in **Table 1**. These responses revealed two overarching categories: reflecting enjoyment of the feelings and emotions that the intervention brought about (127/281; 45.2%), and satisfaction with the materials and activities used in the intervention (150/281; 53.4%). In the feelings and emotions category, the most common response was the enjoyment of experiencing the child's positive reaction to disclosure (67/127; 52.8%), and in the materials and activities category, mothers most frequently expressed enjoying the child-friendly games, storybook, and storytelling activities (64/150, 42.7%). Very little research in the field has explored participant satisfaction with disclosure interventions. As maternal confidence has been shown to be a determinate of disclosure (42), understanding maternal satisfaction – specifically which activities she enjoyed and whether she experienced regrets – is important as they may affect maternal confidence and intervention success.

TABLE 1 | What mothers enjoyed most about the Amagugu Intervention.

Categories of most enjoyable aspects

Feelings and emotions, N = 127/281 (45.2%)

| | |
|--|------------|
| Experiencing the child's positive reaction to disclosure | 67 (52.8%) |
| Pride in the opportunity to be able to educate and support their child | 37 (29.1%) |
| Feeling relief and a sense of acceptance and care from their child | 23 (18.1%) |

Materials and activities, N = 150/281 (53.4%)

| | |
|--|------------|
| Child-friendly games, storybook and storytelling activities | 64 (42.7%) |
| HIV body map educational tool and health promotion playing cards | 40 (26.7%) |
| The combination of materials and how they fitted together in a package | 46 (30.7%) |

Missing, N = 4/281 (1.4%)

Evaluating maternal satisfaction may also allow greater understanding of the maternal experience and the wider application of the intervention. When asked about their regrets, 274 mothers stated they had none, five stated regretting the child's reaction to disclosure, one acknowledged initial regret as the child appeared alarmed after the disclosure (but shortly afterwards the child appeared to be fine), and another stated she regretted disclosing "partially" instead of "fully" to her child. When asked what they found least enjoyable about the intervention, 30 (11%) cited the child's initial reaction, 10 (4%) cited the having to state the disclosure out-loud to the child, 42 (15%) cited some aspect of the using the disclosure materials, while the remaining 199 (71%) cited there was nothing they did not enjoy, suggesting that the intervention is highly acceptable in this population.

When asked if they had involved family members at different parts of the intervention; 17 and 16% of mothers reported having included family members in preparing to disclose and during the disclosure process, respectively. However, encouragingly, 42% of mothers reported that they had involved family post-disclosure, suggesting that the intervention makes mothers feel more confident to involve others and discuss their HIV status. The intervention indicates potential for the involvement of men, as, of the family members included post-disclosure, almost a third were men, most commonly a brother or a boyfriend. The sample characteristics and relationships of the mothers are described in detail elsewhere (25). Adding to evidence of increased confidence, around 90% of the mothers reported that they felt they could help other mothers in their community to disclose to their children.

DISCUSSION

Through the results of the Amagugu intervention, we provide evidence to support our conceptual and intervention model. We have demonstrated that children in this context have the capacity to understand and engage with the concept of HIV as a disease from a young age. Some HIV disclosure-related qualitative research (96) has found that while most mothers only disclose to children aged 7 or 8 years, many report that their children had been aware of illness-related information for at least 3 years prior to the disclosure. In this high HIV prevalent context, it seems likely that more children would have prior experience of illness and death, which may account for children's understanding of HIV and death. This finding is in line with qualitative research in South Africa, which showed that pre-school children have a naïve understanding of human biology and disease, and in a context of high exposure to death, children are likely to assimilate experience and understanding of both external and internal causes of death at a young age (54). This provides evidence supporting the appropriateness of the HIV-related materials in the Amagugu intervention for this primary school-aged group of children.

The evaluation results support the hypothesis that HIV disclosure can be a starting point for health and sex education with younger pre-adolescent children. This is encouraging as existing literature from high income settings shows that parent-child communication about sex can influence later sexual outcomes of the child (73, 74, 97). A recent systematic review (98), examining the impact of behavioral interventions involving parent-child

communications about sex in children who are disproportionately affected by HIV in the United States, showed that 13 out of 15 studies showed at least one significantly improved sexual health outcome compared with controls. Likewise a systematic review of the impact of sex education and HIV education interventions in schools in developing countries (97) showed that 16 of the 22 interventions significantly delayed sexual debut, reduced the frequency of sex, decreased the number of sexual partners, and increased the use of condoms or contraceptives.

Parental disclosure is by no means made easy through Amagugu, and it remains a challenging and emotional task for parents, children, and family, but this intervention illustrates that with appropriately targeted support mothers can undertake disclosure and encourage other healthy behavior changes in their children. Results support the flexible nature of the intervention to include alternative caregivers and family members, with almost half the mothers reporting involving other members of their family post-disclosure. Furthermore, the overwhelming majority of mothers reported feeling confident to help other mothers in their community to disclose, illustrating the potential for the intervention to show sustainable benefits, not only for the family and child but also for the wider community.

Limitations of this research include lack of costing of the intervention package, no control group, and parent-reported data on children's mental health. Furthermore, as a minimum standard we only included mothers who had access to HIV treatment services, which may have limited our sample. The intervention requires further testing with other caregivers (for example HIV-infected fathers) and in other settings.

Amagugu has shown preliminary success in a large-scale evaluation, but these results must be interpreted with caution, given the absence of a control group. In 2013, with funding from the National Institutes of Health (RO1HD074267-01), Amagugu was tested in a randomized control trial (NCT01922882). This trial was completed with follow up to 9 months post-disclosure in December 2015 and results will be published in 2016.

AUTHOR CONTRIBUTIONS

TR contributed to drafting the manuscript and to the design of the conceptual framework and intervention design, critically revised the manuscript, and contributed to analysis and interpretation of evaluation data. JM contributed to drafting and critically revising the manuscript. AS contributed to revising the manuscript and to the design of the conceptual framework and intervention design. NM contributed to design and data collection and to drafting and critically revising the manuscript. RB contributed to the design of the conceptual framework and intervention design, critically revised the manuscript, and contributed to analysis and interpretation of evaluation data.

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Taking HIV Testing to Families: Designing a Family-Based Intervention to Facilitate HIV Testing, Disclosure, and Intergenerational Communication

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Introduction: Facility-based HIV testing does not capture many adults and children who are at risk of HIV in South Africa. This underscores the need to provide targeted, age-appropriate HIV testing for children, adolescents, and adults who are not accessing health facilities. While home-based counseling and testing has been successfully delivered in multiple settings, it also often fails to engage adolescents. To date, the full potential for testing entire families and linking them to treatment has not been evaluated.

Methods: The steps to expand a successful home-based counseling and testing model to a family-based counseling and testing approach in a high HIV prevalence context in rural South Africa are described. The primary aim of this family-based model is to increase uptake of HIV testing and linkage to care for all family members, through promoting family cohesion and intergenerational communication, increasing HIV disclosure in the family, and improving antiretroviral treatment uptake, adherence, and retention. We discuss the three-phased research approach that led to the development of the family-based counseling and testing intervention.

Results: The family-based intervention is designed with a maximum of five sessions, depending on the configuration of the family (young, mixed, and older families). There is an optional additional session for high-risk or vulnerable family situations. These sessions encourage HIV testing of adults, children, and adolescents and disclosure of HIV status. Families with adolescents receive an intensive training session on intergenerational communication, identified as the key causal pathway to improve testing, linkage to care, disclosure, and reduced stigma for this group. The rationale for the focus on intergenerational communication is described in relation to our formative work as well as previous literature, and potential challenges with pilot testing the intervention are explored.

Conclusion: This paper maps the process for adapting a novel and largely successful home-based counseling and testing intervention for use with families. Expanding the successful home-based counseling and testing model to capture children, adolescents, and men could have significant impact, if the pilot is successful and scaled-up.

Keywords: home-based counseling and testing, family-based counseling and testing, HIV testing, adolescents, intergenerational communication, family-based intervention, disclosure

INTRODUCTION

Individual HIV Counseling and Testing Models

In many contexts, voluntary counseling and testing services are predominantly accessed at health-care facilities (facility-based HIV testing). However, facility-based HIV testing does not reach many adults and children (under 18 years) who are at risk of HIV in South Africa (1–5). Most adult women test through antenatal or postnatal care, but many women who are not of reproductive age, older people with high HIV prevalence (9.5%) (6–8), and men are missed by facility-based approaches. Furthermore, the children of HIV-positive women are not routinely tested through prevention of mother-to-child transmission programs (9). Despite high HIV prevalence, adolescent (defined by WHO as 10–19 years) (10) rates of testing are particularly low within facilities (11). These missed testing opportunities underscore the need to increase options to provide targeted, age-appropriate HIV testing for children and adolescents and to create opportunities for adults not accessing facility-based services to learn their serostatus.

Home-based counseling and testing involves the delivery of HIV counseling and testing by lay counselors to adults in their homes. Studies in Uganda, Kenya, Malawi, and South Africa have demonstrated that home-based counseling and testing is a highly acceptable and cost effective approach for large-scale delivery of HIV testing (12–16) and reduces opportunity costs particularly for low-income persons in rural and other under-resourced settings (16, 17). Home-based counseling and testing has also been successful in reaching first-time testers, such as couples and children (18). Increasingly, home-based counseling and testing approaches are effective in identifying and referring populations to HIV care and antiretroviral therapy (14, 19–21). Our team has developed and evaluated (22) a novel approach of home-based counseling and testing plus point-of-care CD4 results testing and facilitated referrals to HIV care in rural KwaZulu-Natal and Uganda. The results showed high (96%) uptake of testing by adults, and equally high linkage to care – at 12 months, 97% of participants eligible for treatment had linked to care – and 76% of people who were eligible, initiated treatment at 12 months (19–21).

Family-Based HIV Counseling and Testing

While home-based counseling and testing has been successful in multiple African settings, very few models for testing entire families and linking them to treatment – the focus of this paper – have been developed or evaluated. A family-based

counseling and testing approach has several potential benefits. First, it has potential to increase testing and counseling of hard to reach groups including children, adolescents, and adults missed through facility-based approaches. Second, it could efficiently link households to comprehensive HIV treatment, care, and prevention services, in particular through use of point-of-care technology. Third, and most importantly, it provides an opportunity for facilitated disclosure of HIV serostatus to family members, including children. A review of literature on home-based counseling and testing studies found that only one intervention included a group rather than individual pre-test counseling session (18); such group sessions could facilitate intra-family decision-making about HIV testing.

Disclosure and Linkage to HIV Care and Treatment in a Family-Based Approach

Despite the inclusion of children in some home-based counseling and testing studies (14, 23–25), little attention has focused on disclosure from parents to children. Children can be affected by living with HIV-infected adults. A recent meta-analysis of demographic and health survey data from 23 countries across sub-Saharan Africa (26) demonstrated that the number of children living in households with tested, HIV-infected adults exceeded 10%; in some countries this rate was as high as 36%. Most of these children are living with parents, often mothers, who are infected. Thus, the challenge and opportunity is to design effective family interventions to support HIV testing and disclosure, which strengthens the family and supports health awareness and prevention among children and adolescents.

While other groups have conducted home-based counseling and testing of entire households, only one intervention provided support for general disclosure (14), although most encouraged couples testing, which involved disclosure (13–15, 18, 25, 27, 28). Our home-based counseling and testing studies showed that when offered, 95% of couples agreed to disclose their results to each other (19, 20). Beyond the one study which facilitated family-wide testing, no home-based counseling and testing studies could be found that describe strategies for dealing with disclosure after HIV testing, including family-based follow-up, facilitated family discussions to share information or encourage disclosure, or provision of tools to assist families dealing with the implications of HIV and AIDS (12, 25). Increased disclosure has been shown to have several benefits, including improved social support and family cohesion (29); less stigma and secrecy (30, 31); improved parent-child relationships and lower emotional difficulties in HIV affected children (32); lowered maternal depression and anxiety in parental figures (30, 31, 33); and improved compliance

with health care and response to treatment for adults living with HIV (29). Thus, a family-based counseling and testing approach could provide an opportunity to encourage disclosure within families, especially between parents and children and, in particular, provide parents with the skills they require for disclosure to their children (34–38).

Early HIV testing, effective linkage to HIV care, and early antiretroviral therapy initiation have implications for prevention because, in addition to reducing morbidity and mortality (39, 40), they reduce infectiousness and, therefore, onward transmission of the virus (41–43). HIV care and treatment programs continue to utilize an individual, clinic-based approach that does not acknowledge that families are the first line in HIV prevention and the provision of support to HIV-positive family members. Children who know their status adhere better to antiretroviral therapy and are more likely to participate actively in health care (44). Similarly, adults with social support or a treatment supporter (person who helps a patient adhere to antiretroviral therapy) are more likely to adhere to treatment (45, 46). A review of family-based approaches to pediatric antiretroviral therapy has shown that the approach is very effective, with better treatment enrollment, adherence, retention, and follow up (47). Parents, in-laws, and other relatives have varying degrees of influence on decisions regarding HIV testing, disclosure, and drug treatment and adherence for children (48) and young people. Testing all family members enables the identification of multiple individuals potentially at risk (49) and could not only contribute to greater social support, pill-taking, and clinic visit adherence among HIV-positive family members on antiretroviral therapy but also prevention awareness and risk reduction (17, 23, 50).

A family-based counseling and testing approach could also address the structural factors that impact HIV transmission and infection and provide a context for more effective and sustained prevention and support. Family-centered care refers to comprehensive, one-stop HIV-prevention care and treatment offered to the family. Family-centered services, including testing and linkage to care, has mostly occurred in prevention of mother-to-child transmission settings (51–53) and has increased case finding of women and children and uptake of treatment services (52). Family-based counseling and testing could build on the family-centered prevention of mother-to-child transmission model by reducing the opportunity costs of seeking facility-based care, reducing the stigma and responsibility that clinic-identified HIV-positive family members may feel, and encouraging a more family-focused and shared response to HIV and AIDS (49, 54).

This paper outlines the process for adapting and expanding our successful home-based counseling and testing model to develop a low-intensity, scalable, family-based intervention in a high HIV prevalence and risk context in South Africa.

MATERIALS AND METHODS

The Research Context

The intervention will be piloted in the Laduma Community, Lower Mpumuzwa of the Msunduzi Municipality, Umgungundlovu District, KwaZulu-Natal, South Africa. The Laduma Community

is a rural area within the Msunduzi Municipality, which has a population of 618,536. It is situated approximately 25 km from Pietermaritzburg, the provincial capital of KwaZulu-Natal. The Msunduzi Municipality is characterized by high unemployment as illustrated by the provincial unemployment rate of 33% (55). This province also remains highly burdened by HIV with an overall prevalence of 16.9% among the general population, the highest of all South African provinces (56). Across all age categories, i.e., children (2–14 years old: 4.4%), youth (15–24 years old: 12%), and people of reproductive age (15–49 years old: 12%), KwaZulu-Natal has the highest prevalence of HIV in the country (56).

Ethics approval for this study was obtained from the Human Sciences Research Council Research Ethics Committee (REC 10/20/11/13). All participants in the qualitative formative phase provided written-informed consent (or assent with guardian permission, in the case of persons below 18 years old).

In this study, we define children as between 0–11 years old, adolescents as 12–17 years old, and adults as persons over 18 years old. These definitions align with the configurations of families and the South African legal framework, which provides that children 12 years and older can independently consent to an HIV test (57).

Aims of the Study

The aim of this research, with funding from the National Institutes of Mental Health (1 R21 MH103066-01), is to develop a family-based counseling and testing model that provides HIV testing, counseling, and linkage to care *and* also supports all family members with disclosure, fosters intergenerational discussion about HIV, and increases support and health promotion among family members affected by HIV. The aims are threefold:

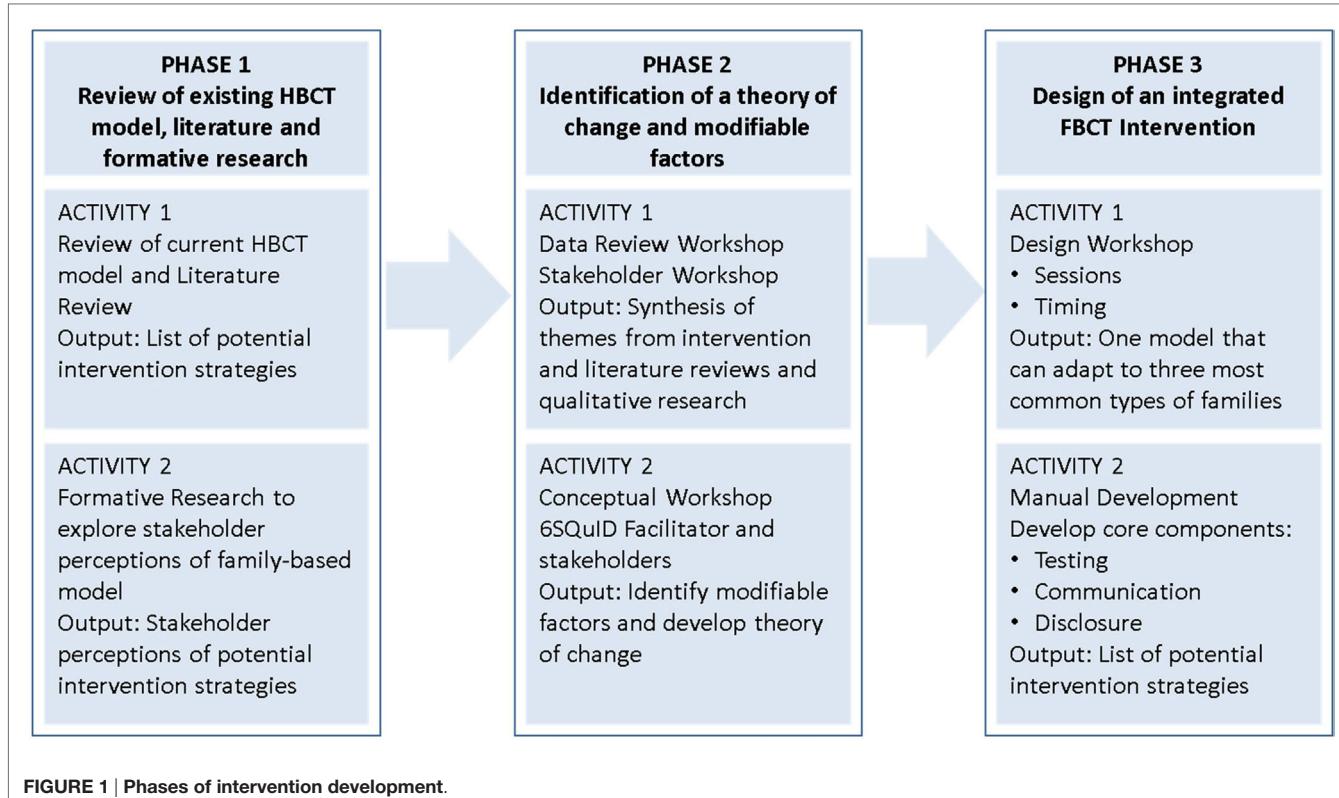
1. Develop a model for providing family-based counseling and testing through adaptation of our home-based counseling and testing model
2. Pilot test the family-based counseling and testing model for feasibility and acceptability
3. Assess the impact of family-based counseling and testing on testing and linkage to care, family disclosure and cohesion, intergenerational communication and stigma, and discrimination.

In this manuscript, we present the results of research objective one.

RESULTS: THE RESEARCH APPROACH

The formative research undertaken to develop the family-based counseling and testing intervention took place in three phases, outlined in **Figure 1**.

The intervention development process was guided by a useful pragmatic framework for developing social interventions called the *Six Steps in Quality Intervention Development* (6SQuID) model (58). This framework comprises six critical steps, namely: (1) defining and understanding the problem and its causes;



(2) identifying which causal or contextual factors are malleable and have the greatest scope for change; (3) deciding how to bring about the change mechanism; (4) identifying how to deliver the change mechanism; (5) testing and adapting the intervention; and (6) collecting sufficient evidence of effectiveness to proceed to rigorous evaluation of the intervention.

The approach taken in this research was not to develop a new intervention, but instead to augment a current successful home-based counseling and testing intervention to include families. During this phase we addressed steps 1–4 of the 6SQuID model through three key activities:

1. A review of the current home-based counseling and testing model, literature, and formative research
2. Identification of a theory of change and modifiable factors
3. Design of an integrated family-based counseling and testing intervention

Phase 1: Review of Existing Home-Based Counseling and Testing Model, Literature, and Formative Research

Review of Current Home-Based Counseling and Testing Model

The home-based counseling and testing model starts with community mobilization to inform and prepare adult household members over 18 years old for the study. Counseling and HIV testing is then conducted by lay counselors or enrolled nurse assistants in the home. HIV seropositive persons receive point-of-care

CD4 testing at the same visit, and referrals to HIV care are made. Follow-up visits of HIV-infected persons are conducted quarterly to assess uptake of clinic visits and antiretroviral therapy initiation and to provide counseling about HIV care and antiretroviral therapy adherence. If a couple participates, they are counseled and tested separately; facilitated disclosure is provided with their permission.

Augmenting the current home-based counseling and testing model to include all family members (adults, adolescents, and children) involved two related activities: (1) a systematic review of the literature on family-based interventions to inform the content, processes, and development of suitable strategies for developing a family-based counseling and testing model and (2) formative research to explore the familial, sociocultural, and community factors that could impact the effective delivery of a family-based counseling and testing model.

Literature Review

We conducted a systematic review of the existing intervention literature focusing on family-based interventions in general, those that addressed HIV testing in families, including children and adolescents, and those that encouraged family disclosure and communication. Key search terms included families, sex/HIV, communication/intergenerational communication, and setting – as well as variations thereof. The preferred reporting items for systematic reviews and meta-analyses (PRISMA) approach was used to guide the review. We searched online databases (ProQuest Central, Pubmed, and EBSCO Host) and numerous additional databases and journals that were indexed within these. The search identified

23,782 articles, after duplicates were removed. After a scan of titles and abstracts, we retained 186 articles, which were separated into primary and secondary papers. Primary papers ($n = 97$) were included in the data extraction and the systematic review. Secondary papers were articles of interest that provided important context/background information for the study. Primary studies were coded according to pre-defined fields, including details of reference (title, author, year of publication), study characteristics, design, setting, outcomes, etc., which were summarized for the systematic review. To ensure consistency in coding, each article was independently coded and summarized by two researchers. Appendix **Table A1** provides a summary of child and adolescent family-based interventions conducted in South Africa.

Formative Research

Formative research is often used to inform the design and delivery of interventions. However, this critical process is rarely reported. Substantial formative work prior to implementing interventions has been recommended by McKleroy et al. (59) and supported by others (60–62). Data collection was undertaken between September and November 2014 to establish adults, children, and adolescents needs, concerns, and perspectives of the potential family-based model. We conducted 40 in-depth interviews with 20 key informants and 20 stakeholder representatives, as well as 12 focus group discussions with male and female adolescents between 13–18 years old ($N = 77$). Participants were purposively sampled. Interviews and focus groups were audio-recorded, transcribed, translated, and thematically analyzed (63) in multiple iterations by two researchers.

Phase 2: Identification of a Theory of Change and Modifiable Factors

Once the qualitative data and review outputs were available, the research team convened in a series of workshops to synthesize results from the systematic review and formative research to develop a conceptual framework and elucidate the theory of change for the family-based counseling and testing model. The involvement of community and implementation stakeholders in these workshops, recognized that intervention development is best approached through multidisciplinary stakeholder teams including researchers, practitioners, the affected population, and policy makers (58).

The first workshop focused on data review and presented the results of the qualitative research to the investigator group. The results are under review elsewhere [Gillespie et al. (2016), Knight et al. (2016), and Ngcobo et al. (2016) – abstracts submitted to International AIDS Society (IAS) Conference, 2016]. The results illustrated that a family-based approach was in principle highly acceptable but that stakeholders expressed concerns regarding testing adolescents with their caregivers, intergenerational communication on subjects such as sex, sexuality, and, thus, HIV. Parental figures expressed a lack of confidence, knowledge, and skills in dealing with this issue with children and adolescents. The outcome of this workshop and review of the literature led to a decision to conduct a second workshop, facilitated by an expert consultant, to better

define the theory of change for the intervention and to clarify which contextual factors were likely to have the greatest impact in reaching our study outcomes.

This second workshop with a group of diverse stakeholders took place over 2 days and attempted to integrate the results from the literature review and the formative data in order to develop a clearer understanding of which causal or contextual factors had the potential to impact the family-based counseling and testing model outcomes and which intervention activities would have the greatest scope for change. During these two workshops, steps 1–4 of the 6SQuID framework were addressed (58). The third and fourth workshops involved the investigators designing the model and refining intervention activities and tools.

As illustrated in **Figure 2** (see below) at these workshops, the main problem we identified was that families had weak support, which led to poor HIV testing, linkage to care, and adherence to treatment. After clarifying the problem, we made efforts to understand its causes (the immediate and underlying influences). Several causal pathways were identified, namely, strength and self-reliance being intrinsic to masculinity, entrenched gender inequalities, poverty and unemployment, hierarchical relationships between generations, absent fathers, men's anxieties regarding exposing infidelity, poor communication skills between partners, poor intergenerational communication skills, and inability to discuss sex across generations (depicted on the left in **Figure 2**). This critical step of representing, diagrammatically, the causal pathways leading to the problem was essential to carefully consider how best to intervene to improve outcomes. These outcomes (depicted on the right in **Figure 2**) included delayed testing (especially among adolescents and men), poor linkage to care, poor adherence, and stigma. Without intervention, these causal and contextual factors ultimately contribute to lower CD4 counts, greater progression to AIDS, and worse treatment outcomes.

As a next step, efforts were made to clarify which causal or contextual factors were modifiable through this intervention and would have the greatest scope for change. The different colors of the boxes on the left in **Figure 2** represent different potential pathways to change. During this step, we carefully considered which of the various pathways would be most amenable to change, which changes would have the most effect, and who would be most affected by them.

Three important modifiable causal and contextual factors were identified, which could form the intervention target. These included hierarchical relationships between generations, inability to discuss sex across generations, and poor communication skills across generations. The formative work and the literature review identified great value in parent-child communication in mitigating high-risk behavior (64). We recognized that adolescents are a key target population for HIV-prevention interventions given their high risk; in South Africa, the incidence among adolescents was higher than for any other age category, at 1.49% (56).

Our formative research, systematic review, and the consultative workshop elucidated that intergenerational communication was the most modifiable causal pathway for this family-based intervention and the one with the greatest potential direct impact on our research outcomes. Given the limited time-frames of this

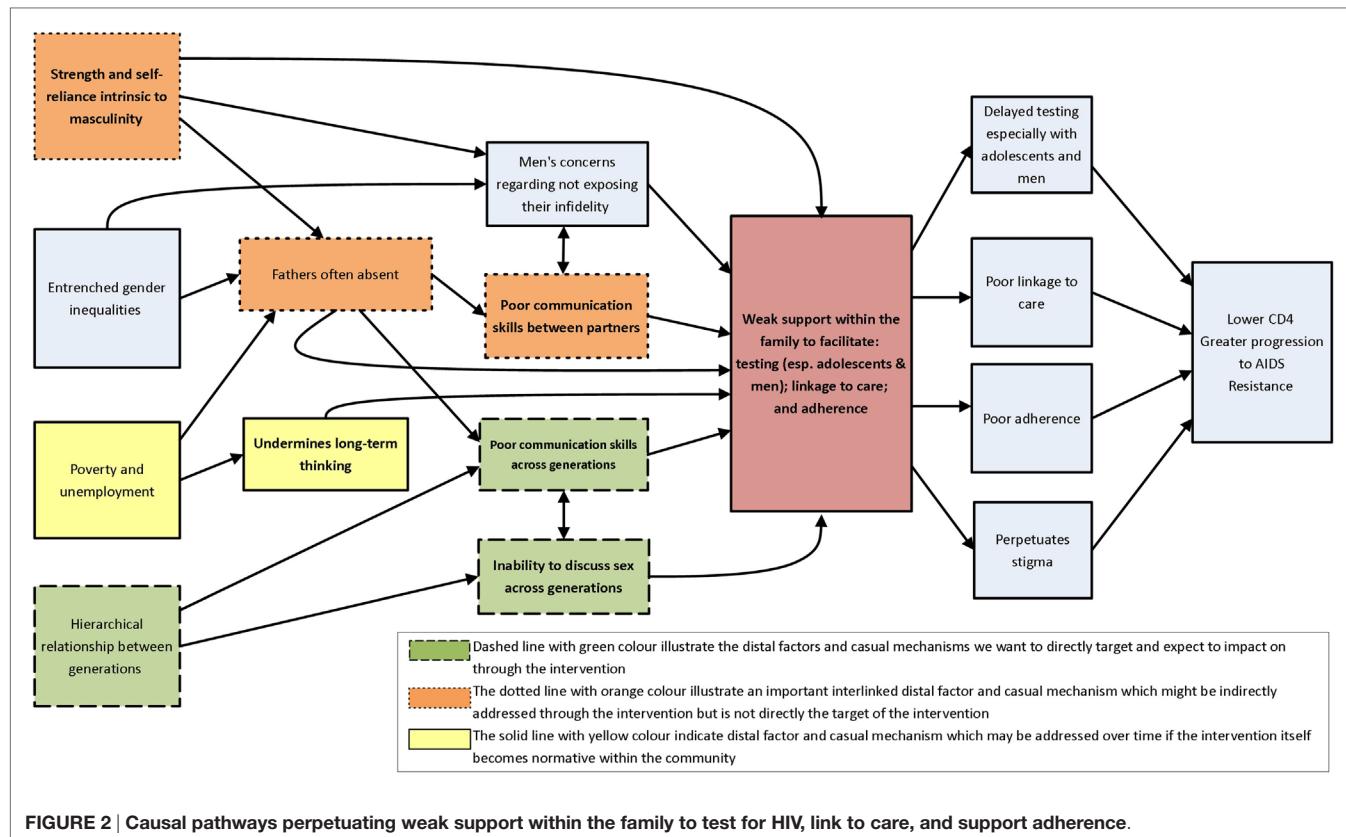


FIGURE 2 | Causal pathways perpetuating weak support within the family to test for HIV, link to care, and support adherence.

study, the team recognized that, while “upstream” structural issues (such as gender inequalities and masculinity) and couple relationships were important distal factors that could impact family-based counseling and testing, these did not represent the most modifiable pathways for this intervention. Our team is also involved in conducting separate studies that directly address couples (1R02MH086346-01A) and male involvement in testing and treatment (1R01MH105534-01A1).

This family-based intervention will use a theory of change informed by a theoretical framework to effect change.

Theory of Change

Hierarchical relationships between generations, inability to discuss sex across generations, and poor communication skills across generations were three important factors that could impact on the primary outcomes of this study that is improved uptake of HIV testing and linkage to care for all family members, improved discussion and disclosure of HIV status among families, improved family cohesion, and improved antiretroviral therapy adherence and retention. Our intervention aims to address these outcomes through changing participants’ knowledge, perceptions of risks and benefits, awareness, social norms, skills, self-efficacy, and intentions regarding testing, treatment, and disclosure. This will occur over a series of sessions with families, through engaging them in counseling, information, and support activities, many of which use modeling. The study will also identify a change agent in the family who could act as a catalyst for change by helping the family transform itself. The change agent will be identified

in the first session and help the counselor lead discussions in the remainder of the sessions.

In developing a family-based home-based counseling and testing model, we drew on Ewart’s social action theory (SAT) (65). The approach has been used successfully in couples and family-based interventions addressing mental illness (66) and interventions to improve HIV medication adherence (67). SAT recognizes the interwoven relationship between the individual, family, and community factors in determining uptake of interventions to promote self-protective behavior. Parent–child relationships may facilitate or impede disclosure and discussion about HIV and AIDS, provide helpful action plans or role models for communication and disclosure, and foster strategies for modifying “scripts” that keep HIV status as a family secret and impede disclosure. We hypothesize that, where whole families are tested and opportunities for family discussions and HIV disclosure are encouraged, HIV testing and antiretroviral therapy uptake may be improved, leading to greater social support for HIV-positive individuals, improved adherence to antiretroviral therapy, and prevention awareness and risk reduction in the family (17, 50).

Phase 3: Design of an Integrated Family-Based Counseling and Testing Intervention

The final step in this phase involved identifying how best to deliver the change mechanism through intervention design. Operationalizing the intervention was an iterative process that

included results from the systematic review and formative research and refinement during the stakeholder conceptual workshop. Investigators drew on these prior steps in two intervention design workshops that focused on refining the family-based counseling and testing model, process, activities, and tools.

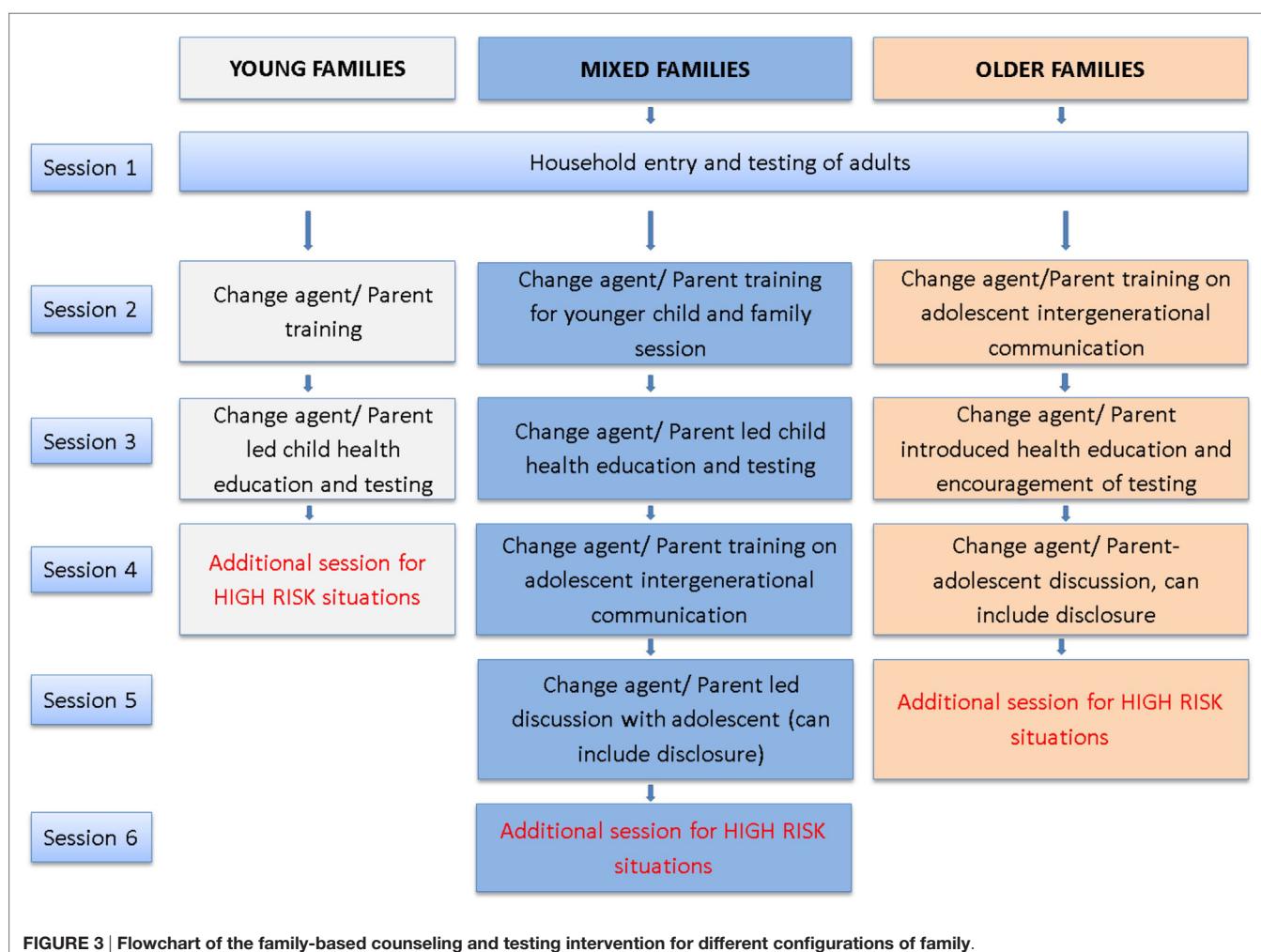
The intervention will be delivered by trained counselors/facilitators. Counselors and implementation staff were included in all aspects of the process drawing on their knowledge and experience to ensure the design of a feasible intervention that could work in this context. We also consulted with experts in child and adolescent development to produce and adapt tools and materials to test children, adolescents, and adults for HIV to encourage disclosure and to improve intergenerational communication.

The proposed family-based counseling and testing behavioral intervention consists of up to five sessions delivered within the household, plus an optional session for high-risk or vulnerable family situations (see **Figure 3** below). The intervention is expected to cater to three configurations of families: (1) young families have adults and children, where all resident children are 11 years or younger; (2) mixed families have adults and children, where some children are 11 or younger and some are 12–17 years old (adolescents); and (3) older families comprising adults and

adolescents (children 12–17 years) with no young children resident. Steps on how the intervention will be approached with each type of family are described in detail below.

Household Entry and Testing of Adults

On a first visit to the household, all families will receive an introduction to the study. This facilitator-led session will identify the family configuration (through various tools and activities) and identify and recruit the change agent(s) who will cofacilitate future sessions with the facilitator/counselor. There may be one change agent or a dyad who could take on the change agent role (e.g., parents, sisters, mother, and grandmother). Change agent(s) will be selected based on pre-defined criteria, namely: they must be available for all sessions of the intervention; preferably older than 18 years; willing to be a change agent; able to facilitate training; and must have good relations within the family. Two sets of activities will be completed in this session. The *Family Tree Activity* (38) will be a joint family activity used to identify all members of the family to assist in categorization of type of family (young, mixed, older), and to identify through discussions potential change agent(s). Participation in this activity may also foster a sense of family belonging. The *Let's Test Activity* for all adult family members is cofacilitated by the



counselor and the identified change agent. This session follows the joint family session and provides information about HIV risk behaviors and encourages HIV testing. The facilitator will then conduct individual or couples pre-test counseling in a private space, test family members who agreed to test, conduct detailed post-test counseling for the tested members, and offer appropriate referrals. Family members will be encouraged to test as a group or as couples. Formative data indicate that generally, respondents perceived the family-based counseling and testing approach as feasible and acceptable, and positively considered receiving the intervention at home instead of at health-care facilities.

A PIMA point-of-care CD4 test will be conducted for all HIV-positive adults to facilitate linkages to care. Adult family members who have tested will be counseled on their results and, if necessary, referred to local health-care facilities. The benefits of disclosure and the importance of treatment and care will be emphasized in discussions, and adult family members will be encouraged to share their results with other adult family members. Our formative research identified some concern about inadvertent disclosure of HIV test results to family members and the community. The intervention is sensitive to this concern and allows for multiple permutations in terms of disclosure (within couples or the larger family group and at different time points). However, disclosure was also identified as a potential positive outcome of the intervention in that it may foster supportive family relationships and facilitate family cohesion.

Change Agent Training

This session is configured differently dependent on family composition. In younger and mixed families, this will involve training the change agent/s to cofacilitate the family health education and testing session with children. Change agents will be trained by counselors/facilitators on several activities or materials, namely, the body map, health promotion cards, and the *Let's Test* poster for children (38). The *Let's Test* activity intends to provide age-appropriate health and illness information to young children in an engaging and informative way. It is a story telling aid that facilitates discussion on health and illness between change agents/parents and their children. Health promotion cards aim to reinforce positive living messages. The activity is supported by a set of 20 playing cards (10 pairs). The cards include images and health promotion messages. A second facilitator will test any adults who did not test during the first session and encourage disclosure among those who did not disclose.

For older and mixed families (during sessions two and four respectively), change agents/parents will undergo training on intergenerational communication, the key change mechanism in the intervention for addressing issues with adolescents. Our formative research revealed that adolescents are open to communicating with their parents, but that several barriers exist. Many adolescents discussed difficulty initiating conversations but parents also noted barriers to intergenerational communication, such as cultural taboos about discussing sex. Through the formative work and stakeholder consultations, we recognized that a focus on intergenerational communication that would support parents/caregivers to develop general communication skills with adolescents in the household and equip them to deal

with sensitive issues, including HIV and disclosure, would be the best causal pathway to effect change in the outcome measures.

When designing the intergenerational communication session, we incorporated common elements of successful intergenerational communication studies (68), including the *Let's Talk* intervention, which has been culturally adapted for South Africa (61). The interactive 90-min session addresses:

1. *Communication skills:* The counselor will discuss various strategies to improve both the quality and quantity of communication with adolescents, including developing listening skills, such as open-ended questions, active/reflective listening, providing verbal support and non-judgmental responses, and rephrasing. Change agents/parents will be provided with the opportunity to role-play some of these critical skills.
2. *Fostering positive relationships between parents and adolescents through identifying and positively reinforcing good behaviors.* Vignettes will be used to help change agents identify examples of opportunities for positive reinforcement and offer an example of a positive parenting strategy.
3. *Talking about sensitive topics, including HIV:* The counselor will describe strategies to discuss sensitive topics with adolescents, using role-plays and vignettes. This component aims to identify social norms, create awareness, and provide parents with skills to communicate difficult issues.

Homework activities tailored to different age categories of adolescents are designed to allow parents the opportunity to implement what they have learnt with their adolescents outside of the training environment. Such homework exercises are supported by research evidence that indicates these activities can increase family communication about sexual issues and successfully delay sexual debut among early adolescents (69).

Finally, the change agent/parent will also be trained on how to encourage their adolescents to test for various health conditions including HIV, using *The Let's Test* activity for adolescents.

Testing of Children and Adolescents

For young and mixed families, at the next session with the family, the change agent will lead a session on child health education and testing for all children 11 years and younger, cofacilitated by the counselor. Children will be tested for HIV with their parent's consent and their assent, according to the ethical-legal framework for HIV counseling and testing in South Africa (57). Children over 5 years old will receive point-of-care CD4 testing, and all HIV-positive children will be referred to local health-care facilities for clinical assessment, care, and treatment. If a child under 5 years old tests HIV-positive, the parent and child will be referred to the local health-care facility for CD4 testing, clinical assessment care, and treatment. Information about the importance of antiretroviral therapy, accessing timely treatment, and the value of social support will be provided to parents of all tested children. Disclosure of the child's HIV status and the process by which this may happen will be discussed with the parent/guardian and facilitated using the *Disclosure Safety Hand* activity (38). Previous research has identified that one of the key barriers in disclosure to children is concern that they may disclose

to others (34, 38). For this reason, this is an interactive activity for facilitated disclosure with children that encourages them to disclose to and have discussions about their (or their parent's/family member's) status with those trusted people specified on the hand only. The facilitator will train the change agent on the *Disclosure Safety Hand*.

For mixed and older families, within 2 weeks of the intergenerational communication training of the change agent/parent, a health education session and HIV testing session for adolescents will be conducted. This *Let's Test* session will be led by the parent/change agent and facilitator.

Adolescents aged 12 years and older are permitted to consent independently for HIV testing (57). The session will emphasize adolescents' rights to privacy and confidentiality of the testing process and their test result, including any information that may emerge in counseling. However, the benefits of disclosure and the possibilities of family support will be discussed during the pre-test information session. Our family-based counseling and testing intervention strongly focuses on supporting disclosure within families and facilitating open and accurate intergenerational communication on sex and HIV. Counseling and testing will be provided to all adolescents in the household as a group. Age-appropriate pre-and post-test counseling messaging will be provided to adolescents in groupings of their preference (individually, pairs, or groups), although they will be encouraged to test as a pair or group rather than individual for mutual support. Adolescents who are HIV-negative will be provided with age-appropriate risk reduction and repeat testing counseling messages. A PIMA point-of-care CD4 test will be conducted in the household in order to facilitate linkages to care. The benefits of disclosure and the importance of treatment and care will be emphasized.

Follow-up for High-Risk Families

The final session is an optional session for high-risk situations available to all three family configurations. High-risk targets will include any households with HIV-positive children aged 0–11 years old; HIV-positive adolescents where disclosure is an issue; individuals with suicidal ideation or a crisis as a result of testing situation; and households where there are other important risks, such as conflict, domestic violence, substance abuse, serious mental health issues, among others.

Where a child has tested HIV-positive on previous visits, we will use this session to ensure that all referrals for follow-up health care, treatment, and support were addressed. If referrals have not been taken up, we will explore the reasons for this and provide strategies and support for how this could be addressed. We will also provide additional communication skills to the parent/caregiver on how to observe and engage with the emotions and feelings of the HIV-positive child.

In the case of adolescents who test HIV-positive and have not disclosed their status, this follow-up session will provide an additional opportunity for adolescents and parents/caregivers to discuss any barriers that may be preventing them from doing so. Staff will address this through facilitated discussions between generations, reinforcing some of the positive parent communication skills addressed in previous sessions. Parents/

caregivers will be encouraged to take the lead in addressing these issues. Follow-up education and support on the benefits of disclosure, treatment, and adherence will be provided to children and adolescents.

This follow-up session also allows us to make a final assessment of family needs and necessary referrals to appropriate services. As we work with households, we may encounter families who may be living in extreme poverty with low food security, or where children are not schooling or we may identify medical needs in children. In all these instances, depending on the issues, referral will be made to local primary health-care clinic, education, and social welfare groups, non-governmental and community-based groups working in study communities, and with whom we have referral networks.

Over and above these situations, we may also encounter a range of risk situations in these families. These may include relationship problems/conflicts, domestic violence, feelings of hopelessness, and suicidal thoughts without serious intent or plans, as well as serious mental health concerns. We will have mechanisms to promptly identify and respond to these through our fieldwork, and appropriate referrals through our networks described above will be made. Management of severe mental health issues and suicide ideation will include referrals to a psychiatric nurse, clinical psychologist, or psychiatrist. As with previous studies, we keep careful documentation of all referrals and any adverse events and report them annually at IRB recertification.

DISCUSSION

This paper described the three phases of intervention development and detailed the various components of the family-based counseling and testing intervention. We end with a discussion of a few issues that may be challenging, as we implement the intervention.

This intervention aims to test all family members for HIV, encourage disclosure, and facilitate linkage to care. In the main, these aims are associated with positive outcomes, such as improved prevention, care, and treatment, and better social support from friends and families. However, some studies have documented potential negative consequences of HIV testing and disclosure. In relation to children younger than 11 years old, key concerns may include that children are too young, they may endure negative emotional consequences as a result of disclosure of their own or their parents' HIV status, and they may inadvertently or otherwise disclose to others outside the family (34, 38, 70). With adults, disclosure of a positive HIV status may also result in disruptions to relationships with families and communities, social isolation and ostracism, abuse, violence, divorce, and rejection (71). In cases where facilitators identify the potential for negative consequences, an additional session (for high-risk situations) will be conducted.

The key to unlocking this intervention rests on communication between adults in the household and adolescents. A primary challenge with this is that many of the communities targeted for HIV-prevention interventions, including ours, are influenced by traditional mores and values, which view sex as a taboo subject that should not be openly discussed (72, 73). Previous research in

a South African rural Zulu community revealed that discussions about sex between younger and older people are largely forbidden, and that, when it does occur, such discussion is obscured by the use of polite language, euphemisms, and gestures (72). A qualitative study with parents and adolescents in Cape Town also found taboos challenged family interactions about sex (73). Further, an absence of parent–adolescent communication about sex reinforced taboos about discussing sex (72, 73).

In such contexts, sex is traditionally only discussed with adolescents when they reach puberty or in preparation for marriage, as rites of passage by an extended family member of the same gender, rather than from parents or caregivers (72, 74, 75). However, these traditions have largely disintegrated, leaving an important gap in terms of the sex education of youth (72, 74). Nevertheless researchers in India, which is characterized by similar conservative cultural mores regarding adolescent sex, found that parents were open to discussions with their children and that training may help mitigate some of the discomfort in discussing sensitive issues (76). This is also supported by evidence from our formative research with adults. This suggests that cultural prohibitions are not unchangeable and may be addressed through appropriately designed interventions that promote open and clear communication about sensitive issues, including HIV and AIDS (76). Our intergenerational session emphasizes parents' critical role in informing their adolescents about sex, including about their perspectives and values. Resonating with our formative research, which found that adolescents are receptive to communication with their parents, research also indicates that adolescents want to discuss sex with their parents but that parents need improved communication skills (77, 78).

In contrast to this conservative sociocultural milieu, South Africa has a progressive legal framework which enables adolescents 12–17 years old to access a range of sexual and reproductive health services including contraceptives, treatment for sexually transmitted infections, and testing for HIV (79). Related to their right to independently consent to various health services, adolescents have a right to privacy of their test results (80). However, this right to privacy is limited by mandatory reporting obligations, which require that all sexual offenses against a child must be reported (80). These legal provisions serve as both barriers and facilitators to the implementation of the family-based counseling and testing intervention.

Since HIV testing and disclosure occur as part of a research study, all children below 18 years old require parental consent to participate (57). As such, parents or guardians who provide consent for their children's participation in the study may reasonably expect to be informed of their child's personal health information (57). However, the South African legal framework provides that adolescents 12–17 years old have the right to privacy regarding certain therapeutic health interventions that form part of the HIV-prevention study, and, therefore, researchers cannot disclose such information to parents/guardians (80). These limits are spelled out in the parental informed consent forms for children's participation in this study. However, given that a central aim of the study is disclosure of HIV test results, trained counselors will

provide support, including practice and feedback through role-playing, and encouragement to adolescents to disclose their HIV status to a family member or trusted adult.

On the other hand, adolescents who are engaged in behaviors that make them vulnerable to HIV infection may be reluctant to discuss these behaviors with their parents and may have legitimate concerns regarding negative reactions from their parents. Therefore, protecting adolescent rights to privacy may encourage them to test for HIV, but create challenges for disclosure.

A further limit to adolescents' privacy rights is the requirement for mandatory reporting of all sexual offenses committed against children, including consensual sexual activity (81). However, recent amendments to the Sexual Offences Act, which decriminalize underage consensual sex, narrows this limit to privacy by restricting the offenses that need to be reported. The impact on adolescents in this study, is that their privacy will be limited only in circumstances where, "the activity was non-consensual; the younger participant was 12–15 years old and the older participant 16–17 years, and the age difference between them was more than 2 years at the time of the act; and the younger participant was 12–15 years old and their partner was an adult" (79). Such limits to confidentiality will be spelled out to parents and adolescents during the informed consent process.

CONCLUSION

Expanding our successful home-based counseling and testing model to a comprehensive family-based model could have significant impact in our high HIV prevalence context. Testing families could increase the identification of HIV-positive children before they become sick enabling early linkage to care and for them to gain larger and longer benefits from antiretroviral therapy. HIV testing of all family members, disclosure, and linkage to care are critical to ensuring that infected family members are enrolled into care timely in order to achieve positive treatment outcomes (21, 82). Our approach treats the family as a social environment (not just a location for service delivery), through which HIV prevention, treatment, adherence, and support could be achieved (50). Our intervention targets families and includes components to improve uptake of testing among children and adolescents, facilitates HIV disclosure and support among families, and encourage intergenerational communication, including regarding sexual risks for HIV. We address the complexities of HIV disclosure and communication between family members through the provision of various tools and strategies (12, 25).

In the next phase of the study, we plan to address study Aims 2 and 3, which align with Steps 5 of the 6SQuID the model – testing and refining the intervention – and Step 6 – collecting sufficient evidence of effectiveness to proceed to rigorous evaluation. In this next phase, the intervention will be piloted with 50 families, using a combination of quantitative and qualitative methods to evaluate the feasibility and acceptability of the model (Aims 2 and 3). This Phase will also help identify any further unanticipated implementation challenges.

AUTHOR CONTRIBUTIONS

HR, ZE, and TR conceptualized the paper. HR and ZE developed the first draft. TR, DW, LK, RB, and CC made comments/inputs on the manuscript. HR and LK analyzed formative qualitative data. DW facilitated the consultation on development of the model.

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Conflict of Interest Statement: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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APPENDIX

TABLE A1 | Summary of child and adolescent family-based interventions conducted in South Africa.

| Reference | Focus | Ages of participants | Intervention description |
|------------------------------|---|---|--|
| Bhana et al. (83) | To support families in promoting the health and psychosocial well-being of youth living with perinatal HIV infection | Children: 10–14 years old Caregivers: Age is not indicated | Six sessions over 3 months Session curriculum involved HIV-infected youth and primary caregiver and other family members. Family group activities and separate parent and child group activities. Cartoon-based storyline was used |
| Bogart et al. (61) | Parent-child communication about HIV and sexual health and parent condom use self-efficacy and behavior | Parents of 11–15 year olds | Five weekly 2-h group sessions with parents of youth. Topics included building relationship with your child, talking about sensitive topics, talking about HIV and condoms and building assertiveness skills |
| Rochat et al. (38) (Amagugu) | Development of a family-centered, structured intervention to support mothers to disclose their HIV status to their HIV-negative school aged children | Children: 6–9 years Mothers | Six sessions using an intervention package that comprised printed materials, therapeutic tools, and child-friendly activities and games to support age-appropriate maternal HIV disclosure. (i) Either a lay counselor or community health worker (CHW) offers assistance and trains the mother toward disclosure, (ii) the mother undertakes disclosure with the child on her own, (iii) the mother takes the child to the clinic independently, and (iv) completes a care plan and custody plan without the counselor being present. |
| Bell et al. (84) (CHAMPSA) | To test the effectiveness of the CHAMP among black South Africans in South Africa. The CHAMPSA intervention targeted HIV risk behaviors by strengthening family relationship processes as well as targeting peer influences through enhancing social problem solving and peer negotiation skills for youths | Children: 9–13 years Adult caregivers | Intervention was delivered on weekends by community caregivers trained as facilitators Intervention was annualized and a step-by-step facilitator manual was developed to guide the facilitators. The manual introduced skills through dramatic depiction in a cartoon-based storyline |
| Bhana et al. (85) | Participatory adult education principles, participatory cartoon-based narrative methods to deliver its content | Adults – age is not specified | Delivered through a series of manual-based sessions to groups of families with pre-adolescent children and evaluated using a treatment vs. a no-treatment repeated measures design. Small groups were used to deliver the intervention. An open-ended participatory approach was used |



Perspectives and Practice of HIV Disclosure to Children and Adolescents by Health-Care Providers and Caregivers in sub-Saharan Africa: A Systematic Review

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Background: Sub-Saharan Africa (SSA) has the highest prevalence of HIV globally, and this is due to persistent new HIV infections and decline in HIV/AIDS-related mortality from improved access to antiretroviral (ART) therapy. There is a limited body of work on perspectives of health-care providers (HCPs) concerning disclosing outcomes of HIV investigations to children and adolescents in SSA. Most studies are country-specific, indicating a need for a regional scope.

Objective: To review the current literature on the perspectives of HCPs and caregivers of children and adolescents on age group-specific and culture-sensitive HIV disclosure practice.

Methods: Electronic database search in PubMed, Google scholar, and the University of South Florida Library Discovery Tool (January 2006 up to February 2016). Further internet search was conducted using the journal author name estimator search engine and extracting bibliographies of relevant articles. Search terms included “disclosure*,” “HIV guidelines,” “sub-Saharan Africa,” “clinical staff,” “ART,” “antiretroviral adherence,” “people living with HIV,” “pediatric HIV,” “HIV,” “AIDS,” “health care provider,” (HCP), “caregiver,” “adolescent,” “primary care physicians,” “nurses,” and “patients.” Only studies related to HIV/AIDS disclosure, HCPs, and caregivers that clearly described perspectives and interactions during disclosure of HIV/AIDS sero-status to affected children and adolescents were included. Independent extraction of articles was conducted by reviewers using pre-defined criteria. Nineteen articles met inclusion criteria. Most studies were convenience samples consisting of combinations of children, adolescents, HCPs, and caregivers. Key findings were categorized into disclosure types, prevalence, facilitators, timing, process, persons best to disclose, disclosure setting, barriers, and outcomes of disclosure.

Conclusion: Partial disclosure is appropriate for children in SSA up to early adolescence. Caregivers should be directly involved in disclosing to children but they require adequate disclosure support from HCPs. Full disclosure is suitable for adolescents. Adolescents prefer disclosure by HCPs and they favor peer-group support from committed peers and trained facilitators, to reduce stigma. HCPs need continuous training and adequate resources to disclose in a patient-centered manner.

Keywords: HIV disclosure, children and adolescents, health-care providers, caregivers, sub-Saharan Africa, ART adherence

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INTRODUCTION

The HIV pandemic is one of the most severe public health challenges facing the world to date. This pandemic has grave economic implications, especially in high prevalent regions like sub-Saharan Africa (SSA) (1, 2). The global HIV burden is estimated at 36.9 million cases; by the end of 2014, approximately 2 million new cases and 34 million deaths were attributed to AIDS-related causes (3–6). Recent data indicate that the top 10 ranking of HIV/AIDS cases by country is populated by countries in SSA (5, 6). In 2015, SSA contributed to 70% of new cases globally (5, 6). Factors contributing to the prevalence of HIV in SSA include improved access to antiretroviral (ART) medications and the resultant decline in mortality, while new infections from HIV/AIDS persist (1, 7).

Majority of new HIV infection cases occur in low- and middle-income countries that lack properly defined guidelines or resources to equip HCPs (3, 8, 9). HIV disclosure may be one of the critical links between new infections and the sustained high prevalence in SSA (10, 11). Inadequate health-care provider (HCP) training in HIV disclosure and testing services appear to contribute to new cases. Unfortunately, limited body of work exists on the prevalence and practice of disclosure by HCPs in SSA (7). Over the last 15 years, there has been a 35% decrease in global HIV infections and a 58% decrease among children, yet more than 54% of children currently infected may be unaware they have the disease (6, 12). A study on resource-limited countries that had available disclosure rates (Ghana, Kenya, and Ethiopia) reported rates that varied from 11 to 38% (11, 13, 14). This variability is consistent with studies in resource-rich countries where disclosure rates to children range widely from 10 to 77% (15–17). Furthermore, HIV disclosure practices in SSA remain complex due to the immense influence of culture, politics, and limited HIV surveillance (5, 10, 18). Disclosure rates in high prevalence regions need to be evaluated and improved drastically in a timely manner as HIV disclosure may be a key factor in reducing the risk of acquiring new infections, adherence to ARTs, and practice of safe sexual behaviors (7, 10, 19, 20).

Taken together, the incidence of HIV infection in SSA may be reduced by understanding the perspectives and roles of HCPs and caregivers in disclosing laboratory HIV test outcomes to children and adolescents in this region. In addition, studies in this region are country-specific; therefore, evaluating the perspectives of HCPs and caregivers across countries may provide more insight to achieve more reduction in new HIV infections. To determine the perspectives of HCPs and caregivers on age group-specific and culturally sensitive HIV disclosure practices in SSA, a systematic review of the perspectives and current patterns of HIV disclosure among HCPs and caregivers of children and adolescents was conducted.

METHODS

We searched for quantitative, qualitative (focus groups, interviews, and surveys), and mixed methods studies on HIV disclosure involving HCPs and caregivers in SSA from January 1, 2006 to February 28, 2016. English language restriction was

imposed. Study participants included combinations of children and adolescents, HCPs and caregivers, or only caregivers or HCPs. Disclosure was categorized as full disclosure, partial disclosure, and non-disclosure (12, 21). Full disclosure is complete disclosure of HIV status with the term "HIV" appropriately used (11, 12, 21). In this case, the potential causes, transmission, and impact of the disease were discussed and treatment was clarified. Partial disclosure was performed similarly to full disclosure but the terms "HIV" or "AIDS" were excluded despite describing the morbidity and mortality from the disease (12, 21, 22). Other aspects present in full disclosure may also be excluded, for example, counseling (20, 21). Non-disclosure signifies no disclosure. In this case, individuals are not provided any information about their positive HIV status (12, 21).

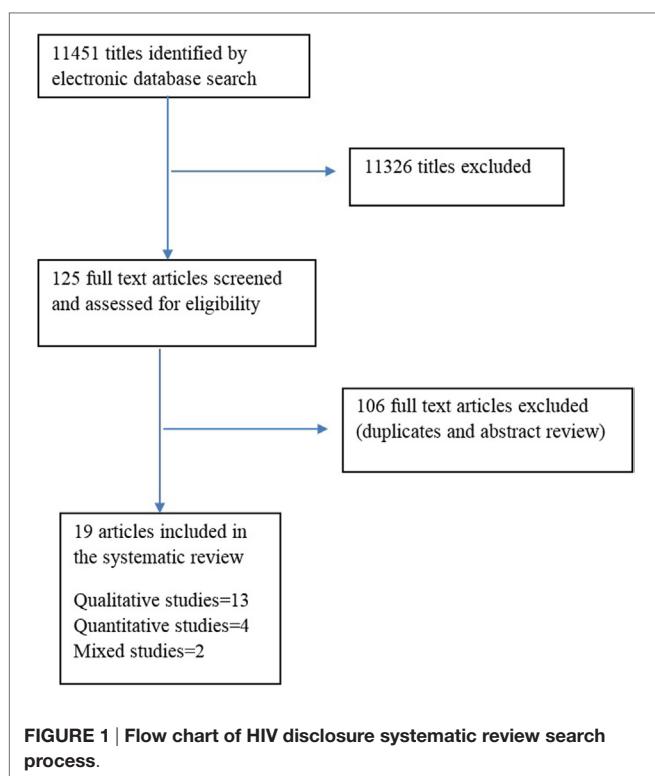
The term "health-care providers" refers to health-care professionals, such as clinical staff, primary care physicians, nurses, midwives, and any health personnel, providing patient care in a clinical setting. A caregiver includes parents, family members, or individuals caring for a child or adolescent living with HIV/AIDS in a non-clinical/professional capacity. Articles were selected on application of the following inclusion criteria: social science work that examined HIV disclosure through qualitative or quantitative studies and mixed methods that clearly described perspectives and interactions among HCPs, caregivers, and infected children and adolescents.

Search Strategy and Search Procedure

A computer-assisted systematic review was conducted, and extraction of articles was independently performed by the three authors who have expertise in community and family health, global health, epidemiology, and HIV management. Disagreements between reviewers were resolved by consensus. Three major electronic databases were searched using dates January 1, 2006 to February 28, 2016. These bibliographic databases included PubMed, Google Scholar, and the University of South Florida (USF) Library Discovery Tool. For USF Library Discovery Tool and PubMed, the term "HIV AIDS disclosure" was searched, then the Boolean operator and last set of terms "health-care provider" OR "caregiver" OR "patient" OR "adolescent" were added. Finally, the inclusion criteria were applied.

For Google Scholar, the term "HIV disclosure" was searched then "AIDS disclosure" and "sub-Saharan Africa" were added. Next, the Boolean operator and keyword "health-care providers" OR "caregiver" OR "patient" OR "pediatric" OR "health-care professionals" were added. Finally, the inclusion criteria were applied. An additional internet search was conducted in Journal Author Name Estimator database (JANE) using the proposed search terms and their variants. Additional articles were cross referenced for further review of all the articles, and some articles were excluded either because they did not meet the inclusion criteria of the review or they were duplicates. **Figure 1** shows a flow diagram of the search process.

Variants of keywords for HCP, caregiver, HIV and AIDS, and disclosure were also used. The search strategy was limited to articles that were accessible through the USF library. Full-text articles of all selected studies were retrieved, and if an article was selected, the bibliographic references were examined for



additional relevant studies. Caregivers, HCP, and patients were combined with the use of the Boolean operator “OR.” The above searches, based on the two main interest HIV/AIDS disclosure and SSA, were combined using the Boolean operator “AND.”

Data Extraction

A data extraction sheet was developed by two of the authors (Oluyemisi Aderomilehin and Angella Hanciles-Amu) and reviewed by the third author (Oluwatobi Ohiole Ozoya). A total of 19 articles met the inclusion criteria. First author, year and title of publication, country of study, population characteristics, study design, and theme topics were included in the sheet (**Table 1**). A summary of the results from included studies that were relevant to perspectives and practice of HIV disclosure to children and adolescents are detailed in **Table 2**.

RESULTS

All studies in the final selection included various types of studies ranging from 13 qualitative study design, including interviews and focus groups (23, 24, 27, 28, 30–32, 34–36, 39, 40), to 4 quantitative study design (21, 26, 33, 37) and 2 mixed methods design (25, 38). The 19 articles included studies conducted in 10 SSA countries. The sample sizes were variable, ranging from 21 to 858 (median 79). Most studies utilized small samples, with the largest four studies including 40 HCPs (34), 394 caregivers (26), and 858 children and adolescents (38). Three studies included only HCPs (32, 34, 40), and five studies included only caregivers (29–31, 37, 39). One study included both HCPs and community members

with focus on HIV disclosure and discussions about grief (21). The three studies that included only HCPs-provided information on types of disclosure in practice and the most suitable person and setting to disclose (32, 34, 40). Some of the studies included caregivers living with HIV and others without HIV. Caregivers were involved in the care of HIV-positive children, adolescents, or family members (29–31, 37, 39). Estimation of disclosure prevalence was limited to two articles (37, 38). The studies explored perspectives on disclosure types, prevalence, facilitators, timing, process, persons best to disclose, disclosure setting, barriers, and outcomes of disclosure. This is described below.

Types and Prevalence of HIV Disclosure

Disclosure was defined by mention of “HIV or AIDS” when explaining the illness to infected children and adolescents, implying full disclosure, otherwise, partial disclosure is the case (21, 24, 26, 33, 34, 38, 40). Non-disclosure was present in two studies where the children were neither aware of the illness nor the reason for taking medications (33, 39).

Only two studies reported on prevalence of HIV disclosure estimated at 30.9% among infected children and 68.1% among infected adolescents (37, 38). In these studies, the infected children and adolescents were aware of their HIV infection, indicating full disclosure. Three other qualitative studies reported less than half of caregivers who had disclosed to their children (25, 29, 39). Two studies reported non-disclosure by 50% of caregivers and simultaneously reported partial disclosure by 15–24.6% of caregivers (33, 39).

Facilitators and Timing of Disclosure Type

Major facilitators for caregivers in initiating disclosure was knowledge of availability of ART therapy (29), view of disclosure as the right of the child and adolescent (29, 41) when adhering to ART therapy was a potential or actual problem for the infected child or there was frequent visits to health facilities despite absence of overt illness (37, 39). Other facilitators to HIV disclosure include persistent inquiries by the HIV-positive child or adolescent (36, 37), presence of chronic illness in the child or a family member (31, 39), or discovery at routine antenatal clinic attendance by infected mothers (36). A common predictor of the timing of disclosure to children was the age of the child; the age for disclosure varied widely among the studies and ranged from 5 to 15 years (21, 26, 29, 31, 33–37). Studies that reported a specific age of disclosure to children included 5 years (36), 7 years (31), above 10 years (33, 34, 37), 12 years (29), and 15 years (26, 35). Three studies distinguished age at full disclosure as above 10 years (34, 36), 14 years (21), and 15 years (26). Two studies specifically reported partial disclosure by caregivers at ages <10 years (21, 34, 36) and 15 years (26, 35).

Process of HIV Disclosure

Irrespective of whether it was a HCP or caregiver being interviewed, some of the studies indicated that the process of disclosure can be complex (23, 24, 26, 29, 37–40). One study reported caregivers who perceived disclosure as a single event (30). Only one study reported different phases of disclosure that included pre-disclosure, disclosure, and post-disclosure phases

TABLE 1 | Study characteristics.

| Study | Title | Location | Population sample size | Study design and methods | Key findings of data collection |
|--------------|----------------------|----------------------|--|--|---|
| 1 | Mburu et al. (23) | Zambia | 223 • 164 adolescents • 21 parents/caregivers • 38 HCPs | Qualitative (interviews and focus group discussions) | • Barriers • Outcomes of HIV disclosure |
| 2 | De Baets et al. (21) | Zimbabwe | 195 • 131 community members • 64 HCPs in primary/rural health centers | Quantitative (anonymous survey) | • Age of disclosure • Best person to disclose to child |
| 3 | Demmer (24) | South Africa | 25 • 13 caregivers (mothers/females with a biological child sick from HIV/AIDS) • 12 HCPs of children and families living with HIV/AIDS. | Qualitative (in-depth interview and semi-structured interview) | • Barriers to disclosure |
| 4 | Gyamfi et al. (25) | Ghana | 118 • 118 caregivers of HIV-infected children and adolescents. • 10 key informants—HCPs and volunteer workers | Mixed method (quantitative and qualitative) | • Best person to disclose • Proportion • Benefits of disclosing |
| 5 | Kajubi et al. (26) | Uganda | 394 • 394 children and their caregivers | Quantitative (cross-sectional survey) | • Disclosure communication pattern • Age (full/partial disclosure) |
| 6 | Kidia et al. (27) | Zimbabwe | 46 • 31 perinatally infected adolescents • 15 HCPs | Qualitative (in-depth interviews with adolescents; focus groups with HCPs) | • Best person to disclose • Disclosure setting • Support |
| 7 | Midtbo et al. (28) | Botswana Tanzania | 14 • 12 adolescents • 2 HCPs 19 • 16 adolescents • 3 HCPs | Qualitative (interviews and observation) | • Stigma • Coping following disclosure |
| 8 | Moodley et al. (29) | South Africa | 174 • caregivers and children living with HIV | Qualitative (semi-structured interviews) | • Disclosure proportion • Age of child at disclosure • Best person • Facilitators • Barriers |
| 9 | Kiwanuka et al. (30) | Uganda | 40 • Primary caregivers of HIV-infected children receiving HIV care but ignorant of their HIV status | Qualitative (in-depth interviews) | • Disclosure-single event/process? • Benefits and barriers |
| 10 | Lorenz et al. (31) | Uganda | 28 • Caregivers of HIV-positive children | Qualitative (semi-structured interviews) | • Facilitators to testing child • Age at disclosure • Barriers • Type of disclosure • Support |

(Continued)

TABLE 1 | Continued

| Study | Title | Location | Population sample size | Study design and methods | Key findings of data collection | |
|--------------|------------------------------|--|-------------------------------|--|--|--|
| 11 | Beima-Sofie et al. (32) | Using health provider insights to inform pediatric HIV disclosure: a qualitative study and practice framework from Kenya | Kenya | 21 • HCPs | Qualitative (interviews) | • HCPs disclosure practices • Family-centered disclosure • Best Person to disclose • Outcomes of disclosure |
| 12 | Mumburi et al. (33) | Factors associated with HIV-status disclosure to HIV-infected children receiving care at Kilimanjaro Christian Medical Centre in Moshi, Tanzania | Tanzania | 236 • 211 parents or caregivers and their children • 25 HCPs | Quantitative (cross-sectional with structured questionnaires) | • Proportion of disclosure • Age of disclosure • Caregiver support |
| 13 | Myer et al. (34) | Health-care providers' perspectives on discussing HIV status with infected children | South Africa | 40 • Health-care providers at a large pediatric clinic | Qualitative (semi-structured interviews) | • Transition from partial disclosure • To full disclosure in children • Best person to disclose |
| 14 | Corneli et al. (35) | The role of disclosure in relation to assent to participate in HIV-related research among HIV-infected youth: a formative study | Democratic Republic of Congo | 72 • 19 adolescents living with HIV • 36 parents and caregivers • 17 HCPs | Qualitative (semi-structured interviews) | • Age of disclosure to children |
| 15 | Gachanja and Burkholder (36) | Model for HIV disclosure of a parent's and/or a child's illness | Kenya | 34 • 12 children (7 HIV+ and 5 HIV– between 8 and 17 years) • 16 HIV+ parents/caregivers • 6 HCPs | Qualitative | • Facilitators/motivation to disclose • Age of disclosure • Associated emotions • Benefits • Negative outcomes |
| 16 | Odiachi and Abegunde (37) | Prevalence and predictors of pediatric disclosure among HIV-infected Nigerian children on treatment | Nigeria | • 110 • Parents/caregivers of HIV-infected children | Quantitative (semi-structured interview) | • Prevalence • Age of disclosure • Facilitators • Barriers |
| 17 | Toska et al. (38) | Sex and secrecy: how HIV-status disclosure affects safe sex among HIV-positive adolescents | South Africa | 858 • Adolescents and their caregivers | Mixed methods [qualitative (interviews, focus group discussions and observations with 43 HIV-positive teenagers and their HCPs; quantitative interviewed using standardized questionnaires)] | • Prevalence of disclosure • Benefits • Barriers |
| 18 | Vaz et al. (39) | Patterns of disclosure of HIV status to infected children in a sub-Saharan African setting | DR Congo | 201 • Primary caregivers of children 5–17 years old in an HIV pediatric care and treatment program | Qualitative (structured interviews) | • Proportion of disclosure • Facilitators • Benefits • Caregiver support in disclosure |
| 19 | Watermeyer (40) | 'Are we allowed to disclose?': a health-care team's experiences of talking with children and adolescents about their HIV status | South Africa | • 23 HCPs | Qualitative (focus groups) | • Barriers to disclosure • HCPs disclosure practices |

of disclosure to children (36). Here, the parents of infected children were counseled to anticipate and resolve questions the children may have prior, during, and following disclosure (36). Some other studies reported caregivers who preferred to receive counsel from HCPs or HIV counselors before disclosing

(29, 31, 39). From the time of diagnosis, some participants adopted partial disclosure till the children were perceived as ready to receive full disclosure (21, 34, 36). Only one of the studies clearly described the post-disclosure phase (36). In the post-disclosure phase, some of the children in the study had

TABLE 2 | High level summary of selected articles.

| | | |
|--|--|--|
| Mburu et al. (23) Barriers and outcomes of HIV disclosure <ul style="list-style-type: none"> • Barriers – local norms that deter parents from communicating with their children about sexuality; fear of HIV stigma; and an underlying presumption that adolescents would not understand the consequences of a HIV diagnosis on their lives and relationships • Outcomes: individual level – anxiety, depression, and self-blame after disclosure. Interpersonal level – disclosure created opportunities for adolescents to access adherence support and other forms of psychosocial support from family members and peers. At the same time, it occasionally strained adolescents' sexual relationships, although it did not always lead to rejection | Watermeyer (40) Barriers to disclosure and HCPs disclosure practices <ul style="list-style-type: none"> • Barriers – complexity of the disclosure process, confusion, hesitancy, and ethical dilemmas regarding disclosure practices • Disclosure practices among HCPs – tensions were noted within the team which seem linked to professional hierarchies. Counselors and nurses preferred an indirect approach of encouraging caregivers to disclose to their children and providing psychosocial support, while doctors tended to become more directly involved in disclosing to children out of a sense of duty, legal responsibilities, and knowledge of the child's rights | Demmer (24) Barriers to disclosure <ul style="list-style-type: none"> • Stigma to HIV/AIDS in South African society made disclosing the child's HIV status very difficult. There was concern about the reaction of partners and family members. Women were afraid of being blamed and abandoned. Stigma resulted in delayed testing of child and delayed treatment. Conspiracy of silence surrounding the child's HIV status prevailed in many households. Teachers and principals were usually not informed about the child's HIV status for fear of discrimination • Perceived immature cognitive development of child, non-disclosure to most of the children who were under 10 years of age • Caregiver anxiety over future disclosure to their child |
| De Baets et al. (21) Age of disclosure and Best person to disclose to child <ul style="list-style-type: none"> • Age of disclosure – partial disclosure from the age of 10.8 (± 4.2) years and full disclosure from the age of 14.4 (± 4.5) years. HCPs openness to disclosure – compared to community members, health-care workers were significantly more open to full disclosure and disclosure at a younger age, but were slightly less open to discussing grief • Best/preferred person to disclose – HCP in 56% of the responses or family member in up to 52%. The most commonly preferred family members – father's sister (up to 37%) and grandmother (up to 40%) rather than the partner (up to 15%). Southern African family dynamics may hinder a mother initiating HIV disclosure and discussions about grief, even though she is traditionally present during HIV diagnosis, counseling, and health education. A more culturally adapted approach than the standard western "couple approach" may thus be required | Gyamfi et al. (25) Best person to disclose, proportion, benefits of disclosing and elements needed in caregiver support <ul style="list-style-type: none"> • Most appropriate person to disclose to infected child – caregiver (47.5%) with the help of the HCP, caregiver alone (34.7%), and HCP (17.8%) • Proportion of disclosure – to infected children and adolescents (48.8%), to mother of child (25.6%), and other family members (25.6%) • Benefits of disclosure: yes (89%), no (11%). Most (46.6%) – improved adherence to medication and 31.4% – reported it promoted healthy and responsible sexual behavior when the child became an adolescent; 16.9% – made the children and adolescents more responsive to their health needs; and 5.1% – helped improve the mental and psychological health of the caregiver and/or the child • Support elements: the main supports required by caregivers during disclosure included biomedical information, emotional and psychological support, and practical guidelines regarding disclosure | Kajubi et al. (26) Disclosure communication pattern and age (full/partial disclosure) <ul style="list-style-type: none"> • 79.6% of the caregivers reported that they explained to the children about the medicines, but only half (50.8%) of the children were aware the medicines were for HIV. • Older children aged 15–17 years were less likely to communicate with a caregiver about the HIV medicines in the preceding month (OR 0.5, 95% CI 0.3–0.7, $p = 0.002$). Children aged 11–14 years (OR 6.1, 95% CI 2.8–13.7, $p < 0.001$) and 15–17 years (OR 12.6, 95% CI 4.6–34.3, $p < 0.001$) were more likely to know they were taking medicines for HIV compared to the younger ones • The least common reported topic of discussion between children and caregivers was "what the medicines are for" while "the time to take medicines" was by far the most mentioned by children |
| Kidia et al. (27) Best person to disclose, disclosure setting and support <ul style="list-style-type: none"> • Health-care workers encouraged caregivers to initiate disclosure in the home environment • In contrast, many adolescents preferred disclosure to take place in the presence of health-care workers at the clinic because it gave them access to accurate information as well as an environment that made test results seem more credible • Adolescents learned more specific information about living with an HIV-positive status and the meaning of that status from shared experiences among peers at the clinic | Midtbo et al. (28) Stigma and coping following disclosure <ul style="list-style-type: none"> • HIV-status disclosure enabled adolescents to engage effectively with their ART treatment and support groups, which in turn provided them with a sense of confidence and control over their lives • Although the adolescents in both studies were still experiencing stigma from peers and community members, most did not internalize these experiences in a negative way, but retained hope for the future and felt pity for those untested and uninformed of their own HIV status | Corneli et al. (35) Age of disclosure to children <ul style="list-style-type: none"> • Parents and caregivers favor disclosure to older children and adolescents than younger for HIV-related research • HCPs and caregivers support disclosure to minors because it would improve adherence to treatment |

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TABLE 2 | Continued

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| Kiwanuka et al. (30) Disclosure as a single event or process, benefits and barriers <ul style="list-style-type: none"> Majority perceived disclosure as a single event rather than a process of gradual delivery of information about the child's illness Benefits – potentially beneficial both to children and themselves, an opportunity to explain the parents' role in the transmission of HIV to the children Barriers – caregivers desired to personally conduct the disclosure but most reported being overwhelmed with fear of negative outcomes (lack of self-efficacy in managing the disclosure process). Most cope by deception to avoid or delay disclosure until they perceive their own readiness to disclose | Lorenz et al. (31) Facilitators to testing child, age at disclosure, barriers, type of disclosure and support <ul style="list-style-type: none"> Facilitators – majority (96%) of respondents, the decision to test the child for HIV was due to existing illness in either the child or a relative Age at disclosure – most (65%) children were informed of their HIV status between the ages of 5 and 9, with the mean age of disclosure occurring at the age of 7 Barriers – existing stigma within community, doubts about cognitive understanding of child Full disclosure – general provision of HIV information typically began at the same age as disclosure Support in disclosing – two-thirds (64%) of the caregivers sought advice from an HIV counselor prior to disclosure | Beima-Sofie et al. (32) HCPs disclosure practices, family-centered disclosure, best Person to disclose and outcomes <ul style="list-style-type: none"> HCPs disclosure practices – providers had limited training but extensive experience in disclosure, endorsed individualized disclosure practices, invested substantial time on disclosure despite clinical burden Family-centered disclosure – child-centered disclosure but should respect caregiver fears and values Best person to disclose – caregiver support was provided to enable caregivers to be the person who ultimately disclosed HIV status to children Outcomes – unplanned or abrupt disclosure to children was reported to have severe and persistent adverse impact and was a stimulus to accelerate disclosure in scenarios when providers believed children may be suspecting their diagnosis |
| Moodley et al. (29) Disclosure proportion, age of child at disclosure, best person, facilitators, and barriers <ul style="list-style-type: none"> Only 9% had discussed HIV with the infected child Mean age of children who had been told their HIV status – 8.1 years Among the 73% of HIV-infected caregivers who had discussed their own infection with the child were more than 7 times more likely to have disclosed the child's status to him/her ($p = 0.07$ after adjusting for age of the child). Age of disclosure – 12 years was the best age to tell a child about his/her HIV infection Best person to disclose to child – parent or primary caregiver (83%), 16% felt it would be best for a health-care provider (doctor, nurse or counselor). 25% reported they had discussed disclosure of the child's HIV status with a health-care provider. Having discussed disclosure with a health-care provider was associated with disclosure to the child ($p = 0.07$). 96% of those who had not discussed disclosure with a health-care provider stated they would like to do Facilitators to disclosure – 98% of caregivers said they felt that the child has a right to know his/her HIV status, 90% gave reasons related to the child's mental health. 70% of caregivers said that the availability of ART could make it necessary to discuss the child's HIV status with him/her Barriers to disclosure – most caregivers (73%) said that they were afraid of the child discussing his/her HIV infection with other people | Gachanja and Burkholder (36) Facilitators, age of disclosure, associated emotions, benefits, and negative outcomes <ul style="list-style-type: none"> Motivation – chronic illness or acute illness presenting with AIDS-associated symptoms, desire to know HIV status, routine antenatal clinic attendance, or during general clinic visits where HCPs counseled HIV-positive parents that their children would eventually need to receive full disclosure of their own and/or their parents' HIV statuses Age of disclosure – partial disclosure between 5–9 years of age; non-disclosure at <5 years Disclosure process and associated emotions – suspicion by non-diagnosed children of affected family members, guilt, and depression after disclosure Benefits – for caregivers, there was improved psychological health, increased support from their children, increased ability to take medications and attend clinic visits openly, improved medication adherence, and increased bonding with their children. For HIV-positive children, the benefits included increased independence; improved self-care, self-medication, and medication adherence; and a greater understanding about their HIV statuses, medications, and clinic attendance Negative outcomes – increased stress from rejection by family members, disrupted relationships. For HIV-positive children, there was drop in school performance; for HIV-negative children there was loss of normalcy in daily living, added responsibility at home | Odiachi and Abegunde (37) Prevalence, age of disclosure, facilitators, and barriers <ul style="list-style-type: none"> Prevalence – based on parents/caregivers' accounts, 34 (30.9%) children knew that they were living with HIV, while 74 (67.3%) did not know Age at disclosure – mean age at disclosure was 10.47 years (± 2.62), with a median (range) of 10.00 (6–17) years Disclosure setting – 79.4% were disclosed at home by their parents/caregivers, rest at the hospital (5 by HCP; 2 accidental disclosure) Facilitators to disclosure – the most common reasons for disclosure were related to adherence issues – either to help prepare the children to take their medicines or that the child had refused to take his/her medicines (39.4%). This was followed by the child asking a lot of questions related to his/her health, frequent visits to the hospital, or why s/he was taking a lot of medicines even though s/he did not feel ill (27.3%) Barriers – most parents/caregivers did not disclose because the child was considered too young (84.0%) or will not be able to keep their HIV status a secret (10.7%). Multivariate logistic regression showed that only child's age was a statistically significant predictor of status disclosure (OR 1.69, $p = 0.002$; 95% CI 1.21–2.34). There was no association between disclosure and self-reported adherence ($p = 0.615$). |

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TABLE 2 | Continued

| Toska et al. (38) | Prevalence of disclosure, benefits, and barriers | Vaz et al. (39) | Proportion of disclosure, facilitators, benefits, and caregiver support in disclosure | Mumburi et al. (33) | Proportion of disclosure, age of disclosure, and caregiver support |
|-------------------|---|-----------------|--|---------------------|--|
| | <ul style="list-style-type: none"> Prevalence – 68.1% of the sample knew their status; 41.5% of those who were sexually active and in relationships knew their partner's status, and 35.5% had disclosed to their partners Benefits – for adolescents, knowing one's status was associated with safer sex ($OR = 4.355$, $CI 1.085$–17.474, $p = 0.038$). Neither knowing their partner's status, nor disclosing one's HIV-status to a partner, were associated with safer sex Barriers – HIV-positive adolescents feared rejection, stigma, and public exposure if disclosing to sexual and romantic partners. Counseling by health-care workers for HIV-positive adolescents focused on benefits of disclosure, but did not address the fears and risks associated with disclosure | | <ul style="list-style-type: none"> Proportion of disclosure – about 50% of caregivers provided no information to their child about their health; 15% had given partial information without mentioning HIV, and 33% provided information that deflected attention from HIV, whether deliberately so or otherwise Facilitators and benefits – almost all caregivers said that the child should be told their status someday, and three-fourths reported having ever thought about what might lead them to tell. However, nearly one-third of caregivers saw no benefits to informing the child of her/his HIV status Caregiver support in disclosure – a majority of caregivers felt that they themselves were the best to eventually disclose to the child, but some wanted support from health-care providers | | <ul style="list-style-type: none"> Proportion of disclosure – 53.1% non-disclosed, 24.6% partial disclosure, 22.3% knew their HIV status The mean age of disclosure was 10.6 years. Most of disclosed children were aged above 10 years ($p < 0.001$) and self-supervised in taking medication ($OR = 33.1$; 95% CI 13.9–78.9). Children who got other support were more likely to be disclosed than those who did not ($OR = 4.4$; 95% CI 1.1–5.0) Caregiver support – parents/caregivers who discussed with health-care providers about disclosure did disclose HIV status more often to their children ($OR = 4.4$; 95% CI 2.2–8.7) |
| | | | Partial disclosure to children and transition to full disclosure, best person to disclose | | Persons Best to Disclose |
| | | | <ul style="list-style-type: none"> Disclosure to children – most providers felt that the optimal age for general discussions about an HIV-infected child's health should happen around age 6, but that specific discussions regarding HIV infection should be delayed to a median of 10 years Best person to disclose – though most providers said that primary caregivers were the most appropriate individuals to lead disclosure discussions, there were strong views that caregivers require support from | | Approach to Disclosure |

questions about transmission of the disease, HIV management, and eventual cure (36).

Persons Best to Disclose

Persons best positioned to disclose varied in different studies and by the key participants asked. Majority of the studies that explored "persons best to disclose" favored disclosure by caregivers with support from HCPs (27, 29, 31–34). One study reported preference for HCPs disclosing rather than caregivers (25). Two studies among caregivers in South Africa and Uganda reported high preference for the parent or caregiver to disclose rather than HCPs (29, 30). A study in Uganda and Kenya indicated that HCPs support caregivers when they initiate disclosure (27, 32), but adolescents preferred HCPs to disclose rather than their caregivers because they had an opportunity for more accurate information about their disease (27). A study in South Africa indicated that caregivers preferred that the HCP or family members, especially the paternal aunt and grandmother disclose rather than the mother (21). Although some caregivers preferred to disclose to infected children themselves, they expressed fears of competence in disclosure; acceptance by the child; stigma from accidental disclosure by the child to others; and need for support (29, 31, 32, 34, 39).

Approach to Disclosure

Perspectives of different groups of HCPs differed on approach to disclosure. Nurses and counselors shared preference for encouraging caregivers to disclose to their children and adolescents with adequate support (40), unlike doctors who preferred direct participation in disclosure from a professional and legal obligation (32, 40). HCPs experienced conflict between human rights or public health safety during disclosure and also required training in decision-making and to reduce inadvertent disclosure (37). When HCPs were to discuss grief or HIV diagnosis with children and adolescents, HCPs preferred full disclosure of HIV diagnosis to children at a younger age (6–15 years) rather than discussing grief. In contrast, caregivers preferred that children were older (10–19 years) since they were more open to discussing grief than HIV.

Disclosure Setting

Disclosure setting was an important consideration in the disclosure process according to some of the studies. The health facility setting was preferred by HCPs because this provided an avenue for caregiver support during the disclosure process (32), and also gave adolescents the opportunity to obtain reliable answers to questions and interact with peers at the health facility (27, 28). For caregivers who preferred their HCPs to be involved in the disclosure process, the health facility was the natural setting where this occurred (29, 33, 34, 40). Where caregivers preferred to handle disclosure to their minors, the home setting was the natural environment (30).

Barriers and Outcomes of HIV Disclosure

Barriers to disclosure by HCPs or caregivers included the fear of HIV stigma, uncertainty about cognitive development of children, and local traditions that limit discussion of sexuality (23,

24, 29, 36). Some studies described benefits from the disclosure process, and this included improved ART adherence and mental health of affected individuals (25, 35), opportunity to cope with the illness, and the associated stigma (27, 28, 30). By contrast, a study reported adolescents who experienced peer-stigma, anxiety, depression, and self-blame after knowing their positive status (28). Furthermore, some studies indicated that disclosure, especially premature or inadvertent disclosure, resulted in harmful outcomes such as stigma, discrimination, and abuse from family and community members (23, 28, 32, 36). Some caregivers coped by adopting a conspiracy of silence (24). Besides, a study in Democratic Republic of Congo reported up to one-third of caregivers who did not see any benefit in disclosing to children (39). In addition, a study involving HCPs and adolescents indicated that adolescents did not see any benefit in knowing their partner's status nor disclosing to a partner (38). Rather, benefit was reported from knowing self-status as this informed safer sexual lifestyle (38). While one study suggested that disclosure may empower the child or adolescent to engage in safe sexual behaviors (25), another study indicated there was no correlation with sexual lifestyle but with medication adherence (38). Caregivers or other family members also had to disclose their HIV status to facilitate the communication of perinatal infection and ART adherence to infected children and adolescents (24, 29, 36). However, some caregivers expressed concerns that this process could generate both positive and negative outcomes (24, 29, 36).

DISCUSSION

The objective of this review was to explore the perspectives and practices of HCPs and caregivers in HIV disclosure to children and adolescents. Findings are categorized as follows: types and prevalence of disclosure; facilitators, timing and barriers; process of disclosure; persons best to disclose, approach to disclosure by HCP versus caregivers; suitable disclosure setting and outcomes of disclosure.

This review showed that the prevalence of full disclosure is relatively low for children compared to adolescents, which is higher (37, 38). However, the prevalence of HIV disclosure needs to be improved for both age groups because more disclosure will reduce the number of infected children and adolescents at risk of morbidity and mortality from poor adherence to ARTs (23, 28, 32, 36). Despite natural concerns of adults about a child's ability to cope with disclosure, empirical studies show that children may be more resilient than assumed (42, 43), appropriate disclosure may enhance psychological stability of the child and improve adherence to ART therapy (28, 42, 44). For adolescents, more disclosure by HCPs or caregivers to infected adolescents directly will encourage safer sexual behaviors that reduce new HIV transmission rather than emphasizing adolescents disclosing to their partners (38).

In SSA, variation exists in the types of disclosure in practice, and this review has highlighted studies where participants utilized partial disclosure before full disclosure of HIV-positive status or adopted outright non-disclosure (21, 26, 33, 34, 36, 41). Most studies identified the age of a child as a key factor that determined

the timing of disclosure. It is important to identify cues to disclosure to children early since appropriate training for HCPs and caregivers may enhance their readiness to disclose. Age, as a key factor, also emerged in a systematic review by Vreeman et al. on pediatric disclosure practices in resource-limited settings (20). Most of the studies in this review suggest that, in SSA, partial disclosure may be appropriate for children up to early adolescence (21, 22, 34, 36), and this is consistent with the report from WHO Guideline on HIV Disclosure Counselling for Children up to 12 years of Age (2011) (12, 43). Despite age as a key factor in disclosure to children, we recommend that consideration needs to be given to communication patterns within families, orphan status, cultural norms, influence of other family members living with HIV/AIDS, and involvement of the child in administering ART medications (33, 36, 37).

Again, this review indicated that the concept of HIV disclosure process is relatively understudied since few studies evaluated perception of HCPs and caregivers. Caregivers described the disclosure process as complex, and one study reported caregivers who viewed disclosure as a solitary event. To reduce the complexity associated with disclosure, it is important to disseminate HIV disclosure as a process originating from the time of initial diagnosis to events beyond disclosure. Here, a series of dialog is made with the child about the terms, course of disease, relationship with others, self-care, and medications over time (36, 45). The dialog between caregivers and their children may be strengthened by providing focused counseling to caregivers throughout the disclosure process (42, 43, 46). Scientific research has demonstrated that the process-oriented approach results in less strain on caregivers and better outcomes for infected children and adolescents (28, 36, 42, 44, 47).

From the selected studies, there was evidence that both HCPs and caregivers perceived the most suitable individuals to disclose to children in SSA are caregivers, with support from HCPs throughout the process (27, 31, 32, 35, 37, 41). The WHO guideline on disclosure counseling to children under 12 years of age (2011) indicated that there is no evidence for either HCPs or caregivers disclosure as the best to disclose, but emphasized that disclosure should be in the best interest of the child (12). Adolescents had a preference for disclosure by the HCP because they received more biomedical information and could cope better with the disease than information received from their caregivers alone (27). Adolescents also indicated that peer-group support was important to them (23, 27). This suggests that the support needs of adolescents during the disclosure process differ from those of younger children in the region.

The health-care setting also plays a critical role in disclosure practice. Among HCPs, physicians tended to disclose more directly from a legal, moral, and ethical obligations compared to other workers who emphasized provision of support to caregivers who should disclose directly to infected children (40). As more HCPs disclose, it is critical to expand the locations where their services can be accessed by affected families. A review by Obermeyer and colleagues provided evidence that increased HIV/AIDS services in areas with limited services may facilitate disclosure and reduce stigma in the affected communities (46). Creating more health-care centers for HIV/AIDS services is

an additional cost in resource-limited parts of the SSA, but the World Health Organization, in 2015, recommended HIV counseling and testing by trained lay providers (community health workers) to reduce the cost of providing needed services and to increase access to care (48). Some success is being recorded with lay providers in this regard, but this strategy requires more studies and careful review of existing policies to seamlessly integrate lay providers in provision of counseling and testing services (49–51).

Stigma and discrimination remain a persistent threat to the potential benefits of HIV disclosure. Sadly, local norms that deter discussion of sexuality also indirectly limit HIV disclosure by their HCPs and caregivers to children and adolescents (23). While advocating for any type of disclosure, it is important to consider individual rights and safety carefully balanced with public health safety.

Limitations

Some limitations are inherent in this review. For example, although our review focused on SSA, not all countries in this region had adequate research available on HIV disclosure by HCPs and caregivers. SSA was only represented by 10 countries out of 46 (Botswana, Democratic Republic Congo, Ghana, Kenya, Nigeria, South Africa, Tanzania, Uganda, Zambia, and Zimbabwe). Four studies performed prior to or during the period (2008) of increased access to ART in SSA may not have clearly depicted the current disclosure process and practices because of the recent discovery of a relationship between access to ART and HIV disclosure (7, 29, 34). Reported perspectives and practices may slightly differ in the health-care setting or living situation of participants; therefore, caution must be applied in interpretation of the findings and in making generalizations.

The quality of the studies varied especially with majority consisting of convenience sampling. Restricting the search to English-language publications may have excluded studies or participants from non-English speaking parts of SSA. Paucity of research on this topic limited the discussion of several other issues, such as specific disclosure communication and practices. Studies on prevalence and proportions of disclosed patients were largely for children and relatively less for adolescent, again limiting the scope of the review.

Implication

Because timing is an important factor to consider, best practices would have to include training of HCPs and caregivers to identify appropriate timing for disclosure, especially at the early phase of diagnosis (43). Continuing education and training that incorporate health policies and are amenable to local norms may contribute to the efficacy of HCPs when addressing barriers to HIV disclosure in their communities (48). Since the advent of more available ART, the focus has been on prompt diagnosis, prevention of mother-to-child transmission (PMTCT), partner disclosure, and testing with some success in HIV risk behavioral changes. However, success in individual behavior change will remain a challenge where the route of transmission involves at least two individuals or children infected perinatally. Findings

from this review indicate the importance of broadening the scope of current HIV intervention programs to include adequately informed and appropriate disclosure. Therefore, long-term HIV/AIDS program funding should provide for resources to ensure that disclosure does not stop at informing individuals (e.g., infected mothers) of their HIV status or encouraging ART adherence; rather these resources should also be channeled to ensure adequate counseling and support after disclosure to minimize stigma, abuse, poor ART adherence, and transmission of new HIV infection.

Peer groups are helpful to adolescents but require participation of motivated members living with HIV and ought to be facilitated by trained personnel (27, 28). Although two studies among adolescents referred to peer support as a coping method for this population, stigma from peers was a reality in other studies (27, 28, 33). Therefore, when peer groups are being facilitated by HCPs, caution must be exercised to ensure appropriate groups are created and proactive measures undertaken to minimize stigma from peers.

The role of HCPs in HIV disclosure is challenged by insufficient number of HCPs relative to the sub-Saharan population (52, 53). Poor training, difficult working conditions, and increasing emigration to urban areas and developed countries has contributed to HCP shortage in about 31 countries in SSA (52, 53). The shortage in HCPs who daily endure stressful working conditions inadvertently impinge on optimal disclosure practices. To reduce the burden on HCPs, trained lay providers (community health workers) should be integrated in the disclosure process. Also, the responsibility to disclose can be shared equally by all cadres of HCPs trained in HIV disclosure, and team work should be driven by a patient-centered approach to caring for infected children and adolescents. An extension of this collaboration is a family-centered approach, where the health-care team collaborates with family members (or caregivers) directly involved in the care of the child at home or with individuals selected by family members to represent them (21, 43).

The ethical issues involved in disclosure have contributed to the complexity associated with establishing specific HIV disclosure guidelines in SSA (7, 8). To get the best result from disclosure, HCPs need to disclose in the most ethical and culturally competent manner with full inclusion of patient confidentiality. Broad guidelines may be more effective for SSA as this lends itself to accommodate the cultural diversity of each country and even regions within specific countries. From these broad guidelines, hospital or clinic leaders can provide specific guidelines based on the local context as this would be helpful to HCPs and caregivers when taking care of their patients and children, respectively. Beyond the perspectives of HCPs and caregivers, the perspectives of people and communities with high HIV burden need to be incorporated in revising or creating local guidelines on HIV disclosure. Other factors, such as facilitators and barriers associated with HIV disclosure to children and adolescents, need to be factored into new guidelines. The degree to which these broad factors are considered in the development and implementation process will likely result in a more successful adoption of disclosure guidelines.

CONCLUSION

This review evaluated the perspectives of HIV disclosure and practices currently used in delivering age- and culture-sensitive HIV disclosure to children and adolescents by health caregivers or caregivers in SSA. Further evidence has been generated on the emerging topic of HIV disclosure in this region following the advent of ART. Partial disclosure is appropriate for children in SSA up to early adolescence. Caregivers should be involved in disclosing to children, and they require adequate disclosure support from HCPs. On the other hand, full disclosure is suitable for adolescents. Adolescents prefer disclosure by HCPs and they favor peer-group support from committed peers and trained facilitators, to reduce stigma. HCPs need continuous training and adequate resources to disclose in a patient-centered manner. Community members need education in HIV stigma reduction.

The evidence-based information from this review informed the following recommendations. First, caregivers and HCPs require collaborative training to ensure the best interest of infected children and adolescents are addressed throughout the disclosure process. Second, public health education should promote HIV/AIDS as a shared burden and create opportunities for community members to accept families of children and adolescents living with HIV to reduce stigma in the communal life. Inclusion of trained lay providers selected from affected communities may also

ensure more culturally acceptable management of HIV disclosure in these communities. Third, family counseling and community education that encourages discussion of sexuality within local norms will empower children and adolescents to make better informed sexual health- or HIV-related choices. Finally, more studies are needed to determine the role of social determinants in HIV disclosure practices in resource-limited communities.

AUTHOR CONTRIBUTIONS

All the authors made substantial contributions to the conception and design of the work and in the acquisition, analysis, and interpretation of data for the work. They also drafted the work or revised it critically for important intellectual content. Final version of the article to be published was approved by all the authors. They also agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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A Systematic Review and Narrative Synthesis of Interventions for Parental Human Immunodeficiency Virus Disclosure

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Introduction: Disclosure of parental human immunodeficiency virus (HIV) infection to their children remains a difficult process for parents living with HIV (PLWH). In order to identify the best strategies to facilitate parental HIV disclosure, it is necessary to examine the efficacy of existing interventions designed to help PLWH parents with the disclosure process to their children.

Objectives: To systematically review the efficacy of interventions designed to assist PLWH disclose their HIV status to their children.

Methods: We conducted a systematic review and narrative synthesis of interventions designed to assist PLWH disclose their HIV status to their children. MEDLINE/PubMed, PsycINFO, Embase, Global Health, and Web of Science were searched.

Results: Studies were eligible for inclusion if they evaluated an intervention for parental HIV disclosure. Five studies published between 2001 and 2015 met the inclusion criteria. The interventions were conducted in South Africa, China, and the United States. Three of the studies used two-arm randomized controlled trials, in which the intervention group was given enhanced care while the control group received standard care. Four of the five studies included a theoretically informed intervention and three were limited to mothers. Results showed that four of the interventions increased parental HIV disclosure.

Conclusion: The findings suggest that parental HIV disclosure interventions are successful in assisting parents with the disclosure process and can be adapted in different cultural context. Future parental HIV disclosure interventions should include fathers in order to assist men with parental HIV disclosure.

Keywords: parental human immunodeficiency virus disclosure, interventions, systematic review, human immunodeficiency virus-affected families, children

INTRODUCTION

Disclosure of parental human immunodeficiency virus (HIV) infection to children remains a difficult process for families affected by HIV. In fact, parents living with HIV (PLWH) describe disclosure as one of their greatest challenges (1). Research indicates that anywhere from 34% to over 80% of PLWH have not disclosed their HIV status to their children (2) and that they often struggle to figure out when and how to disclose to their children (3–7). Many parents, for example, do not disclose to their children for a number of reasons including children's lack of cognitive-developmental ability to understand the illness (1, 8–10).

Although the World Health Organization Guidelines on Disclosure to Children suggest that school age (i.e., 6–12 years) children can potentially understand and cope with their parent's illness (11), numerous disclosure barriers exist. For example, some parents report that they do not disclose their HIV status to their children because they lack self-efficacy and simply do not know how to disclose (12–15). Others indicate that they do not disclose due to fear of children's inadvertent disclosure of parents' HIV-positive status to others in the community and the ensuing stigma and discrimination children and parents may face (16–18). For some, disclosure of sero-positive status requires an understanding of the sociocultural factors that shape individual and collective decisions surrounding health and well-being. Sociocultural factors which refer to the factors that represent the collective consciousness of people, active enough to influence and condition perception, judgment, communication, and behavior have been found to influence the taken-for-granted assumptions about identity and issues of belonging with parents' fear of rejection and loss of respect from their children, for example, serving as barriers to parental HIV disclosure (14, 19–21). Still, others cite concerns about causing their children emotional pain and psychological harm (15, 22).

To date, the literature on the psychological effects of parental HIV disclosure on children is mixed (1). Some researchers have reported that there is no relationship between parental disclosure and child functioning (23–25). Other studies have found that children who are aware of their parents' HIV status have lower social and emotional functioning (26), greater mental distress (24), and more externalizing symptoms (16). The amount of information children receive about their parents' illness during the disclosure process may influence the disclosure outcome, particularly the psychological impact on children. For example, parents who inform their children that they have HIV but that they are also taking antiretroviral medicines can effectively reassure children that the medication will improve their health, thereby reducing the child's worry about their parent's health (27). In contrast, parental HIV disclosure without further explanation about treatments may lead to fear and anxiety that can impair children's psychological functioning (26).

Based on the challenges HIV-positive parents face with the disclosure process to their children regarding when and how to disclose to their children, and the possible negative consequences of disclosure, more interventions are needed to assist PLWH who want to inform their children about their HIV status, especially

in low-and-middle income countries (28). In order to identify the best strategies to facilitate parental HIV disclosure, it is necessary to examine the efficacy of the existing interventions designed to help PLWH parents with the disclosure process to their children. Although a number of review papers have been published describing the factors that influence parental disclosure, their focus was not on the effectiveness of existing interventions (1, 2, 29–34). We aim to fill an important gap in the literature by conducting a systematic review and narrative synthesis of interventions designed to promote parental HIV disclosure to children.

METHODS

Search Strategy

A literature search was conducted in May 2016 for papers that met the inclusion criteria. The electronic search included MEDLINE/PubMed, PsycINFO, Embase, Global Health, and Web of Science. These databases were selected to cover a wide range of disciplines, from social sciences to interdisciplinary and medical research. A combination of controlled vocabulary and Boolean-paired keywords were used, relating to acquired immunodeficiency syndrome (AIDS), HIV, disclosure, parents or children, and interventions (Table 1). In addition to searching electronic databases, the authors also reviewed the bibliographies of selected studies for other relevant citations.

Inclusion Criteria

Research studies that met the following criteria were included: (i) the paper discussed disclosure of HIV status by parents to their children, (ii) the study population included HIV-infected parents, (iii) an intervention was evaluated, and (iv) the paper was published in English. Exclusion criteria included non-parental HIV infection disclosure intervention including conference abstracts or dissertations, and papers written in languages other than English. There were no limits for study location or publication date.

Full Text Review

All articles were initially screened by two reviewers who independently reviewed the titles and abstracts of studies to accept or reject for full text review. The same two reviewers independently reviewed the full texts of the studies identified from the electronic search to determine if they were still eligible to undergo data extraction. In order to be included, studies had to evaluate an

TABLE 1 | Search strategy for MEDLINE/PubMed.

| Search category | Acquired immunodeficiency syndrome/human immunodeficiency virus | Disclosure | Children/parents | Interventions |
|-----------------|---|--------------------------------------|--|---------------------------------|
| Search terms | ("acquired immunodeficiency syndrome" OR HIV) | (Disclosure OR tell OR talk OR told) | (Children OR child OR mothers OR fathers OR parents) | (Intervention OR interventions) |

intervention designed to promote parental HIV disclosure to their children. Data were extracted from eligible studies into an electronic spreadsheet. Reviewers discussed any disagreements in the data extracted, and referral to a third reviewer was done to resolve any disputes. We extracted the following data: study characteristics (author, sample, study design, comparison/control components, intervention components, assessment, outcome variable, and outcomes) (**Table 2**). Finally, we conducted a narrative synthesis of studies meeting the inclusion criteria. Narrative synthesis which is “*an approach to the systematic review and synthesis of findings from multiple sources and relies primarily on the use of words and text to summarize and explain the findings of the synthesis*” (35). It is used when statistical meta-analysis or another specialist form of synthesis (such as meta-ethnography for qualitative studies) is not feasible particularly due to substantial methodological and clinical heterogeneity between studies identified (35).

RESULTS

Inclusion and Exclusion of Studies

The electronic database searches retrieved 1,210 records (172 from PsycInfo, 184 from Global Health, 313 from Web of Science, 273 from Embase, 268 from PubMed). After removing the duplicates in RefWorks, 579 records were screened (**Figure 1**). Of these, 544 were excluded because they were mostly general HIV studies examining prevention of mother-to-child transmission, treatment adherence, etc. Thirty-five records were selected at the abstract level for full text review because they described a study focusing on parental HIV infection. Thirty of the 35 were excluded because they were cross-sectional or qualitative studies of parental HIV disclosure, and systematic reviews.

The final sample consisted of five studies published between 2001 and 2015, all of which evaluated interventions designed to promote parental HIV serostatus disclosure to children. The children in two of the studies (38, 39) were HIV-negative, and the remaining three studies (36, 37, 40) did not specify the HIV status of the children. The sample size for these studies ranged from 20 families (40) to 307 families (36). Two of the studies were conducted in South Africa (38, 39), two in the United States (36, 37), and one in China (40).

Intervention Theoretical Framework and Design

Four of the five studies selected for this review included a theoretically informed intervention to improve parental HIV serostatus disclosure to their children. Rotheram-Borus et al. (36) employed social learning theory, which provides a framework for how individuals can change their behavior while highlighting a set of factors that must be changed, such as skills, expectations of competence and efficacy, and ability to express and control one's feelings. Rochat et al. (38, 39) developed the Amagugu intervention based on the Model of HIV-Disclosure Decision Making (MHDDM). One of the key characteristics of MHDDM is the encouragement of individuals to consider potential benefits and risks of disclosure while allowing for different types and levels of

disclosure. Murphy et al. (37) also relied on MHDDM to guide the development of the Teaching, Raising, and Communicating with Kids (TRACK) Program. Simoni et al. (40) drew from the Disclosure Process Model of Chaudoir et al. (30), the model for maternal HIV disclosure from Murphy et al. (37) and qualitative interviews with PLWH, community advisory board members, and HIV care providers to develop the Chinese Parental HIV Disclosure Model. The model comprises of three main components which include decision-making, the disclosure event, and related outcomes.

Three of the studies used two-arm randomized controlled trials (RCTs), in which the intervention group (IG) was given enhanced care while the control group received standard care (36, 37, 40). The other studies used an uncontrolled pre- and post-intervention evaluation (38, 39).

Intervention Content

Rotheram-Borus et al. (36) implemented a 24-session intervention for the participants in the IG over 12 Saturdays in small groups. The intervention was divided into two modules, and two sessions were held each Saturday; the first module was delivered to parents alone for four Saturdays, and the second module to both parents and their adolescents for eight Saturdays. Module 1 focused on parents' adaptation to living with HIV, how to cope with the health effects of HIV, opportunities for disclosure to children, and plans to help children cope with the diagnosis. In module 2, parents learned to initiate custody plans, reduce risk behaviors, create, and maintain positive family routines. Adolescents in module 2 focused on healthy adaptation to their parents' illness, worked to improve parent-youth relationships, and learned ways to reduce youths' risk behaviors. The Amagugu intervention implemented by Rochat et al. (38, 39) included printed materials, therapeutic tools, and child-friendly activities and games on HIV disclosure. It was delivered in six structured counseling sessions, with each session having specific contents, activities, and materials. The sessions included topics on positive parenting, positive families, positive life stories, positive practices, positive planning, and positive futures. As there was no direct intervention with children, mothers were supported to disclose independently.

The intervention by Murphy et al. (37) included three sessions. The first session addressed children's typical development, *pros and cons* of disclosure, and family routines as a foundation for disclosure. The second session focused on mother-child communication and provided quotes from mothers and children on disclosure. The last session utilized roleplaying to practice disclosure, during which the facilitator also provided positive reinforcement. The intervention conducted by Simoni et al. (40) was also composed of three sessions. The first session involved a discussion on the advantages and disadvantages of disclosure, and the provision of instructional information on useful family communication skills. The second session addressed what the parents can expect from their children during disclosure. During the third session, parents created a plan that would help them reach their goal on the disclosure continuum (0—no disclosure to 6—complete disclosure).

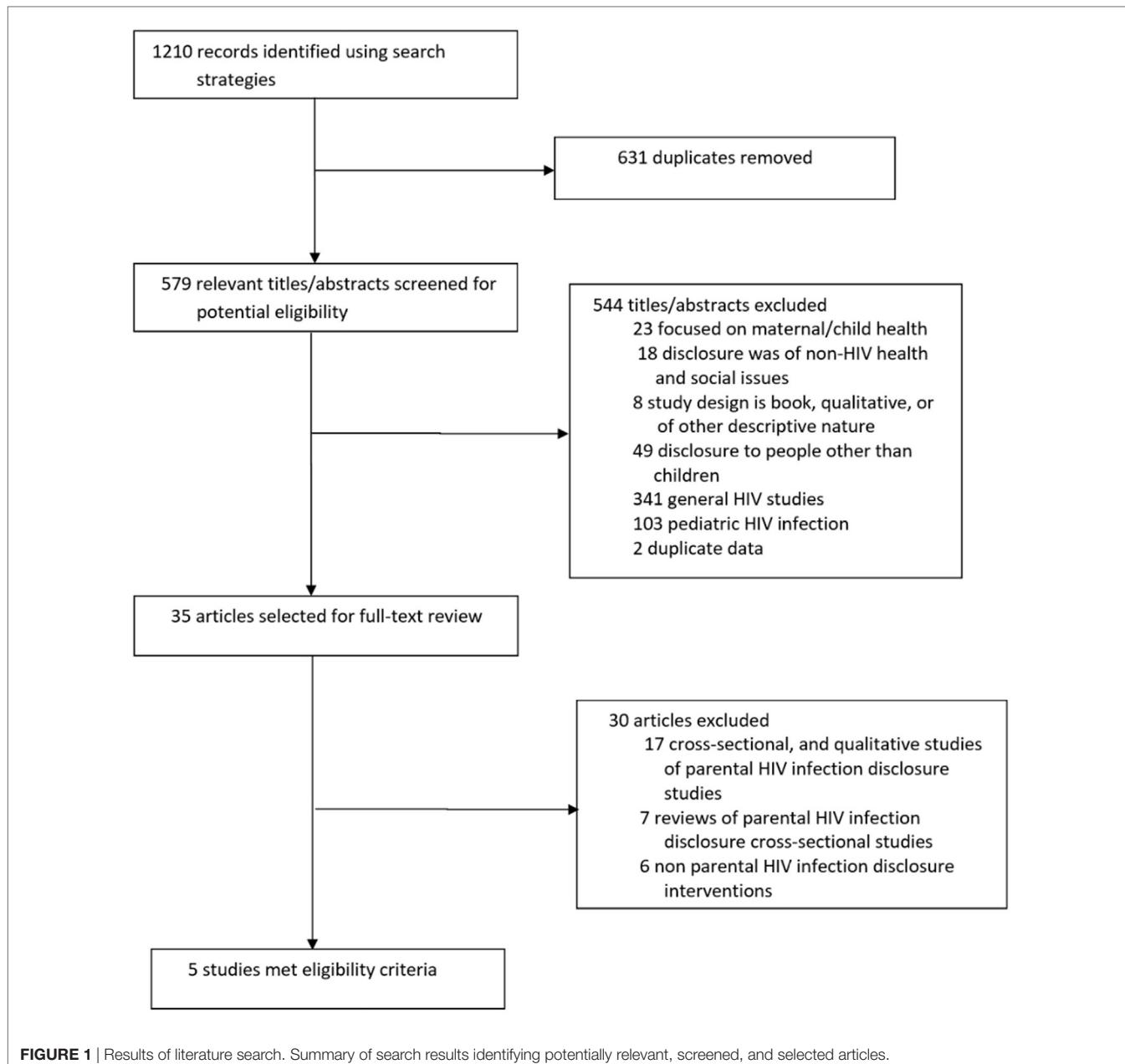
TABLE 2 | Study and intervention characteristics of the five studies.

| Reference | Sample characteristics | Study design | Comparison/ control components | Intervention components | Assessment (compensation paid) | Outcome variable | Outcomes |
|----------------------------|--|-----------------------------------|--|--|--|---|--|
| Rotheram-Borus et al. (36) | Parents with acquired immunodeficiency syndrome (<i>n</i> = 307) and their adolescent children (<i>n</i> = 412) in New York City | Randomized controlled trial (RCT) | Control condition (parents: <i>n</i> = 154, youths: <i>n</i> = 207) received standard care | Intervention group (IG) (parents: <i>n</i> = 126, youths = 118; of 153 parents, 27 were ineligible and of 205 youths, 87 were ineligible) received an intensive intervention. The intervention was delivered in 2 modules, the first module to parents alone (4 Saturdays) and the second module to both parents and adolescents (8 Saturdays). In module 1, parents made decisions regarding disclosure. In module 2, each Saturday involved some time with parents meeting alone while their children met in separate groups, along with sometime during which parents and youths were together in groups. Two sessions were held each Saturday, one 2-h session in the morning and another 2-h session in the afternoon (after lunch). The design of the intervention was based on social learning principles | Parents and adolescents were assessed in individual interviews at 3-month intervals over 24 months, and subjects received \$25 for each interview (\$50 for parent and youth assessment) | Presence (1) or absence (0) of human immunodeficiency virus (HIV) disclosure to each adolescent and to all adolescents in the family was calculated | There were no significant differences in disclosure or custody plans across conditions, as the completion of repeated interviews regarding disclosure and custody plans represents a significant intervention in itself, and families in both conditions experienced these assessments |
| Murphy et al. (37) | 80 mothers living with HIV and child dyads in Los Angeles, United States | RCT | Control condition (<i>n</i> = 41) received standard care (e.g., medical care and case management) | IG (<i>n</i> = 39) received three-session intervention in addition to standard care. Intervention sessions addressed children's typical development, pros and cons of disclosure, mother-child communication, and behavioral practice for disclosure | Baseline, 3, 6, and 9 months. After each completed appointment, mothers were paid \$45 for each interview and \$45 for each intervention session, and children were allowed to select a toy or toys worth approximately \$25 or a retail gift card | At each follow-up, the mother was asked whether she had disclosed to the child that she is HIV+. If the mother had not disclosed, the above baseline information was collected again. If the mother had disclosed, information was collected on the disclosure, including the date of the disclosure, the child's reactions to the disclosure, and how the mother felt she handled the disclosure | MLHs in the IG were 6 times more likely to disclose their HIV status than those in the control group (OR = 6.33, 95% CI: 1.64, 24.45), with 33% disclosing in the IG compared with 7.3% in the control group. MLHs in the IG showed increases in disclosure self-efficacy across time, increased communication with their child, and improvement in emotional functioning. Children of MLHs in the IG exhibited reductions in depression and anxiety, and increases in happiness |

(Continued)

TABLE 2 | Continued

| Reference | Sample characteristics | Study design | Comparison/ control components | Intervention components | Assessment (compensation paid) | Outcome variable | Outcomes |
|--------------------|---|--|--|--|---|--|--|
| Rochat et al. (38) | 24 Zulu families in rural South Africa (within the Africa Centre Demographic Surveillance Area); all mothers were HIV-positive and had an HIV-negative child aged 6–9 years | Uncontrolled pre- and post-intervention evaluation | Each mother served as her own control | Lay counselors delivered the six session "Amangugu" intervention over a 6- to 8-week period. Intervention has three main aims: increasing maternal HIV disclosure; to increase children's knowledge about HIV and health; to improve the quality of custody planning for children with HIV-positive mothers | Pre- and post-data collection, including qualitative measures, were completed for all mothers irrespective of the level of disclosure they achieved | Maternal disclosure (partial or full) to the study child following participation in the study was collected at visit 5 | All mothers disclosed something to their children: 11/24 disclosed fully using the words "HIV" while 13/24 disclosed partially using the word "virus" |
| Rochat et al. (39) | 281 HIV-infected women and their HIV-uninfected children aged 6–10 years in South Africa | Uncontrolled pre and post-intervention evaluation | Each mother served as her own control | The "Amangugu" intervention includes six structured counseling sessions conducted with the mother at home but no direct intervention with children. There were two intervention stages: a pre-disclosure stage when the counselor worked with the mother to prepare and train her toward disclosure, and a post-disclosure stage, when the mother was counseled on health promotion and custody planning | Pre- and post-intervention evaluation; In addition to baseline and post-intervention, maternal and child mental health was assessed using the General Health Questionnaire (GHQ12) and the Child Behavior Checklist | The primary outcome of this research was disclosure (full, partial, none) and secondary outcomes included maternal and child mental health | 171 (60%) women "fully" disclosed and 110 (40%) women "partially" disclosed their HIV status to their child. Women who perceived their health to be excellent were less likely to "fully" disclose compared to those considering their health to be poorer [adjusted odds ratio 0.48 (0.28–0.95), $P = 0.11$]. Compared to those not in a current partnership, those with a current partner were almost three times more likely to "fully" disclose [adjusted odds ratio 2.92 (1.33–6.40), $P = 0.008$] |
| Simoni et al. (40) | 20 HIV-positive outpatients with at least one child who was unaware of the parent's HIV status in Shanghai, China | RCT with blinded assessment | Control condition ($n = 10$) received treatment as usual | IG received three counseling sessions for up to 1 h per session over 4 weeks in addition to standard care. The intervention (based on Chinese Parental HIV Disclosure Model) has three components: decision-making, the disclosure event, and related outcomes. Session 1: parents share the story of their diagnosis. Session 2: provision of psycho-education of what parents should expect during disclosure. Session 3: parents develop a plan for achieving their desired position along the disclosure continuum | Baseline, immediate post-intervention (4 weeks), and follow-up (13 weeks). Patients were given 1-h paper-based assessment survey. Participants in both conditions were reimbursed 150 RMB (~\$25) for completing each session | Disclosure distress (3 item questions, numerical response ranging from 1 to 4), disclosure self-efficacy (2 item questions, numerical response 1–4), and disclosure behaviors (continuum ranging from 0 = no disclosure to 6 = full disclosure and open communication about HIV) | Participants in the intervention arm indicated a sharp decrease in level of disclosure distress from baseline to follow-up ($OR = 0.17$, 95% CI: 0.03–0.91). Disclosure self-efficacy improved significantly for the IG than the control group from baseline to follow-up ($OR = 9.00$, 95% CI: 2.06–39.29). Participants in the IG reported significantly greater movement along the disclosure behavior continuum than those in the control from baseline to post-intervention ($\beta = 1.40$, 95% CI: 0.31–2.50) |



Disclosure Measurement

Disclosure was measured differently across the studies. In the study conducted by Rotheram-Borus et al. (36), presence and absence of disclosure to all adolescents in the family was recorded numerically, with 1 for presence and 0 for absence. Studies by Rochat et al. (38, 39) considered all levels of disclosure, including partial (i.e., explaining that the mother has a “virus”), full (i.e., the mother used the term “HIV”), and no disclosure. Murphy et al. (37) asked mothers if they had disclosed to the child at each follow-up. If she had not disclosed, baseline information was used again. If she had disclosed, the following information on disclosure was collected: date of disclosure, the child’s reaction to disclosure, and how the mother felt she

handled the disclosure. Simoni et al. (40) measured disclosure behaviors by using a visual Disclosure Behaviors Continuum, which ranged from 0 for no disclosure to 6 for full disclosure and open communication about HIV.

Summary of Study Findings

The findings of the interventions were mixed across the studies. Murphy et al. (37) found that mothers in the IG were more likely ($OR = 6.33$, 95% CI: 1.64–24.45) to disclose their HIV status than those in the control group, with 33% disclosing in the IG compared with 7.3% in the control group. Rotheram-Borus et al. (36) found no statistically significant difference in disclosure across conditions. In the pilot study by Rochat et al. (38), all mothers

disclosed to their children with a varied level of disclosure, with 11 of 24 mothers reporting full disclosure by using the word "HIV" while the remaining 13 mothers disclosed partially using the word "virus." In the follow-up study conducted by Rochat et al. (39), about 60% of the mothers ($n = 171$) disclosed fully and 40% ($n = 110$) partially disclosed their HIV status to their child. They also found that mothers who reported excellent health were less likely ($OR = 0.48$, 95 CI: 0.28–0.95) to fully disclose their status than those who reported poorer health. In addition, mothers who were in a relationship were more likely ($OR = 2.92$, 95% CI: 1.33–6.40) to disclose their relationship fully than those who were not in a current partnership. In the study conducted by Simoni et al. (40), participants in the IG reported statistically significant greater movement along the Disclosure Behaviors Continuum than those in the control from baseline to post-intervention ($\beta = 1.40$, 95% CI: 0.31–2.50), with the intervention parents moving on average from 1.2 to 3.0, and the TAU parents from 0.7 to 1.4.

DISCUSSION

The objective of this paper was to contribute to the growing literature on interventions for parental HIV serostatus disclosure. We systematically reviewed the literature and found a small number of studies have evaluated such interventions. The findings of the interventions were mixed, with four (37–40) of the studies reporting an increase in parental HIV disclosure. Although there was no geographical limit for the search, the location of the studies that met the inclusion criteria for this review were the United States, China, and South Africa. The cultural differences in the settings where the interventions were conducted may also influence if, and how parents disclose their status to their children. Disclosure of HIV status is behavioral in nature and driven by many contextual issues including culture. For example, the barriers and cultural norms that prevent open communication about sexuality and HIV/AIDS between parents and children in sub-Saharan Africa (41, 42) may not be present in the United States. However, in sub-Saharan Africa, the desire to disclose knowledge of a HIV-positive status is perhaps a consequence of growing up in a society where there are frequent reminders that identities are relational and that this rationality is vital for necessary support with living with HIV. Disclosure occurred because parents naturally belonged to, or are part of, particular familial, local, or ethnic groups, whereby illness was viewed as a responsibility of the collective (20).

Additionally, three of the studies included only mothers living with HIV (37–39). The predominance of women in parental disclosure interventions to an extent may reflect the gender proportions of the adult population infected with HIV globally (43). Since child care is often the sole responsibilities of mothers, it was not uncommon for some of the mothers to fully disclose their status following knowledge of their sero-positive status (20). The generally held view that mothers are expected to provide emotional care and support for their children or family members even in the context of HIV disclosure (20) was evident in the interventions involving mothers. Another interesting finding is that mothers who were in a relationship were more likely to disclose to their

children than those who were not (39). A potential explanation for this finding may be that parental HIV disclosure to children becomes easier once parents have disclosed their HIV status to a primary sexual partner, hence providing support for parental HIV disclosure interventions to have a disclosure to sexual partner component (44).

Similar to other studies, parental HIV disclosure was associated with positive mental health outcomes for the children in the IG (14). For example, Rochat et al. (39) found a significant decrease in anxious-depressed, withdrawn-depressed, aggressive behavior, and rule-breaking syndromes among children. However, the decrease in withdrawn-depressed syndrome after the intervention was larger among children of mothers who partially disclosed than those who fully disclosed, indicating the importance of gradual disclosure or partial disclosure. Similarly, Murphy et al. (37) reported a reduction in depression and anxiety among children of mothers in the IG. Rotheram-Borus et al. (36) also reported lower levels of emotional distress, of multiple problem behaviors, of conduct problems, and of family-related stressors. These findings suggest that parental HIV disclosure can be beneficial for children when parents receive the proper training and guidance on how, and when to disclose to their children. In contrast, unintentional and poorly prepared parental HIV disclosure can have detrimental effects on children (1). The benefits observed among children in the IG may be the results of other areas addressed by the intervention such as parenting skills and communication with children (39). The ability for parents and children to openly communicate about HIV and other concerns with their children may improve parent-child relationship and children's coping behaviors (45).

While most of the interventions included in this review for parental HIV disclosure offer promising findings, there are a number of limitations from the existing literature that need to be addressed in future studies. First, only two of the interventions included fathers. The other three focused only on mothers. The lack of disclosure interventions for HIV-positive fathers reflects the broad HIV literature as HIV-positive men are overlooked and understudied (46). Research indicates that notions of male identity, family, and community influence disclosure among HIV-positive men (19). However, little research has examined how fatherhood affects men's experiences with their HIV status, especially in the context of parental disclosure (47). Future studies should include HIV-positive fathers or both parents, if available, in order to understand their approach to parental disclosure and address their needs. Second, the South African studies were unable to directly interview the children due to ethical reasons. More efforts are needed to provide approval for studies conducted in developing countries to include children in order to better assess the effect of the intervention on their mental health. Third, more rigorous studies are needed to determine the best practices for parental disclosure as only three of the included interventions were RCTs, with one of the studies having a sample size of 20 (40). The three successful RCTs provide the foundation for future studies to adapt the materials for interventions in different cultural settings such as Europe, Asia, the Caribbean, and other African countries. Fourth, none of the studies focused on immigrants. Immigrants affected by HIV face additional challenges with

parental disclosure such as legal status and geographical separation from family and are in need of culturally adapted strategies to help them with the disclosure process to their children (34, 48). Finally, the individual studies meeting the inclusion criteria were limited by a number of methodological issues, including sampling and disclosure measurements used by different interventions.

Non-disclosure of personal health information has been shown to be unhealthy (49). Likewise, research indicates that lack of disclosure may negatively affect parents' health. For example, parents who have not disclosed their HIV status have reported skipping medication and medical appointments in order to prevent their children from becoming aware of their ill health (14). The health benefits of disclosure can extend beyond the parents as findings from the studies suggest the children in the IG have better mental health outcomes than those in the control group due to the possible improvement in parent-child communication and relationship. Therefore, it is crucial for healthcare professionals to receive training on how to facilitate parents to make informed choices about disclosure and provide the tools and resources to disclose when they are ready. These resources can include printed materials and child-friendly activities and games (39) that parents can use to help them move along the disclosure behavior continuum (40).

Despite these potential benefits, parental HIV disclosure remains challenging and many parents may never disclose. More evidence-based interventions are needed to help parents facilitate and manage the parental disclosure process. As more people continue to live longer with HIV and desire to have children

(50–52), more parents will be faced with the decision to disclose to their children. Overall, this review has identified intervention strategies that have proven to be efficacious in improving parental HIV disclosure and can be modified to encourage and support parents in different cultural contexts with the difficult process of disclosing to their children.

AUTHOR CONTRIBUTIONS

All authors are in agreement regarding the content of the article. All authors have contributed to the conceptualization, design, and analysis, and all were involved in drafting and reviewing the article. DC took overall responsibility for the conceptualization and design of the review, collating the articles, analyzing the data, and writing the article. MT, JI, and SM were involved in conceptualization and design of the review as well as writing and editing the article. LH and GS searched for the articles in the review, assessed them for relevance, and were involved in writing, reviewing, and editing the final article.

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Why Tell Children: A Synthesis of the Global Literature on Reasons for Disclosing or Not Disclosing an HIV Diagnosis to Children 12 and under

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While the psychological and health benefits of knowing one's HIV diagnosis have been documented for adults and adolescents, practice is still in development for younger children. Moderating conditions for whether or not to tell a child he/she has HIV vary by region and local context. They include accessibility of treatment, consideration of HIV as a stigmatizing condition, prevalence of HIV, and an accompanying presumption that any illness is HIV-related, parent or caregiver concerns about child reactions, child's worsening health, assumptions about childhood and child readiness to know a diagnosis, and lack of policies such as those that would prevent bullying of affected children in schools. In this systematic review of the global literature, we summarize the reasons caregivers give for telling or not telling children 12 and under their HIV diagnosis. We also include articles in which children reflect on their desires for being told. While a broad number of reasons are given for telling a child – e.g., to aid in prevention, adaptation to illness (e.g., primarily to promote treatment adherence), understanding social reactions, and maintaining the child–adult relationship – a narrower range of reasons, often related to immediate child or caregiver well-being or discomfort, are given for not telling. Recommendations are made to improve the context for disclosure by providing supports before, during, and after disclosure and to advance the research agenda by broadening samples and refining approaches.

Keywords: HIV, disclosure, stigma, children, global review

INTRODUCTION

In countries spread across the globe, mothers, fathers, grandparents, aunts, uncles, sisters, brothers, and foster parents must face telling one or more of the children in their care that the children have a diagnosis of HIV. Their disclosures often occur against a backdrop of multiple family losses (1–3), and in families and communities where not everyone is accepting of those with HIV (4–6). Caregivers may face the disclosure process alone, have the assistance of health-care providers, delegate the task to providers, or be pre-empted by health systems or inadvertent disclosure (e.g., community gossip, visible records, overheard conversations) (7–9). Caregivers face multiple issues during disclosure, anticipated by those with experience with children and with global health issues.

In the opening paragraph of their 1999 recommendations for disclosure of HIV/AIDS diagnoses to children, the American Academy of Pediatrics (AAP) Committee on Pediatric AIDS [(10), p. 164] succinctly states, "Disclosure of HIV infection status to children and adolescents should take into consideration their age, psychosocial maturity, the complexity of family dynamics, and the clinical context." The World Health Organization [WHO (11), p. 12] in its 2011 guidance on disclosure to children 12 and under provided greater specificity – "children of school age should be told their HIV-positive status; younger children should be told their status incrementally to accommodate their cognitive skills and emotional maturity, in preparation for full disclosure." The guidance also broadened the AAP statement to include the community context – schools, institutions, and local and national laws and policies. The broader context was deemed important so that disclosure could be addressed in a culturally sensitive manner, and so that laws, policies, and institutional or community cultures that may be damaging (e.g., lack protections against stigmatization of those with HIV) could be changed to foster the well-being of HIV+ children and their caregivers (10). Both the AAP and WHO documents describe disclosure as a process rather than a single event, suggest that HIV+ children's caregivers may need to be supported in the disclosure process, and underline the well-being of affected children as a fundamental guide to disclosure decision-making.

Several clinicians, researchers, and reviews have suggested that knowing their HIV diagnosis in a timely manner enhances children's cooperation with antiretroviral therapy (ART) (11–14), helps children understand their illness and promotes self-care (15), relieves a burden of secrecy within families (5), prepares children to protect others as they approach the teen years which often include greater sexual and drug transmission risks (16), and, fundamentally, is a right as children mature (4, 8, 17). Risks of disclosure to children have also been noted (14), but these appear outweighed by benefits (18).

Although progress has been made in reducing HIV prevalence among children, especially in preventing mother to child transmission during pregnancy, childbirth, and through breastfeeding, timely disclosure to HIV+ children remains a concern. At the end of 2014, an estimated 2.6 million children under age 15 were living with HIV worldwide, the majority in low and middle income countries, an estimated 85% in 21 sub-Saharan countries and India. There were approximately 220,000 new infections that year; and only an estimated 32% of children living with HIV or AIDS were accessing ART, much lower than the figures for the adolescent/adult population (10, 19). Worldwide a minority of HIV+ children 12 and under (<5%) have acquired HIV through blood transfusion, needle sticks, sex (sexual abuse, early sexual debut, or sex trafficking), or injected drug use (20); the majority acquired HIV through mother to child transmission (20).

Researchers and clinicians have worked to translate the general guidance for disclosure to children into workable and context-sensitive interventions [e.g., Ref. (3, 9, 21–23)]. However, in the literature to date, it is most often the primary caregiver, with or without assistance from health care workers, who actually discloses to the HIV+ children in their care. In fact, many

interventions to aid disclosure, recently developed or under development, begin with interviews of caregivers about the issues facing them around disclosure. The current review synthesizes articles published about caregivers worldwide as they reflect on the reasons they have or have not disclosed to HIV+ children. In Section "Discussion," the review is expanded by including articles, which summarize the viewpoints of health-care personnel and articles summarizing the reflections of HIV+ children subsequent to their disclosure experiences. Finally, recommendations are made for improving research and practice for disclosure to children 12 and under.

METHODS

Definition of Disclosure

In 1997, Funck-Brentano et al. (24) proposed patterns of disclosure: (1) full disclosure in which HIV is named as the diagnosis, (2) partial disclosure in which factual discussions are held about symptoms, treatments, and immunodeficiency, and (3) two forms of non-disclosure – avoidance/delay and misnaming of the illness. In our review, we are defining disclosure as full disclosure, thus limiting the number of articles eligible for inclusion.

Eligibility of Articles

To be included, articles needed to focus on issues regarding disclosure of children's HIV status to HIV+ children 12 and under. Articles were included if some, but not all, children met the age criteria, i.e., if an article concerned 10–18 year olds. Since ART has had a profound effect on the conception of HIV as a treatable illness, articles prior to 1996, considered the benchmark year for the introduction of ART (21), were excluded. Articles published through December 2015 were included. A subset of eligible articles was entered into a database concerning caregivers' rationales for disclosing or not disclosing. The remaining articles served as background material to enhance discussion of the database summary and of recommendations concerning disclosure research and practice.

Eligibility for Inclusion in a Database of Disclosure Rationales

To be included in a database summarizing the reasons caregivers gave for fully disclosing or not fully disclosing, the caregivers had to be discussing an actual, rather than hypothetical, disclosure situation. That is, their descriptions were focused on the child/children they were caring for and why they had or had not told the child his or her HIV status. General discussions about how caregivers ought to behave, what respondents thought guided caregivers in general, or what caregivers said they might do in the future were excluded from the database.

Search

A search of the 60 international databases of the academic arm of EBSCO¹ was made using the terms (HIV or AIDS), (disclosure or telling or diagnosis), and (children or adolescents) from January

¹<https://www.ebscohost.com/academic>

1996 through December 2015. The search was repeated with the additional terms (reason or rationale or influenc* or decision or factor). Results of the search were checked and expanded by a hand search of references in review articles and by a search of references in key articles. The current search replicated a search conducted by two health librarians, two senior researchers (the first and second authors of the current manuscript) and two research assistants summarizing literature through June 30, 2010 for the WHO guidance on disclosure (18). However, the current search was limited to disclosure of the child's own HIV status, limited to the post-ART era, and extended to the end of 2015. The current search was conducted by the first and third authors and checked by the second author through hand search of references in key articles and reviews.

Analysis

Abstracts and Method sections were read to ascertain eligibility. Full text copies of all eligible articles, save one, were obtained. The remaining article was read on-line as full text. Two articles were translated into English from Spanish and from Portuguese sources; the remaining full texts were in English.

All eligible articles were read in full and then summarized, with a subset of articles read by two to three of the authors to confirm the accuracy of the summaries. An Excel database was created for the 18 articles concerning caregivers' rationales for full disclosure or non-disclosure. It included the source of the sample, data sources (e.g., interview, questionnaire), country in which the research was conducted, descriptors of the total child sample, descriptors of the children told and the caregivers who told, rationales for telling and not telling, additional predictors of disclosure, and notes about special concerns regarding the context or the data. As rationales were accrued, higher order categorizations were made, e.g., reasons related to the child's illness, to the parent-child relationship. Categories and higher order categories were cataloged in the database. Disagreements between the author/analysts were noted and were resolved by discussion.

RESULTS

Search

The full complement of search terms yielded 5,099 articles, the vast majority of which were irrelevant, e.g., hearing "aids." Removal of articles focused solely on the clinical picture of HIV/AIDS in a pediatric population or treatment of pediatric HIV, disclosure of parental HIV, disclosure in serodiscordant couples, disclosure to family and friends by older youth and adolescents, and disclosure for illnesses other than HIV infection also greatly reduced the number of articles. Of the remaining 147 articles, seven were removed as ineligible (three, although published after January 1, 1996, concerned HIV+ children pre-ART; one was available only as a conference abstract; one concerned HIV+ children above the age range; and one focused solely on the prevalence of mental health issues among HIV+ children with disclosure mentioned as a potential correlate of adjustment). Hand search of the reference sections of review and key articles yielded five additional articles. Thus, the total sample

consisted of 145 articles pertinent to disclosure to children with HIV.

Articles Concerning Caregivers' Reasons for Fully Disclosing or Not Disclosing

Of these 145 articles, 18 (22, 23, 25–40) were selected as meeting inclusion criteria for this review. Listed in **Table 1**, articles concerned (1) caregivers' rationales for fully disclosing and not disclosing children's HIV status to the children and (2) included HIV+ children 12 and under. Five discussed only reasons for non-disclosure (22, 29, 31, 37, 40); 3 documented only reasons for full disclosure (25, 38, 39); and the remaining 10 covered both full disclosure and non-disclosure (23, 26–28, 30, 32–36). Data originated from 11 countries: 9 of the 22 United Nations priority countries (10) for the elimination of childhood HIV [Democratic Republic of the Congo (DRC), Ethiopia, Ghana, India, Kenya, Nigeria, South Africa, Uganda, and Zambia], and Thailand and the United States of America (USA). Nearly all data were collected from urban, regional, or district hospitals and clinics or networks of clinics through face-to-face interview, or structured, and semi-structured interviews of caregivers, with one study collecting sealed confidential surveys (29). Two investigators (31, 34) purposively collected rural samples. In 7 of the 18 articles, HIV+ children or older youth aware of their status also provided data (26, 28, 30, 35, 38–40).

Disclosure

Reasons for Full Disclosure

Reasons that caregivers gave for telling their child(ren) are summarized in **Table 2**. Thirteen articles examined their reasons for full disclosure (23, 25–28, 30, 32–36, 38, 39). Since these articles varied in whether or not they calculated the frequency with which caregivers used these reasons, the reasons are tabulated according to the number and percentage of articles in which they appeared in tables or text. Heading the list was the "child's questions or curiosity" (mentioned in 69.2% of the articles). This rationale was followed by "improve adherence" (61.5%), "child age/maturity" (46.2%), "be the one to tell" (46.2%), and "assist child to reduce risks to self and others" (46.2%). Seven additional rationales were, in order of frequency: "child's right to know" (38.5% of articles), "promote self-care and general health" (38.5%), "keep an honest relationship" (30.8%), "explain disease progression and/or symptoms" (30.8%), "start medication" (15.4%), "explain discrimination" (15.4%), and prepare the child for the disclosure of other's HIV status, e.g., the status of relatives or friends (7.7%). With the exception of the last two rationales, reasons were distributed across multiple countries. Thus, the rationales appeared to concern maintaining an open parent-child relationship, recognizing the child's needs and rights, and enlisting the child's cooperation in promoting health and protecting others.

Who Is Told, When, and by Whom

The 13 studies documenting full disclosure together covered children in the age range of 4–18 years old. The disclosure rate was 31.0% across the 11 (23, 25–28, 31–36) studies for which it could be calculated; less than a third of the 1,168 HIV+ children

TABLE 1 | Characteristics of articles 1996–2015 describing caregivers' reasons for telling or not telling children in their care the children's HIV diagnoses.

| Reference | Country | Sample source | Source of data | Reasons for disclosing mentioned | Reasons for not disclosing mentioned |
|-----------------------------|--|--|---|----------------------------------|--------------------------------------|
| Abebe and Teferra (22) | Ethiopia | Pediatric infectious disease clinic associated with a hospital | Open- and close-ended questionnaires for caregivers | – | Yes |
| Atwiline et al. (23) | Uganda | Tertiary referral pediatric clinic | Structured questionnaire for caregivers and medical records of youth | Yes | Yes |
| Bhattacharya et al. (25) | India | ART clinic of a North Indian hospital | Semi-structured questionnaire for caregivers and patient records | Yes | – |
| Boon-Yasidhi et al. (26) | Thailand | Pediatric HIV clinic associated with a hospital | Semi-structured interview of caregivers and youth ^a | Yes | Yes |
| Brown et al. (27) | Nigeria | University hospital | Semi-structured questionnaire for caregivers | Yes | Yes |
| Fetzer et al. (28) | Democratic Republic of the Congo | HIV clinic | Semi-structured interview with caregivers and youth ^a | Yes | Yes |
| Flanagan-Klygis et al. (29) | USA | Hospital-based HIV clinic | Sealed confidential questionnaire for caregivers | – | Yes |
| Kallem et al. (30) | Ghana | Pediatric HIV clinic | Structured questionnaires for caregivers and youth ^a and medical records | Yes | Yes |
| Kiwanuka et al. (31) | Uganda | Rural regional hospital | In-depth interview of caregivers | – | Yes |
| Lester et al. (32) | USA | Children's and general hospital | Questionnaires and interview of caregivers | Yes | Yes |
| Mahloko and Madiba (33) | South Africa | District hospital | Interview of caregivers | Yes | Yes |
| Mweemba et al. (34) | Zambia | Two clinics and a hospital in a rural area | Case studies and in-depth interview of caregivers | Yes | Yes |
| Naidoo and McKerrow (35) | South Africa | Pediatric ART clinic associated with a hospital | Questionnaires administered to caregivers and youth ^a | Yes | Yes |
| Oberdorfer et al. (36) | Thailand | A university and a district hospital | Semi-structured questionnaire for caregivers | Yes | Yes |
| Tadesse et al. (37) | Ethiopia | Hospital-based HIV/AIDS clinic | Structured questionnaire for caregivers and patient records | – | Yes |
| Vaz et al. (38) | Democratic Republic of the Congo (DRC) | Three urban care and treatment organizations | Interviews of caregivers and youth ^a | Yes | – |
| Vaz et al. (39) | Democratic Republic of the Congo (DRC) | | In-depth interviews of caregivers and youth ^a | Yes | – |
| Vreeman et al. (40) | Kenya | Eight HIV treatment health facilities | Baseline questionnaires of caregivers and youth in a disclosure intervention study | – | Yes |

^aIn the indicated articles, youth who already had been told their HIV status were interviewed about the disclosure experience.

and youth sampled had been told their diagnosis. The rate varied from a low of 13.5% in a relatively large Nigerian study (27) to a high of 56.7% in a small Zambian study (34).

Calculating across the 12 studies where the mean or median age at disclosure was reported or could be calculated (23, 25–27, 31–36, 38, 39), on average HIV+ children were 10.6 when told their diagnosis. Mean age varied from a low of 8.7 to a high of 15.0 across studies. Many studies did not include measures of range or variability, so it is difficult to infer the youngest and oldest ages at disclosure.

Caregivers were described with varying degrees of specificity (e.g., parent vs. mother or father) study to study. **Table 3** suggests that a significant minority of caregivers were grandparents and other relatives and that health-care personnel had taken on an important role in disclosure. Further, at least three studies (32, 36, 38) documented that children may learn about their HIV

status inadvertently or by inference (e.g., looking at their medical records, overhearing discussions, or inferring from HIV public service announcements or talk among school friends).

Reasons for Not Disclosing

Table 4 summarizes the reasons that caregivers gave for *not* telling their child(ren). Fifteen articles (22, 23, 26–37, 40) discussed these reasons. The most prevalent reasons were “anticipation of the child's negative psychological reaction” (mentioned in 93.3% of the articles). This rationale was followed by “the child is too young to understand” (86.7%), “the child is unable to keep a secret” (66.7%), “potential social rejection of the child” (60.0%), and “the parent fears anger/blame from the child” (53.3%). Five additional rationales were, in order of frequency: “caregiver feels he/she lacks the skills to communicate HIV status to the child” (40.0% of articles), “parent fears shame/guilt” (20.0%), “parent

TABLE 2 | Number of articles citing the specific reasons caregivers offer for disclosing a child's HIV status to the child.

| Rationale for telling a child his or her HIV status | Number (%) of articles in which mentioned (N = 13) | Countries represented | Reference |
|---|--|--|--|
| Maintain the caregiver-child and other relationships | | | |
| Be the one to tell | 6 (46.2) | Uganda Thailand India S. Africa Zambia DRC | Atwiine et al. (23) Boon-Yasidhi et al. (26) Bhattacharya et al. (25) Mahloko and Madiba (33) Mweemba et al. (34) Vaz et al. (38) |
| Keep an honest relationship | 4 (30.8) | Thailand USA Zambia DRC | Boon-Yasidhi et al. (26) Lester et al. (32) Mweemba et al. (34) Vaz et al. (38) |
| Prepare child for disclosure of others' HIV | 1 (7.7) | USA | Lester et al. (32) |
| Child-related reasons | | | |
| Child's questioning/curiosity | 9 (69.2) | Uganda Thailand Nigeria Ghana USA S. Africa Zambia S. Africa DRC | Atwiine et al. (23) Boon-Yasidhi et al. (26) Brown et al. (27) Kalem et al. (30) Lester et al. (32) Mahloko and Madiba (33) Mweemba et al. (34) Naidoo and McKerrow (35) Vaz et al. (38) |
| Child's age/maturity | 6 (46.2) | Uganda Thailand Nigeria Ghana S. Africa DRC | Atwiine et al. (23) Boon-Yasidhi et al. (26) Brown et al. (27) Kalem et al. (30) Mahloko and Madiba (33) Vaz et al. (38) |
| Child's right to know | 5 (38.5) | Uganda Thailand Nigeria USA S. Africa | Atwiine et al. (23) Boon-Yasidhi et al. (26) Brown et al. (27) Lester et al. (32) Naidoo and McKerrow (35) |
| Social | | | |
| Explain discrimination/stigmatization | 2 (15.4) | Thailand Thailand | Boon-Yasidhi et al. (26) Oberdorfer et al. (36) |
| Prevention | | | |
| Reduce risks to self and others | 6 (46.2) | Uganda Thailand USA S. Africa DRC DRC | Atwiine et al. (23) Boon-Yasidhi et al. (26) Lester et al. (32) Mahloko and Madiba (33) Vaz et al. (38) Vaz et al. (39) |
| Illness-related explanations and events | | | |
| Improve adherence | 8 (61.5) | Uganda Nigeria DRC USA | Atwiine et al. (23) Brown et al. (27) Fetzer et al. (28) Lester et al. (32) |

(Continued)

TABLE 2 | Continued

| Rationale for telling a child his or her HIV status | Number (%) of articles in which mentioned (N = 13) | Countries represented | Reference |
|---|--|---|---|
| Promote self-care and general health | 5 (38.5) | Nigeria India Ghana USA DRC | Brown et al. (27) Bhattacharya et al. (25) Kalem et al. (30) Lester et al. (32) Vaz et al. (38) |
| Disease progression/symptoms | 4 (30.8) | Uganda S. Africa Thailand DRC | Atwiine et al. (23) Mahloko and Madiba (33) Oberdorfer et al. (36) Vaz et al. (38) |
| Start medication | 2 (15.4) | Thailand DRC | Oberdorfer et al. (36) Vaz et al. (39) |

fears rejection by the child" (20.0%), "parent fears child may reject drugs" (20.0%), and "parent fears questions from the child" (13.3%). The rationales appear to concern potential sociopsychological harm to the child or the family with only one rationale focused on managing the illness.

Correlates of Full Disclosure

It should be noted that for studies that assessed correlates/predictors of full disclosure rarely did the fact that the child was male or female or parent characteristics have an influence. More frequently, significant correlates were related to the child's illness and health. These included non-perinatal mode of transmission (25); the relative health of the child (feeling well, having hospitalizations, having new symptoms or suddenly worsening health) (35, 36, 40); other health transitions (e.g., starting ART) (25, 33, 40); and experience managing the illness (e.g., longer duration of illness, longer time on ART, self-administration of medicines) (25, 30). Child social and intellectual factors included life transitions (e.g., enrolling in school) (25, 33), and signs of cognitive maturity (being in school, being more educated, higher IQ) (30, 32, 33). For caregivers, both higher (25) and lower education (35) have been associated with disclosure. Disclosure of either the caregiver's HIV status to the child or the child's HIV status to other family members (23, 37) have been cited as promoting disclosure. Family communication factors have also been significantly associated with disclosure: children's persistence in asking questions about their illness (33) and a family environment that encourages the direct expression of feelings (32). Only the presence of the biological father seems to be associated with lower disclosure (30, 33, 36).

DISCUSSION

Eighteen articles, January 1996 through December 2015, cataloged caregiver's rationales for fully disclosing or not disclosing

TABLE 3 | How many are told, at what age, and by whom.

| Reference | Total child N | Age range of total sample | Mean age (SD) of total sample | N (%) of sample told | Age range when told | Mean age (SD) when told | Who told N (%) ^b |
|------------------------------|---------------|---------------------------|-------------------------------|----------------------|---------------------|-------------------------|---|
| Atwiine et al. (23) | 307 | 5–17 | Median 8 | 95 (30.9) | – | 11.6 (–) | Mother 47 (50.0) Other relative 28 (29.8) Father 10 (10.6) Grandparent 9 (9.6) |
| Bhattacharya et al. (25) | 145 | ≥5 | 9.1 (–) | 60 (41.4) | ≥5 | 9.1 (1.4) | Parents 51 (85.0) Other relative 6 (10.0) Health care 3 (5.0) Staff |
| Boon-Yasidhi et al. (26) | 96 | 5–15 | 8.6 (–) | 19 (20.0) | – | 9.6 (–) | Mother 7 (36.8) Step-parent 5 (26.3) Father 3 (15.8) Grandparent 3 (15.8) Sister 1 (5.3) |
| Brown et al. (27) | 96 | 6–14 | 8.8 (2.2) | 13 (13.5) | 4.5–13 | 8.7 (2.2) | Mother 6 (46.1) Father 3 (23.1) Stepmother 1 (7.7) Aunt 1 (7.7) Grandfather 1 (7.7) Health care 1 (7.7) Worker |
| Fetzer et al. (28) | 20 | 9–17 | – | 4 (20.0) | – | – | Caregiver 3 (75.0) Other 1 (25.0) |
| Kallem et al. (30) | 71 | 8–14 | 10.4 (1.7) | 15 (21.1) | – | 11.7 (1.9) | Caregivers 15 (100.0) |
| Lester et al. (32) | 51 | 6–10 | 8.3 (–) | 22 (43.1) | – | Median 9.7 | Caregivers 16 (72.7) Child knew 3 (13.6) Inadvertent 2 (9.1) Health care 1 (4.5) Worker |
| Mahloko and Madiba (33) | 149 | 4–17 | 8.2 (3.1) | 59 (39.6) | 4–17 | 9.3 (2.9) | Mother 23 (39.7) Grandparent 17 (29.3) Health care 13 (22.4) Worker Other relative 5 (8.6) |
| Mweemba et al. (34) | 30 | 10–15 | 11.9 (–) | 17 (56.7) | 10–15 | 12.2 (–) | – |
| Naidoo and McKerrow (35) | 100 | 8–14 | 10.9 (–) | 27 (27.0) | – | 11.6 (0.3) | Parent 23 (84.6) Grandparent 3 (11.5) Nurse 1 (3.9) |
| Oberdorfer et al. (36) | 103 | 6–16 | 9.5 (–) | 31 (30.1) | 4–15 | 9.2 (3.0) | Grandparent 10 (32.2) Health care 9 (29.0) Provider Mother 5 (16.1) School friends 5 (16.1) Other relative 2 (6.4) |
| Vaz et al. (38) ^a | | | | 19 | 10–18 | 15.0 (–) | Health care 11 (52.4) Worker Parent 9 (42.9) Inadvertent 1 (14.3) |
| Vaz et al. (39) ^a | | | | 8 | 8–16.5 | 12.6 (–) | Mother 5 (71.4) Father 1 (14.3) Health care 1 (14.3) Worker |

^aVaz et al. (38, 39) studied only HIV+ youth who had been disclosed to; thus, the proportion who experienced disclosure could not be calculated.

^bIn some cases, the number of caregivers is greater than the number of children told, because the youth were told jointly by multiple caregivers; in others, the number of caregivers is less because multiple children were told.

children's HIV status to children 12 and under post-ART. The studies covered an age range for children from 4 to 18, and across 11 countries, including 9 targeted by the United Nations for the

elimination of childhood HIV, documented an average rate of disclosure of 31%. On average, HIV+ children who were told were over 10, well beyond the recommendation to tell school-age

TABLE 4 | Number of articles citing the specific reasons caregivers offer for not disclosing a child's HIV status to the child.

| Rationale for not telling a child his or her HIV status | Number (%) of articles in which mentioned (N = 15) | Countries represented | Reference |
|---|--|---|--|
| Parent-child relationship reasons | | | |
| Fears anger/blame from child | 8 (53.3) | Uganda Thailand Nigeria Uganda USA S. Africa | Atwiine et al. (23) Boon-Yasidhi et al. (26) Brown et al. (27) Kiwanuka et al. (31) Lester et al. (32) Mahloko and Madiba (33) Mweemba et al. (34) Naidoo and McKerrow (35) |
| Fears rejection by child | 3 (20.0) | Thailand USA Uganda | Boon-Yasidhi et al. (26) Lester et al. (32) Kiwanuka et al. (31) |
| Fears questions from child | 2 (13.3) | USA S. Africa | Flanagan-Klygis et al. (29) Mahloko and Madiba (33) |
| Child-related reasons | | | |
| Anticipates negative psychological reaction by child | 14 (93.3) | Ethiopia Uganda Thailand Nigeria USA Ghana Uganda USA S. Africa Zambia S. Africa Thailand Ethiopia Kenya | Abebe and Teferra (22) Atwiine et al. (23) Boon-Yasidhi et al. (26) Brown et al. (27) Flanagan-Klygis et al. (29) Kalleem et al. (30) Kiwanuka et al. (31) Lester et al. (32) Mahloko and Madiba (33) Mweemba et al. (34) Naidoo and McKerrow (35) Oberdorfer et al. (36) Tadesse et al. (37) Vreeman et al. (40) |
| Too young to understand | 13 (86.7) | Ethiopia Uganda Thailand Nigeria USA Ghana USA S. Africa Zambia S. Africa Thailand Ethiopia Kenya | Abebe and Teferra (22) Atwiine et al. (23) Boon-Yasidhi et al. (26) Brown et al. (27) Flanagan-Klygis et al. (29) Kalleem et al. (30) Lester et al. (32) Mahloko and Madiba (33) Mweemba et al. (34) Naidoo and McKerrow (35) Oberdorfer et al. (36) Tadesse et al. (37) Vreeman et al. (40) |
| Child unable to keep a secret | 10 (66.7) | Ethiopia Uganda Thailand Nigeria | Abebe and Teferra (22) Atwiine et al. (23) Boon-Yasidhi et al. (26) Brown et al. (27) |

(Continued)

TABLE 4 | Continued

| Rationale for not telling a child his or her HIV status | Number (%) of articles in which mentioned (N = 15) | Countries represented | Reference |
|--|--|---|---|
| Potential social rejection of child | 9 (60.0) | USA DRC USA Uganda USA S. Africa Zambia S. Africa Thailand Kenya | Flanagan-Klygis et al. (29) Kallem et al. (30) Lester et al. (32) Mahloko and Madiba (33) Oberdorfer et al. (36) Tadesse et al. (37) Fetzer et al. (28) Flanagan-Klygis et al. (29) Kiwanuka et al. (31) Lester et al. (32) Mahloko and Madiba (33) Mweemba et al. (34) Naidoo and McKerrow (35) Oberdorfer et al. (36) Vreeman et al. (40) |
| Caregiver-related reasons | | | |
| Caregiver feels he/she lacks the skills to communicate HIV status to the child | 6 (40.0) | Uganda Thailand Uganda S. Africa Zambia S. Africa | Atwiine et al. (23) Boon-Yasidhi et al. (26) Kiwanuka et al. (31) Mahloko and Madiba (33) Mweemba et al. (34) Naidoo and McKerrow (35) |
| Parent fears shame/guilt | 3 (20.0) | Uganda Thailand Zambia | Atwiine et al. (23) Boon-Yasidhi et al. (26) Mweemba et al. (34) |
| Illness-related reasons | | | |
| Fears child may reject drugs | 3 (20.0) | Nigeria S. Africa Ethiopia | Brown et al. (27) Naidoo and McKerrow (35) Tadesse et al. (37) |

children (primary school starting ages are typically 5–7 worldwide according to World Bank Data²) or the age of assent, 7 years old, for children in clinical trials (18, 41, 42). Indeed some studies did not include children in lower age ranges [e.g., Ref. (32, 39)] restricting the range for mean age of disclosure. A few children learned their HIV status inadvertently; a significant minority was told by grandparents, other relatives or by health-care providers; an apparent majority were told by biological parents.

Although data were gathered principally from urban treatment centers, 69% of the more than 1,100 children and youth in these studies had not learned their HIV status.

Across articles, caregivers cited reasons *for* disclosing that emphasized the child's needs (the child's questions or curiosity,

²<http://data.worldbank.org/indicator/SE.PRM.AGES>

child's age/maturity, child's right to know, explain discrimination), maintenance of an open caregiver-child relationship (be the one to tell, keep an honest relationship, prepare the child for the disclosure of others' HIV), and enlisted the child's cooperation in promoting health and protecting others (improve adherence, assist child to reduce risks to self and others, promote self-care and general health, explain disease progression and/or symptoms, start medication) (23, 25–28, 30, 32–36, 38, 39). In addition, external events, such as enrollment in school (25, 33) or admission to the hospital (35, 36, 40), were cited as motivating disclosure.

Reasons for *not* disclosing concerned fears about potential sociopsychological harm to the child (anticipation of the child's negative psychological reaction, child is too young to understand, potential social rejection of the child) or to the family (child is unable to keep a secret, parent fears anger/blame from the child, caregiver feels he/she lacks the skills to communicate HIV status to the child, parent fears shame/guilt, parent fears rejection by the child, parent/caregiver fears questions from the child) (22, 23, 26–37, 40) with one rationale focused on managing the illness (caregiver fears child may reject drugs) (27).

Some of these fears have merit as documented by a number of studies. Children's initial reactions of sadness, worry, confusion, and shock have been described (36, 39, 43), as have instances of discrimination and bullying at school and in communities (1, 8, 44). Caregivers and even health-care providers may lack the knowledge and skills to effectively communicate an HIV diagnosis to the child (45), and some of this may be due to HIV+ caregivers' own negative disclosure experiences (3).

However, an even broader literature indicates that children's initial reactions dissipate relatively quickly over time (43, 46) and may be overestimated by caregivers, especially caregivers who themselves have issues of anxiety or depression (35, 47). At least one study, interviewing children, reported that disclosure was not associated with more negative psychological outcomes (40). Knowing one's HIV status does appear to be associated with stable or improved child well-being (18, 48) and disease management (11–13). Children, themselves, reflecting on disclosure often mention a sense of relief, wishing that disclosure had happened earlier, that their questions had been answered more directly and that more support had been available initially and subsequently in the family, community, and health-care setting (33, 39, 45, 49, 50). In some studies, children also described their own improved adherence (28, 40).

Regarding discrimination, the literature seems to suggest intervention at the local, institutional, and national policy level. It is not only children with HIV who experience teasing and bullying – often especially upsetting to children because of pervasive messages about sexual transmission – but those *presumed* to have HIV because of a rash, an illness, a family illness, slight stature, or geographic location of high HIV prevalence, whether indeed they have HIV or not (1, 6, 44).

Research Recommendations

Include a Broader Set of Populations

In the search for articles worldwide that focused on caregiver reasons for disclosure to children, only 9 of the 22 high

priority countries for the elimination of childhood HIV were represented (10). Missing from the 18 articles found were the remaining 13 countries: Angola, Botswana, Burundi, Cameroon, Chad, Cote d'Ivoire, Lesotho, Malawi, Mozambique, Namibia, Swaziland, United Republic of Tanzania, and Zimbabwe. Thus, we do not know if the limited set of rationales, documented here and relatively stable across the countries studied, would also hold for the remaining highly affected countries.

Samples were almost always drawn from urban treatment centers. Many excluded orphans or children at boarding schools. Almost all focused exclusively on perinatally infected children and youth. Thus, our picture of disclosure to children would be enhanced by looking at rural, out-of-treatment, orphaned, boarding school, and non-perinatally infected children as well (22, 31, 51). Some research programs in progress have made steps in that direction (25, 27, 34, 45, 52); some have conducted research at community sites overcoming biases toward studying only treated populations and overcoming barriers to participation in research such as travel to health center research sites [e.g., Ref. (22)].

Gather Data in a Way That Enhances Systematic Review or Cross-Study Comparisons

Data standards, such as CONSORT,³ recommend collection of summary statistics *and* their precision. That is, statistics ought be reported with accompanying measures of variability; many times, mean age at disclosure was reported without a measure of variability such as the SD; sometimes only frequencies of varying age ranges were reported (e.g., ages 5–9, 10–12, etc.) from which the current authors may or may not have been able to calculate a summary measure such as the median. Standards were often not met regardless of qualitative, quantitative, or mixed-method approaches.

Improve Description with More Precise Measures

Articles differed in the precision with which variables were described, e.g., some articles excluded from the current summary did not specify whether the age of the child at the time of disclosure or age at time of interview about disclosure were being discussed. In describing who disclosed, some articles indicated "caregivers" or "health-care personnel," while others specified the precise relationship of the discloser to the child (e.g., grandfather) or the exact role of the health-care provider (e.g., nurse, infectious disease doctor). Some indicated who was present when a number of individuals participated in disclosing (e.g., multiple people, suggesting some caregivers rely on the simultaneous support of health-care providers and other family members). The greater the precision, the easier it is to make cross-study comparisons and summaries. Further, the literature indicates that health personnel in differing roles may have differing attitudes (34, 53) and that caregivers in differing relationships may have differing issues about HIV disclosure (3, 15). Doctors appear to be greater advocates of early disclosure; HIV+ parents and grandparents may be involved in disclosing their own and relatives' HIV along with the HIV status of the child (4).

³<http://www.consort-statement.org/>

No article asked the caregivers to reflect in a systematic way (e.g., Likert scales, paired comparison) on what experiences or what rationales were most influential in making the disclosure decision. Only one article (29) tried to eliminate the social desirability reporting bias that comes with face-to-face interviews or questionnaires handed directly to study personnel. New techniques, used with low literacy populations, may help reduce such biases by using voice recordings of questionnaires/interviews with study personnel available for assistance.

Improve Prediction with Longitudinal Data and Child Well-being Outcome Measures

By definition, the articles summarized here dealt with reflection on past behavior and thus were subject to biases of memory. Most studies relied on caregivers' recall about date of disclosure, child reactions, and who may have been present. In fact, sometimes HIV+ children's and caregivers' accounts did not agree (14, 26, 35). Further, although a rationale may be thought to be influential, until research occurs pre- to post-disclosure, its influence cannot be verified. For example, Jemmott et al. (54), in research on *intention* to disclose found multiple reasons endorsed, but only normative beliefs – the perception that friends, relatives, and others important to the caregiver would want them to tell the child – and self-efficacy – belief they can tell the child – were significant predictors in a multiple regression of the intention to disclose. Further, it is as yet unknown, whether "telling" under certain circumstances or for certain reasons is more or less beneficial for the HIV+ child in physical and mental health domains and in social adjustment.

Longitudinal analysis about illnesses can be exacting (48): over time individuals get better with treatment or decline, older age brings new challenges such as older youth being more involved in maintaining their own treatment, caregiver-child relationships change with time, health-care settings, and personnel change with time. Disclosure unfolds alongside these processes. Documentation over time would inform interventions that could meet time- and maturation-dependent challenges.

Transition to Evaluation of Interventions

As suggested by multiple authors (14, 18, 27, 30), the research question no longer seems to be whether or not to fully disclose to children, but when and how. Several promising interventions have been designed or piloted (9, 15, 55, 56), with their common elements described below under clinical recommendations. Nearly all carry with them advice to be age- and context-sensitive.

Measure and Report Context at the Individual, Family, Community, Institutional, and National Levels

In largely quantitative articles, however, context is rarely described beyond a few characteristics of the affected children, their caregivers, several attributes of the family situation (e.g., child being raised by relatives, or an HIV+ parent) or where disclosure took place (e.g., home or clinic setting). The articles, providing background for this review, that do describe context – sometimes in case studies, policy papers or research on allied topics such as adherence – are compelling. A few examples will suffice: dilemmas faced by a grandmother who had promised her deceased

daughter to never reveal the daughter had died of AIDS, but now discovers the grandchild she is raising is HIV+ (57); disclosure occasioned in a rural district by the child having to travel alone to get care (34); the differing issues for child-headed households in post-genocide Rwanda (8); marginalized and at-risk child and youth populations in India such as street children and children pressed into sex trade (51); secrecy and collusion about illness and medicine-taking within families in a community with high stigmatization of HIV (5); cultural conflict when fathers are family decision-makers, but mothers manage health care and are being told to disclose (15); and the surprise an HIV+ child felt when told her HIV+ status by an apparently healthy HIV+ adult nurse because of the child's assumptions about how HIV progresses (58). Again some research programs are beginning to assess not only caregiver and health-provider attitudes but attitudes and policies of surrounding communities and institutions such as health-care clinics, hospitals, churches, and schools (1, 7, 8, 52, 54, 59), leading to additional targets for intervention. Systematic reporting about issues at multiple levels will aid context-sensitive full disclosure.

Improve Understanding with Mixed Qualitative–Quantitative Research

Several studies summarized here reported comments by older children, caregivers, and health-care providers reflecting on disclosure experiences. Such qualitative data were illuminating. For example, several disclosures were initiated because children did not understand why they had to keep taking medicines if their symptoms had disappeared (28, 34). Importantly, some researches documented that children who had not been told, already knew or suspected their diagnosis (35), or children who supposedly knew had not understood the disclosure fully (26, 40). Children in one study reported having questions post-disclosure while caregivers were unaware of their questions (39). Qualitative data, especially from the viewpoint of the children whose well-being is being fostered, can anticipate and correct likely misunderstandings.

In additional research (50, 60), older youth also indicated where they received valuable support for coping with HIV, described more fully below (see Expand Training before Full Disclosure).

Clinical Recommendations

Abrupt, delayed, or inadvertent disclosure has been described as harmful (15), while full disclosure has been cited as helpful to HIV+ children (18). As described in Sections "Common Elements in Interventions for Full Disclosure," "Expand Training before Full Disclosure," "Expand Support during Full Disclosure," and "Expand Support after Full Disclosure" interventions are being developed to assist caregivers and children before, during, and after full disclosure so that the potential health benefits of full disclosure can be realized, and potential negative effects anticipated and ameliorated.

Recommended Age for Disclosure

While caregivers' attitudes and beliefs about the best age for disclosure vary widely, systematic guidelines recommend age-appropriate disclosure to school-age children (18). While

caregivers hold understandable concerns about potential negative consequences for children of early school age, objective information about children's short-term reactions such as shock and fear and about long-term benefits such as improved adherence to health regimens may mitigate these worries and provide the impetus for full disclosure. Health-care providers also may often be unaware of best practices in terms of child age; for example, they may lack knowledge of how to use age-appropriate language during full disclosure (9, 15, 55, 56).

Common Elements in Interventions for Full Disclosure

Several systematic disclosure interventions have been designed or piloted (9, 15, 55, 56). They have the following common elements: (1) train health-care providers to assist with disclosure, (2) elicit caregiver concerns regarding disclosure, (3) assess child and caregiver readiness for full disclosure, (4) improve readiness by addressing concerns and rehearsing communications to child, (5) disclose with requested assistance, and (6) follow-up with assessment. Generally, the interventions take place in a health-care setting.

Expand Training before Full Disclosure

Several articles have suggested the need for training before full disclosure for health personnel, for parents/caregivers, and for children (22, 23, 26–31, 33–35, 37–39). Commonly, pre-disclosure interventions suggest responding to triggers such as questions from the child in honest, age-appropriate ways: for example, explaining about germs and medicines with drawings, and analogies such as the body protecting itself with little soldiers and medicines to help the soldiers (56, 58). Suggestions for health personnel include the use of simple language – terms such as “positive” have a vernacular meaning – and educating caregivers about HIV (57).

However, it also seems to be the case that garnering the community support that will ultimately be needed ought to begin prior to full disclosure [e.g., Ref. (32)]. HIV+ children, ages 10–14, reflecting on their disclosure experiences, commented that safe persons (relatives and friends who knew and understood) and safe places (e.g., a church group) were particularly helpful to them in their adjustment to living with HIV after learning their diagnosis (50). But schools have often been described as not safe. At least one article suggests that few families disclose to school personnel but may need special school services for their HIV+ children (61). It seems reasonable that educative efforts should be extended to these ultimate sources of support, especially since the majority of children in the articles summarized here are in school, some in boarding school separated from family supports (22, 25, 27, 30, 33, 37).

Expand Support during Full Disclosure

Blasini et al. (55), in early work, stressed the importance of letting caregivers decide whether they wanted to disclose alone or with the assistance of health-care providers. Preferences in the articles summarized here seem to vary country to country and person to person, with some caregivers wishing to disclose alone, or with other relatives present, or with assistance from health-care

providers, or with another complement of individuals (22, 30, 35). Some caregivers wished to defer and let health-care providers disclose directly to the child (7). Sometimes the caregiver decision was co-opted by the health-care system; disclosure occurred without caregiver input [e.g., Ref. (41, 43)]. In some cases, caregivers were actively discouraged from disclosing by health-care personnel (23, 34). Neither article explicated the health-care worker's reasons for being discouraging, but one documented the caregivers' strong perception of health personnel's negative attitudes toward disclosure (34).

Older HIV+ youth reflecting on their earlier disclosure experiences may be an important source of decision-making. In at least one study (62), health-care workers encouraged disclosing alone at home, while youth preferred disclosure with health personnel and the caregiver in a health setting. Youth also often complained that their questions were not heard or answered; communication was directed to adults rather than to them (39). These two studies concern youth who had been told when they were older than early school age. It is likely that preferences might vary by context and child maturity.

Consensus guidelines on breaking bad news in the field of cancer suggest that disclosure should take place across several meetings including enough time to assess the patient's understanding and emotional status, encourage expression of feelings and respond empathetically, arrange a time to review the situation, offer assistance telling others, and provide information about support services as well as discussing treatment (63, 64). Yet, some caregivers in the studies reviewed here believed disclosure should be a discreet event (31).

Expand Support after Full Disclosure

Several articles recommended continuing supports for both caregivers and children post-disclosure (13, 22, 28, 31). Peer groups would assist both caregivers and children to adjust to HIV post-disclosure as would continuing education about HIV and its treatment. Caregivers may need support concerning caregiver-child communication, including appropriate language to use with children, how to explore local cultural factors influencing adjustment to illness, and how to deal with caregiver or child fears about the consequences of disclosure (16). Children may need resources to deal with stigmatizing experiences, to support their physical and mental health, and to aid their access to health care.

Concluding Statement

The emphasis on whether or not to disclose an HIV diagnosis to children, driving research since the early 1990s, has now shifted to when and how children should be told. Recent evidence suggests that caregivers may want to tell an HIV+ child that the child has HIV, but may fear negative consequences for their families and children. To alleviate their concerns, more support may be necessary prior to, during, and after disclosure. The nature of this support should include the voices of older HIV+ youth aware of their diagnoses, caregivers, health-care providers, and those knowledgeable about local context. To address stigma, support may require changes in institutional policies to address stigmatizing behaviors, encourage physical/mental health, and foster

social acceptance in the communities where HIV+ children live. To promote child well-being across the local, institutional, and national contexts that HIV+ children face, future research should aim toward developing “best practice” child-sensitive and context-sensitive standards of HIV disclosure for caregivers and health-care providers.

AUTHOR CONTRIBUTIONS

BK and SL made substantial contributions to the conception, design, acquisition of articles, analysis, and interpretation of data for this review. BK and SL had been part of the team that drafted the WHO guideline for disclosure to children 12 and under (18), looking at literature through June 2010 on outcomes for children who had and had not been disclosed to. CO made substantial conceptual and interpretive contributions. For her Capstone Paper in fulfillment of a Master’s Degree in Urban Public Health at City University of New York School of Public Health, Spring 2011, CO focused on the reasons caregivers gave for disclosure within an expanded HIV disclosure literature. The current review updates literature from January 1996 through December 2015 concentrating on caregiver reasons for disclosing and not

disclosing to HIV+ children 12 and under. All authors have read, revised, and approved the manuscript, and are accountable for the accuracy of its content.

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The Impact of Disclosure on Health and Related Outcomes in Human Immunodeficiency Virus-Infected Children: A Literature Review

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This review explores the association between pediatric human immunodeficiency virus (HIV) disclosure and health and related outcomes among children living with HIV. A multi-stage process was used to search for relevant articles on the ISI Web of Knowledge database. Fifteen articles met the inclusion criteria. Five major outcomes emerged from children's knowledge of their HIV-seropositive status: physical/physiological outcomes; adherence to antiretroviral therapy; psychosocial outcomes; sexual and reproductive health, including HIV prevention outcomes; and disclosure of status by the children. Disclosure of a child's HIV status to the child has value in terms of positive health outcomes for the child, such as better adherence and slower disease progression—albeit the different studies did not always reach the same conclusions, and some suggest negative health outcomes, such as increased psychiatric hospitalization. Yet, there does not seem to be a systematic or coherent system for child disclosure. One recommendation from this review, therefore, is for government and program policies and guidelines that will promote child HIV disclosure in order to address the current low rates of disclosure in sub-Saharan Africa (SSA). More rigorous and longitudinal studies on the outcomes of disclosure, with larger sample sizes, and in SSA, are also needed.

Keywords: human immunodeficiency virus, children living with human immunodeficiency virus, pediatric disclosure, health outcomes, review

INTRODUCTION

More than 80% of the estimated 1.8 million children <15 years infected with human immunodeficiency virus (HIV) in 2015 lived in sub-Saharan Africa (SSA) (1). The global initiative—*The Global Plan toward the elimination of new HIV infections among children by 2015 and keeping their mothers alive (Global Plan)*—was launched in 2011 at the United Nations General Assembly High Level Meeting on acquired immune deficiency syndrome (AIDS) (2). The plan prioritized the 22 countries that in 2009 accounted for 90% of the global mother-to-child HIV transmission burden: 21 of the Global Plan priority countries were in SSA. Among other things,

Abbreviations: AIDS, acquired immune deficiency syndrome; ART, antiretroviral therapy; ARV, antiretroviral drug; CLHIV, children living with HIV; HCW, health care worker; HIV, human immunodeficiency virus; PMTCT, prevention of mother-to-child transmission of HIV; QoL, quality of life; SDQ, strengths and difficulties questionnaire; SRH, sexual and reproductive health; SSA, sub-Saharan Africa.

the plan sought to increase the coverage of prevention of mother-to-child transmission of HIV (PMTCT) interventions and reduce the incidence of new infections in children. At the end of the initiative in 2015, there were remarkable results as a result of significant increases in access to antiretroviral (ARV) drugs, with six priority countries meeting the Global Plan goal of 90% ARV coverage for pregnant women living with HIV; a reduction in final mother-to-child transmission rates to 8.9% from 22.4% in 2009 (with four countries reaching the milestone of <5% transmission); and 60% decline in new infections in children in the 21 SSA priority countries (3). Despite this progress, PMTCT programs in resource-limited countries are still fraught with challenges. Consequently, many children continue to be infected perinatally with HIV. In 2015, there were 150,000 new HIV infections in children 0–14 years globally. Of these, 122,000 (> 80%) were in SSA (1). Data suggest that 60% of these new infections may be happening during breastfeeding, due to poor treatment adherence and systems for following up breastfeeding HIV-positive women and their babies (2). However, as a result of increased ARV availability to these children, they are living longer (4). Thus, a generation of children living with HIV (CLHIV) is coming of age. As these children approach adolescence, many of them have not been disclosed to. The term *disclosure*, in this context, refers to informing children that they have HIV.

The World Health Organization *Guideline on HIV Counseling for Children up to 12 years of Age* recommends that children of school age (6–12 years) be told they have HIV (5). The American Academy of Pediatrics also recommends HIV status disclosure to school aged children (6). Disclosure prevalence from four studies in developing countries ranged from 29 to 62% (4). Vaz et al. (4) reported only 3% pediatric disclosure in their study in the Democratic Republic of Congo, while Vreeman et al. (7) also reported almost 100% non-disclosure in Kenya. More recent studies in SSA have similarly reported low disclosure rates—13.5% (8) and 30.9% (9) in Nigeria; 21% (10) in Ghana; 17.4% (11) and 39.5% (12) in Ethiopia; 19% (13) and 26% (14) in Kenya; and 32.6% (15) in Côte d'Ivoire.

Factors that influence pediatric disclosure include child's age and cognitive development (10, 12); concerns around antiretroviral therapy (ART) adherence (8, 9); imminent onset of sexual activity (4); and the need to protect others from infection (16). Benefits of pediatric disclosure include improved adherence to ART, and psychosocial well-being and mental health (17). Despite these benefits of disclosure, non-disclosure remains high because of the association of HIV-positive status and promiscuity in parents (18). Disclosure of HIV status to CLHIV or to adult partners remains "navigation in a moral field" (18). Therefore, to protect the family name and one's reputation, and avoid rejection and discrimination, many parents choose not to disclose HIV status to children (18). Other reasons for non-disclosure include caregivers' concerns that children were too young (9, 10) and caregivers' fear of the psychological impact of disclosure on the children (8, 12).

Literature on disclosure suggests that when disclosure does happen, it is not done in a systematic way (4, 19). The process remains largely context dependent. Also, many SSA countries do

not have clear and detailed policies and guidelines on pediatric disclosure. Yet, disclosure could be a potent force in the prevention and control of HIV infection to those not infected (4, 20). And for those who are already infected, it provides an opportunity for improved quality of life (QoL) for the HIV infected and their families, slowing of disease progression (4).

This literature review, therefore, explores the association between pediatric disclosure, i.e., disclosure of child's seropositive HIV status, and health outcomes among CLHIV: is there any correlation between HIV disclosure and improved or worsened health—physical, psychological, or other dimensions of health? While the review looked at pediatric HIV disclosure in all contexts, particular interest was on SSA, since most CLHIV reside in this part of the world (21). This review focuses solely on the impact of disclosure, unlike other reviews (22, 23), which focused on themes such as process, prevalence, impact, and other aspects of disclosure. As such, this review looks at disclosure outcomes in more detail and highlights these findings in-depth, as a result of its single focus.

METHODS

Search Process

A multi-stage process was used to search for data on disclosure of HIV status to CLHIV in 2011. Articles pertinent to the research question, "The Impact of Disclosure on Health Outcomes for HIV-Infected Children," were searched for in the ISI Web of Knowledge database, using the terms arrangement as follows: ((Child* OR adolescent OR p*iatric OR perinatal*) AND (HIV OR status) AND (Diclos*)). This database was expected to provide a robust number of search findings. The search strategy was repeated in 2014 for additional peer-reviewed articles that may have been published since the last search. This second search was limited to studies conducted in SSA, since that was the region of immediate interest. This decision was informed by the assumption that more readily applicable research findings would likely come from similar SSA settings.

Inclusion Criteria

Only articles on studies published in peer-reviewed journals were included in the review. Articles had to focus on disclosure of HIV status to children (persons under 18 years) living with HIV and be based on primary data collection. Since it was anticipated that there would be a wealth of available primary data on the subject (and there were) systematic reviews or meta-analyses were not included in the review. Commentaries were also not included in the review. Studies could be qualitative or quantitative, or both. However, they had to contain an explicit definition of the term disclosure or a clear indication that children knew their positive HIV-serostatus, and the consequences and outcomes of such disclosure as a dependent or independent variable. Studies could focus on only children to whom their status had been disclosed to them, or also contain a control group whose status was not disclosed to them. The most important element was that studies were

limited to those where full disclosure of HIV status was done. “A child was considered to be fully informed of his or her status if the term HIV, AIDS, or any local term specifically associated with HIV/AIDS has been used in a discussion with the child about the child’s health”—[page 248 of Ref. (4)]. Reviewed articles also had to include a clear description of the population size, data collection process, the independent and dependent variables (for quantitative studies), how data were analyzed, and the main themes from data analysis (for qualitative studies).

Exclusion Criteria

Disclosure studies of HIV status of others—adults and parents—were not included. Only studies where disclosure was by a parent, caregiver, or health care provider were included. Studies where children learned of their serostatus inadvertently through other sources were not included in the review, as it is believed that the effect of such disclosure may be different from that through a controlled environment through a parent/caregiver or health provider.

Studies where there was only partial disclosure, i.e., discussing with children about the child’s health in general terms, without specific mention of HIV or AIDS, and non-English language articles were not included. There was no time limit or country or regional restriction to the studies or publications included in the review from the first search. However, the second search was limited to only SSA studies.

Identified Studies

The initial search in 2011 yielded a total of 426 articles. After a review of the article titles, 242 articles that were not relevant to the research question were eliminated from further search. Abstracts for the remaining 184 articles were reviewed, after which a further 144 articles were excluded because of content

(135), three were in French, and the rest were editorials, articles, and letters. Another three articles could not be retrieved from the UNC library. No further attempts were made to retrieve the articles.

Full text of the 44 articles that appeared relevant to the research question was then reviewed for eligibility. Fifteen articles from this initial search in 2011 met the inclusion criteria, but two articles were publications on the same study, so one was eliminated from further review (**Figure 1**).

An additional eight studies were identified from the 2014 search. While all reported disclosure rates and factors that affected status disclosure, only one study assessed the association between disclosure and health outcomes, namely ART adherence, and stigma and depression (14), and was included in the review, making a total of 15 articles that were included in the review (**Table 1**).

Due to the limited number of studies that met the inclusion criteria, the inclusion of articles did not focus on their internal validity based on the study approaches, strong statistical power, or an experimental approach. Nor was the external validity of articles a limiting factor in terms of a large study population, random sample, and explicit analysis of context and intervention factors for which generalization is possible. (The impact is discussed under the Discussion section, as a limitation of the studies in this review.)

Data Extraction

Information on authors, year of article, and country where study was conducted, participant characteristics (study participants, children’s age), and study characteristics (sample size, study type and design, type of analysis, dependent and independent variables, results, statistics, significance, and study validity information), and the health outcomes of disclosure were extracted from the studies (see **Table 1**).

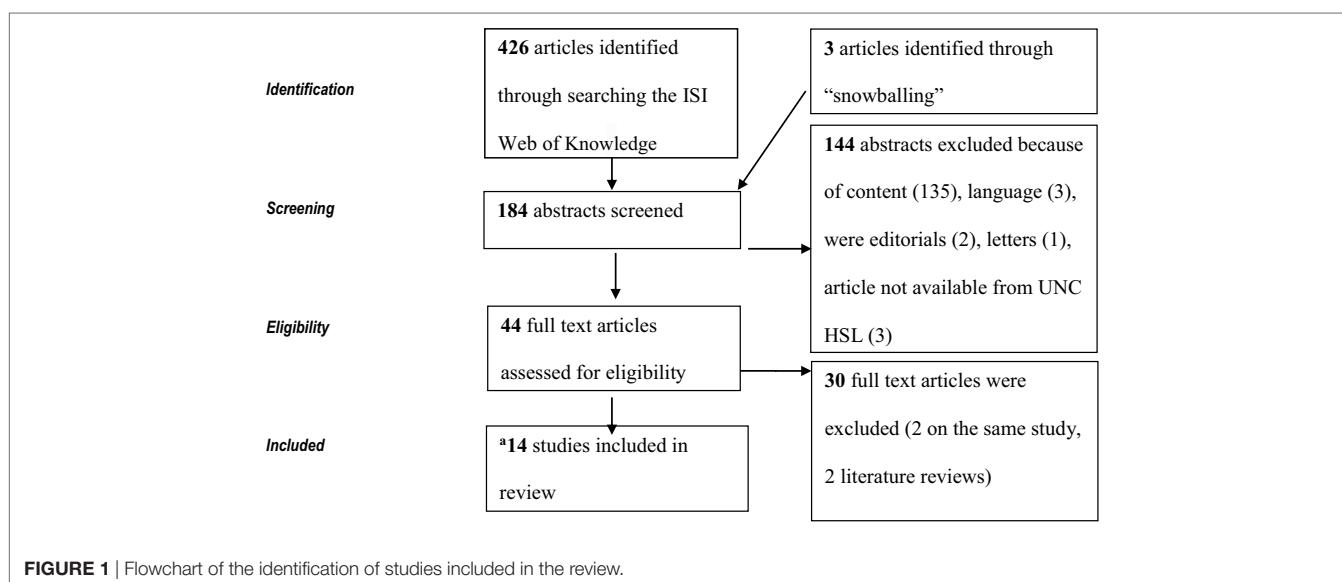


FIGURE 1 | Flowchart of the identification of studies included in the review.

TABLE 1 | Effect of human immunodeficiency virus (HIV) disclosure on health and related outcomes.

| # | Effect of disclosure on health outcomes | Reference | Study goal | Country | Sample size | Study type | Study design | Type of analysis | Independent variable | Dependent variable | Results |
|---|---|-------------------------|--|----------------|--|------------------------------|--|---|--|---|--|
| 1 | Mental and psychosocial outcomes; Sexual and reproductive health outcomes; Child's disclosure of status to others | Battles and Weiner (29) | Examine psychosocial factors associated with long-term survival of pediatric HIV infection | USA | 80 parent–children living with HIV (CLHIV) dyads | Quantitative | Descriptive longitudinal study | Pearson product moment relations, Chi-square, Student's <i>t</i> tests | HIV disclosure Child's disclosure of status to others | Social support, child (problem) behavior, self-perception, competence | Of 67 disclosed CLHIV, 4 had psychiatric hospitalization, 19 clinical anxiety, and 25 clinical depression 21 disclosed CLHIV were sexually active—with or without condom use Pearson product moment correlations showed that disclosure was positively related to social support ($r = 0.35, p < 0.05$), self-competence ($r = 0.35, p = 0.08$), decreased problem behavior ($r = -0.21, p = 0.08$). However, public disclosure (i.e., disclosure through television and newspaper), showed negative association with global self-competence ($F = 3.5, p < 0.05$) |
| 2 | Sexual and reproductive health outcomes; Child's disclosure of status to others | Birungi et al. (20) | Examine sexual expressions and experiences and preventive practices and needs of CLHIV | Uganda | 732 CLHIV 4 health care workers (HCWs) | Qualitative and quantitative | Cross-sectional study | Quantitative: cross tabulations, Chi-square, significance tests of proportions; qualitative: content analysis | HIV disclosure | Condom use, contraceptive use; HIV status disclosure to others | 47% of (disclosed) CLHIV who had ever had sex reported currently using condoms, compared to general adolescent population (15–19 years) who had ever had sex, where 44% had ever used any form of contraception and only 11% reported currently using condoms 49% of 158 CLHIV in a current relationship had disclosed to their partners |
| 3 | Adherence to treatment; Mental and psychosocial outcomes; Child's disclosure of status to others | Blasini et al. (27) | Describe effect of disclosure on health care professionals, caregivers, and HIV-infected youth | Puerto Rico | 40 CLHIV 39 caregivers 16 HCWs | Quantitative | Quasi experimental design (comparison of before and after disclosure). | Fisher's exact test | HIV disclosure | Sadness, worry, insecurity, and other psychosocial outcomes | 42% CLHIV felt sad immediately after disclosure. At 6 months, 70% youth reported normalcy. One patient reported depression after 6 months 62% CLHIV chose not to disclose their status to others. 38% CLHIV disclosed to close family (siblings and cousins) 58% CLHIV reported better adherence to treatment after disclosure |

(Continued)

TABLE 1 | Continued

| # | Effect of disclosure on health outcomes | Reference | Study goal | Country | Sample size | Study type | Study design | Type of analysis | Independent variable | Dependent variable | Results |
|---|--|----------------------|---|----------------|--------------------------------|-------------------|---|---|-----------------------------|--|--|
| 4 | Physical/physiological outcomes; Mental and psychosocial outcomes | Butler et al. (26) | Examine impact of disclosure on health-related pediatric quality of life (QoL) and describe distribution of age at disclosure | USA | 395 CLHIV (2,423 study visits) | Quantitative | Prospective cohort study (PACTG 219 C, comparison of QoL domains before and after disclosure) | Wilcoxon signed rank tests, multivariate mixed-effects model | HIV disclosure | Six QoL domains: (general health perception, symptom distress; psychological status, physical functioning; social/role functioning, and health care utilization) | In mixed-effects models, disclosure did not significantly impact QoL for any domain when comparing before and after disclosure: General health perception ($p = 0.70$); symptom distress ($p = 0.31$), psychological status ($p > 0.999$), physical functioning ($p = 0.79$); social/role functioning ($p = 0.69$); health care use ($p = 0.61$) |
| 5 | Mental and psychosocial outcomes; Child's disclosure of status to others | Campbell et al. (33) | Investigate impact of HIV transition program on participants' lives | UK | 6 CLHIV | Qualitative | Individual interviews (by telephone or in-person) | Thematic approach | HIV disclosure | Disclosure to others; hopes for the future | CLHIV were hopeful about the future However, they expressed concerns about disclosure to romantic/sexual partners |
| 6 | Physical/physiological outcomes | Cohen et al. (25) | Describe issues related to school attendance and HIV disclosure to CLHIV | USA | 92 CLHIV | Quantitative | HIV surveillance, cross-sectional clinic survey, abstraction of medical records | χ^2 , logistic regression | HIV disclosure | Clinical severity of symptoms (CDC categories—mild, moderate, and severe) | Clinical severity of child's symptoms was not associated with child's knowledge of status. 49% of children with severe symptoms were disclose, compared with 39% of children with mild and moderate symptoms |
| 7 | Physical/physiological outcomes | Ferris et al. (24) | Investigate disclosure effect on disease progression (death, CD4 decline) | Romania | 325 CLHIV | Quantitative | Retrospective database analysis (comparison of disclosed vs. non-disclosed children) | Student t tests, Chi-square test, Fischer's exact test, Cox regression models | HIV disclosure | Death, CD4 decline, combined, time to HIV disease progression | Non-disclosed children were more likely to experience disease progression through either death or CD4 decline than children who knew their HIV diagnosis ($p = 0.03$) |
| 8 | Mental and psychosocial outcomes | Gaughan et al. (28) | Determine the incidence of psychiatric hospitalizations among CLHIV and predictors of first psychiatric hospitalization | USA | 2,298 CLHIV, 1,021 non-CLHIV | Quantitative | Prospective cohort study (PACTG 219 C) | Relative risks using Poisson rate parameters; Cox proportional hazards regression | HIV disclosure | Psychiatric hospitalization | CLHIV who were aware of their status were six times more likely to be hospitalized due to psychiatric illnesses, compared to CLHIV not aware of their status (hazard ratio 6.13) |

(Continued)

TABLE 1 | Continued

| # | Effect of disclosure on health outcomes | Reference | Study goal | Country | Sample size | Study type | Study design | Type of analysis | Independent variable | Dependent variable | Results |
|----|--|----------------------|--|--------------|---------------------------|------------------------------|--|---|-----------------------------------|--|--|
| 9 | Mental and psychosocial outcomes | Lester et al. (30) | Determine factors related to timing and probability of non-disclosure of HIV status to CLHIV and factors associated with emotional distress in CLHIV | USA | 51 CLHIV, 49 parents | Quantitative | Cross-sectional study | Content data analysis; Kaplan-Meier, Cox proportional hazards model, multiple linear regression | HIV disclosure | Anxiety and depression in children—rated separately by children and their parents | Parents' ratings of children's anxiety show an association between HIV disclosure and greater child anxiety ($t = 2.15, p = 0.04$). However, children's own reports of anxiety and depression did not show corresponding elevations in distress in relationship to HIV disclosure |
| 10 | Mental and psychosocial outcomes | Menon et al. (32) | Examine emotional and behavioral difficulties in HIV-positive adolescents, and relationship between HIV disclosure and mental health | Zambia | 127 CLHIV–caregiver dyads | Quantitative and qualitative | Cross-sectional survey | Mann-Whitney U test, χ^2 , Spearman, content analysis | HIV disclosure | Strengths and difficulties questionnaire (SDQ), scores for emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, and prosocial behavior | Univariate analyses showed no differences in continuous SDQ-Y scores between disclosed and non-disclosed children. However, fewer disclosed CLHIV had extreme scores for emotional difficulties (18.8 vs. 38.8%, $\chi^2 = 4.1, df = 1; p = 0.04$) Non-disclosed CLHIV were twice as likely to experience concerning levels of emotional difficulties as disclosed CLHIV (OR = 2.63, 95% CI: 1.11–6.26) |
| 11 | Adherence to treatment; Mental and psychosocial outcomes; Child's disclosure of status to others | Petersen et al. (17) | Understand psychosocial challenges and protective influences that promote socio-emotional coping in HIV+ adolescents | South Africa | 25 CLHIV, 15 caregivers | Qualitative | Individual interviews (in-person) | Thematic analyses | HIV disclosure | Identity, psychosocial issues, internalized stigma | All 25 adolescents reported good adherence 22 CLHIV reported that knowing their status was emotionally difficult; 9 CLHIV (36%) withdrew from friends, as a result of difficulty in accepting an HIV+ identity. 13 CLHIV (>50%) showed internalized stigma CLHIV expressed concerns about how to negotiate future sexual relationships. Also, only 13 CLHIV had disclosed their status beyond the immediate family |
| 12 | Child's disclosure of status to others | Sherman et al. (34) | Examine physiological and psychological consequences of children's self-disclosure | USA | 64 CLHIV–caregiver dyads | Quantitative | Comparison of CLHIV who had self-disclosed their status (disclosers) to CLHIV who had not (non-disclosers) | χ^2 , Tukey's honestly significant difference tests | Univariate ANOVA, self-disclosure | Child's CD4% (disease progression); self-concept, behavioral problems (psychological well-being) | CLHIV who disclosed their HIV status to friends had a significantly larger increase in CD4% (mean = +5.55, SD = 5.92), implying a slowing of disease progression, relative to non-disclosers (mean = 0.00, SD = 5.75); ANOVA $F(2,60) = 4.28, p < 0.05$ |

(Continued)

TABLE 1 | Continued

| # | Effect of disclosure on health outcomes | Reference | Study goal | Country | Sample size | Study type | Study design | Type of analysis | Independent variable | Dependent variable | Results |
|----|---|---------------------|---|------------------------------|---------------------------|-------------------------------|---|---|----------------------|---|--|
| | | | | | | | | | | | ANOVA analysis of changes in self-concept did not approach significance between disclosers and non-disclosers, $F(2,60) = 0.56$, $p > 0.15$ |
| | | | | | | | | | | | ANOVA analysis of changes in levels of behavioral problems (comparing disclosers and non-disclosers) also did not approach significance, $F(2,57) = 0.69$, $p > 0.15$ |
| 13 | Mental and psychosocial outcomes | Sopena et al. (31) | Identify if CLHIV had poor psychological adjustment and clarify relationship between coping and psychological adjustment in CLHIV | UK | 30 CLHIV | Quantitative | Correlational design (comparison of disclosed CLHIV and general British population) | t-test, Pearson correlations | HIV disclosure | Total strengths and difficulties, SDQ, score on psychological subscales (emotional, conduct, inattention-hyperactivity, peer problems, and prosocial); coping behaviors | Disclosed CLHIV did not exhibit problems with psychological adjustment as measured by SDQ scores No significant difference between disclosed CLHIV and general UK population: Psychological adjustment total SDQ score $t(29) = -1.03$. $p > 0.05$ |
| 14 | Mental and psychosocial outcomes | Vaz et al. (4) | Explore events before, during and after disclosure | Democratic Republic of Congo | 8 CLHIV-caregiver dyads | Qualitative | Individual interviews (in-person) | Content analysis | HIV disclosure | Disclosure experiences and reactions | Children felt sad immediately after disclosure. But later did not state any negative effect of knowing their status. Benefits of disclosure included relief, not being worried and avoiding being sicker; and being able to protect others |
| 15 | Physical/physiological outcomes; Adherence to treatment; Mental and psychosocial outcomes | Vreeman et al. (14) | Assess association between disclosure and key child level demographic, clinical, and psychosocial characteristics | Kenya | 792 caregiver-CLHIV dyads | Cross-sectional, quantitative | Comparison of disclosed vs. non-disclosed children, medical chart review | Pearson's Chi-square test, multivariate logistic regression with odds ratio | HIV disclosure | Clinical characteristics—adherence, CD4 count, CD4%, WHO staging; psychosocial characteristics (stigma, depression) | No association between disclosure and WHO staging ($p = 0.079$), and CD4% ($p = 0.582$) Disclosure was associated with child-reported adherence ($p = 0.03$) Caregiver-reported child-experienced stigma and child depression symptoms were both significantly associated with disclosure ($p < 0.01$) |

RESULTS

Five major health and related outcomes emerged from children's knowledge of their seropositive status (**Table 1**): disease progression (CD4 count, death) and other physical/physiological outcomes; adherence to ART; self-esteem, mental, emotional, and other psychosocial outcomes; and sexual and reproductive health (SRH), including HIV prevention outcomes. The latter was particularly relevant to another theme that emerged from the results that was not in the original review conceptualization—disclosure of status by the children to friends and sexual partners.

Physical/Physiological Outcomes

Four studies described the physical/physiological health outcomes of status disclosure in CLHIV. The first, a comparison study of 325 Romanian children aged 5–17 years on ART, some of whom had been told their serostatus and others who were non-disclosed, showed a significant difference in disease progression as measured by decline in CD4 count and death (24). A Kaplan–Meier survival analysis showed that non-disclosed children were more likely to die ($p = 0.03$). Although there was no significant difference in CD4 decline, a greater proportion of non-disclosed children experienced CD4 decline ($p = 0.26$) and were more likely to experience death than children who knew their status ($p = 0.03$).

A 1997 multicentre Pediatric Spectrum of Disease active surveillance study of 92 American school CLHIV in Massachusetts, however, did not show any association between clinical severity of children's symptoms (CDC clinical stage of mild, moderate or severe) with whether a child was told of his or her disease status (25). Forty-eight percent of children with severe symptoms had been told of their status compared to 39% of children with mild to moderate symptoms. Cohen's 1997 study seems to suggest that if a child had severe symptoms they were more likely to know their status, even if this was not statistically significant.

Butler et al. (26) reported that there were no significant changes in physical functioning, or health care utilization domains between pre-disclosure and post-disclosure in their PACTG QoL study of 395 perinatally HIV-infected youth. Similarly, Vreeman et al. (14) did not find any associations (in multivariate analysis) between disclosure status and clinical indicators, like CD4% ($p = 0.582$) and WHO disease stage ($p = 0.079$) in their study of 792 caregiver-child dyads in Kenya.

Adherence to Treatment

Three studies focused on the effect of disclosure of child's status to the child and treatment adherence. The quasi experimental study of disclosure's effect on 40 children on ART in Puerto Rico showed that over half (58%, 95% CI 41–73%) self-reported that knowing their status had helped them develop better adherence to their medicines (27). All 25 adolescents and their caregivers in the South African qualitative study reported good adherence as a result of the children knowing their status (17). These adolescents reported adherence to treatment as a positive coping strategy for their HIV+ status, as such adherence would help them live longer. In the Kenya study by Vreeman et al. (14)

disclosure status was not associated with adherence as reported on the clinical encounter form or by caregivers. However, disclosure was associated with child-reported adherence ($p = 0.03$) and disclosed children reported more non-adherence than non-disclosed children.

Mental and Psychosocial Outcomes

Majority of the studies reviewed focused on the mental, emotional and other psychosocial effects of disclosure, since this is one of the reasons often cited for both disclosure and non-disclosure to children. Eleven articles, four of which were in SSA, focused on this health outcome (see **Table 1**). While two of the articles were on the same Pediatric AIDS Clinical Trials Group (PACTG) 219 C prospective cohort study (26, 28), the authors and foci of the two articles were different and were therefore included as separate studies in this review. The first PACTG 219 C study focused on the effect of HIV disclosure on the QoL based on 2,423 study visits by 395 CLHIV in USA (26). The study showed that there were no statistically significant differences between pre-disclosure and post-disclosure QoL domains (general health perception, symptom distress, psychological status, health care utilization, physical functioning, and social/role functioning). Disclosure was not significantly associated with QoL in crude or adjusted mixed-effects model analyses, indicating that QoL did not change because of disclosure of HIV infection status. Caregivers reported lower QoL scores after disclosure for all domains except social/role functioning, although these differences were not significant. The other PACTG 219 C study, however, reported that CLHIV were at increased risk of psychiatric hospitalization than the general pediatric population, and knowledge of seropositive status was significantly associated with increased risks of admission in this population (28). Multivariate analysis showed that CLHIV who were aware of their status were six times more likely to be hospitalized because of psychiatric illnesses compared to those who were not, mostly for depression and behavioral disorders—which are precursors for more severe pathologic conditions, such as bipolar disorder and suicide. Battles and Wiener (29) also reported that four of 67 disclosed CLHIV (≥ 13 years) in their US study had been hospitalized for psychiatric illness. In addition, 19 and 25 CLHIV had received a clinical diagnosis for anxiety and depression, respectively, by a psychiatrist. Four CLHIV had also attempted suicide. The authors, however, did not indicate how these numbers compared with the general US adolescent population, or non-disclosed CLHIV.

The progression of patients' self-reported emotions after disclosure ranged from sadness immediately after disclosure to normalcy by most youth (70%, $N = 40$, $p < 0.05$) after 6 months of disclosure (27). However, one patient remained depressed 6 months after disclosure and wished he had never learnt of his status (27). A majority (85%) of the children they felt disclosure was a positive event for them and their family. While 90% of the children favored disclosure, 10% did not. Incidentally the 10% who did not favor disclosure, learnt of their status accidentally, and wished that they had learnt of their serostatus from family or health care workers. Lester et al. (30), however, suggest in their US study of 51 CLHIV that disclosure of status may not

necessarily minimize emotional distress in children, as HIV disclosure was associated with increased anxiety in HIV-infected children reported by parents ($p = 0.04$). Interestingly, the children's own report did not show corresponding increases in anxiety and depression in relation to HIV disclosure.

A UK study of 30 disclosed CLHIV did not show any statistical difference in psychological (emotional and behavioral) adjustment than the general population, as measured by the strengths and difficulties questionnaire [total SDQ score $t(29) = -1.03$, $p > 0.05$; SDQ score of 0.56 which approaches acceptability levels] (31). However, a similar study in Zambia using the same SDQ methodology showed increased mental health problems (OR = 2.1), especially emotional symptoms (OR = 3.6) and peer problems (OR = 7.1) than the UK sample (32). Univariate analysis showed no difference between children who knew their HIV status and those who were non-disclosed. However, there were fewer participants in the disclosed group with extreme scores in the borderline or abnormal range for emotional difficulties (18.8 vs. 38.8%, $\chi^2 = 4.1$, df = 1; $p = 0.04$); and non-disclosed children were twice as likely to experience emotional difficulties (OR = 2.63, 95% CI: 1.11–6.26) than disclosed children (32).

The South African study by Petersen et al. (17) showed similar emotional difficulties for children who received disclosure of their positive HIV diagnosis. Thirty-six percent ($N = 9$) reported withdrawing from their friends and social activities, as a result of the difficulty they experienced in accepting an HIV+ identity. Over 50% reported internalized stigma. But for the eight children in an exploratory study in the Democratic Republic of Congo who knew their status, despite the negative emotions experienced at the time of disclosure (such as sadness and worry), there were no subsequent negative effects of knowing their status (4). For them, the benefits of knowing their status included relief, no longer worrying (so they could avoid being sicker), and being able to protect others from HIV infection.

The Kenya study of 792 caregiver–CLHIV dyads found that in univariate analysis, there was a significant association between disclosure and caregiver-reported child-experienced stigma ($p < 0.01$) and child depression symptoms ($p < 0.01$) (14). While 2% caregivers of non-disclosed children reported stigma and 4% reported depression symptoms, 10% of caregivers of disclosed children reported stigma and 12% reported depression symptoms in their children. However, only depression symptoms were significantly associated with disclosure in multivariate regression (OR = 2.6, 95% CI 1.1–6.2) (14).

A small-scale qualitative study of six program participants at a transition to adulthood program in the UK showed that participation in the transition program facilitated a positive attitude toward medication and hope for the future in disclosed CLHIV (33).

Sexual and Reproductive Health

Young CLHIV receive health services under pediatric care and are often not being adequately prepared for adult life (20). Two studies focused on SRH issues for CLHIV (20, 29). In terms of SRH services, especially in relation to preventive practices, such as condom or contraceptive use among sexually active CLHIV,

only 37% ($N = 236$) of CLHIV in a Population Council study in Uganda reported using a condom at time of first sex (20). Only 50% used any form of contraception in current or previous relationships, and 47% reported current condom use. (All figures were statistically significant, $p < 0.05$.) These are relatively high use rates compared to the general population, and especially for adolescent population (20). While this may seem to suggest more careful behavior by CLHIV, other findings from the study paint a different picture: only a third of CLHIV currently in a relationship knew the HIV status of their partner. Also, there was no significant difference in the use of condoms by CLHIV who knew the status of their sexual partner and those who did not (57 vs. 58%).

Battles and Wiener (29) reported in their US study that two (5.3%) of 40 disclosed CLHIV (13–17 years) and 19 (70.4%) of 27 disclosed CLHIV (≥ 18 years) were sexually active—with or without using condoms. There was no information on how these children compared to the general US population or non-disclosed children.

Disclosure of Status to Others by Children

Parents of CLHIV worry about whether to let their children disclose their (CLHIV) status to others, usually because of fear of stigma and discrimination (9, 34). However, research has shown that self-disclosure of traumatic or secretive information produces observable health benefits (34). In this regard, the focus is on the extent of self-disclosure, and whether such self-disclosure influences health outcomes, such as the immune response, psychological well-being, and other health outcomes. Six studies on this issue met the inclusion criteria (17, 20, 27, 29, 33, 34). In the US study on 64 CLHIV–caregiver dyads, Sherman et al. (34) showed that CLHIV who knew their positive HIV status and had in turn self-disclosed their HIV status to their friends over the past year (recent disclosers), had a significantly higher CD4% (mean = +5.55, SD = 5.92) than CLHIV who had not self-disclosed (mean = 0.00, SD = 5.75) (ANOVA $F(2,60) = 4.28$, $p < 0.05$), implying a slower disease progression in disclosed CLHIV. Psychological well-being, as measured by self-concept for disclosers vs. non-disclosers, did not approach significance [$F(2,60) = 0.56$, $p > 0.15$]. Similar ANOVA analysis for changes in behavioral problems also did not approach significance [$F(2, 5) = 0.69$, $p > 0.15$].

Battles and Wiener (29) conducted semi-structured interviews with disclosed CLHIV as part of their US long-term pediatric HIV survival study on 80 parent–child dyads, in order to assess the degree of disclosure to others of the child's diagnosis and whether such disclosure had an effect on psychosocial outcomes. Pearson product moment correlations showed that disclosure was positively related to social support ($r = 0.35$, $p < 0.05$), self-competence ($r = 0.35$, $p = 0.08$), and decreased problem behavior ($r = -0.21$, $p \leq 0.08$). However, for public disclosure (i.e., disclosure to the media—television and newspapers), Student's t -test showed a negative association with self-competence ($F = 3.5$, $p < 0.05$). In other words, greater disclosure was associated with increased social support, social

self-competence, and decreased problem behavior, but public disclosure was associated with lower self-competence (29).

In the Puerto Rico study by Blasini et al. (27), 62% of the 40 children in the study chose not to disclose their status to others. The remaining 38% who disclosed, did so to family members—siblings and cousins. Only three of them disclosed to a close friend.

Another aspect of disclosure of status to others relates to disclosure to sexual partners. That is, how knowledge of one's status prompts disclosure to sexual partners, or not, as disclosure could prompt the adoption of HIV prevention strategies in the relationship. A Uganda study (20) showed that only 77 of the 158 adolescents (i.e., 49%) in a relationship had disclosed to their partners. Respondents in a small qualitative study based on a UK transition program reported not disclosing their status to others, including sexual partners (33). They expressed their concerns about status disclosure in their romantic/sexual relationships, and therefore, the importance of meeting other HIV+ young people. The adolescents in the South Africa study by Petersen et al. (17) also expressed concerns about how to negotiate future heterosexual relationships, wondering how they would disclose to future partners. Furthermore, only 13 of the 25 adolescents in the study had disclosed to persons beyond their immediate family for fear of stigma and discrimination. Such disclosure was usually to a school teacher (so as to receive academic support), or a friend.

DISCUSSION

Findings

One major health outcome of HIV disclosure was ART adherence. Since ART is life long, one recurring challenge for caregivers and CLHIV is how to maintain treatment adherence. With ART, a high adherence level of up to 95% or more is necessary to avoid drug resistance and its very serious consequence of treatment failure (35). As such ART adherence is a critical factor in managing HIV infection. One would, therefore, have expected more studies on the effect of disclosure on CLHIV treatment adherence, since this is the reason most often given for promoting status disclosure. However, only three studies focused on the effect of disclosure of child's status to the child and treatment adherence (14, 17, 27). As expected, the children and their caregivers reported improved adherence to treatment as a result of the children knowing their HIV status. Incidentally, the small sample sizes (40 and 25) (17, 27) and the less than rigorous analysis limit any broad conclusions on the impact of disclosure on treatment adherence. This review, therefore, calls for more studies considering the importance of adherence on HIV treatment for CLHIV.

A second major finding from this review is that HIV disclosure to CLHIV appears to be associated with disease progression in terms of clinical severity of symptoms, CD4 percent and ultimately death. While the Romanian comparison study (24) showed that HIV disclosure was associated with a slowing down of disease progression through higher CD4 cells, the US study did not show any impact of HIV disclosure on clinical severity

of disease symptoms (25), or did the Kenya study show any association with CD4 count (14). It may be argued that the US study used a limited sample size, and no information on the statistical significance of the results was presented compared to the more rigorous analysis of the Romanian study, which included adjusting for confounders. All the same, more prospective studies on larger sample CLHIV populations are needed to draw any definitive conclusions on the effects of HIV disclosure on disease progression and severity.

Understandably, majority of the studies in this review focused on the mental, emotional, and other psychosocial effects of disclosure, since this is one of the reasons often cited for both disclosure and non-disclosure to children. Five of the 11 studies on mental health reported a negative impact of disclosure on some aspect of mental health (14, 17, 28, 29, 32), while two showed disclosure had a positive impact (27, 33). The remaining four studies either showed minimal, short-term negative impact or no impact (4, 26, 30, 31). Only three of the studies (two in the US and from the same PACTG 219 C prospective study and one from Kenya) had sufficiently large sample sizes (14, 26, 28), but both US studies reached differing conclusions. While the Butler et al. (26) study of 2,423 visits of 395 CLHIV did not show any statistically significant difference between pre and post HIV disclosure on QoL (general health perception; symptom distress; psychological status and physical functioning; social/role functioning and health care utilization), Gaughan et al. (28) showed in their study of 2,298 CLHIV and 1,021 children not living with HIV that knowledge of HIV status was significantly associated with increased risk of psychiatric hospitalization, with CLHIV who were aware of their status being six times more likely to be hospitalized due to psychiatric illnesses, compared to CLHIV not aware of their status (hazard ratio 6.13). It is not clear what the reasons could be for the different conclusions from the two studies. A possible explanation could be that while Butler et al. (26) measured pre- and post-disclosure QoL changes in the same CLHIV, Gaughan's study compared psychiatric hospitalization in HIV disclosed CLHIV to children not living with HIV. The experience of a significant life event (such as death in the family and beginning school) also contributed to the positive correlation between disclosure and hospitalization and may partly explain the contrasting conclusions from the studies. Menon et al. (32) suggest that disclosure did not have a negative impact on mental health. On the contrary, their study suggests that disclosed children may have better mental outcomes than non-disclosed peers. Although the Kenya study by Freeman et al. (14) had a large sample of 792 and reported higher rates of depression and stigma among disclosed children, and the study was not designed to assess the impact by pre- and post-disclosure characteristics. These different findings underscore the need for longitudinal and more rigorous studies.

The Uganda study on the impact of disclosure on SRH outcome showed a positive and statistically significant correlation between disclosure and condom use and contraceptive use rates that are even much higher than the general population rates for adolescents, in addition to status disclosure to partners (20). However, Battles and Wiener (29) reported that disclosed CLHIV were

sexually active—with and without using condoms. The authors, incidentally, did not state how this differed from the general US population, or non-disclosed children. Obviously, this is a less well researched area and further studies are needed (20), since it is important for control of the pandemic.

Finally, a child's knowledge of their HIV status, and the child's subsequent disclosure of their status to others (friends and sexual partners) had an effect on child's health outcomes. Two studies showed a positive correlation between child's disclosure of their status on the child's health outcome, such as increase in CD4 percent (34), increased self-competence, and decrease in problem behavior (29). However, the children's knowledge of their serostatus did not necessarily result in high rates of status disclosure to sexual partner (20, 33): an observation that has important consequences for HIV sexual prevention efforts and HIV control.

Implications and Recommendations

Disclosure of a child's HIV status to the child has value in terms of positive health outcomes for the child, such as better adherence and slower disease progression (24). Yet, there does not seem to be a systematic or coherent system for child disclosure in SSA or globally. One recommendation from this review, therefore, is the need for government and program policies and guidelines that will promote child HIV disclosure in order to address the current low rates of disclosure in SSA where most CLHIV live. It is encouraging that some SSA countries have developed pediatric disclosure guidelines—either as stand-alone documents or embedded in other guideline documents (36). However, it is important that these guidelines provide enough information that will enable health care workers and/or parents/caregivers to effectively disclose to HIV-infected children. WHO has also published the *Guideline on HIV Counseling for Children up to 12 years of Age* for adaptation in countries (5). Existing pediatric disclosure models and tools, such as children's books, videos, job aides, and curricula, aim to assist health care providers, caregivers, and/or children in disclosure (37–39). These models and tools also address some of the health outcomes identified in this review. For instance, the SANKOFA disclosure model, which is family-centered, clinic-based, and health worker facilitated, addresses adherence, viral and immunologic markers, and mental health outcomes (39).

As many CLHIV are of school age, such policies and guidelines also need to include disclosure to education personnel in the school environment, as well as how to build capacity in the school environment to limit stigma and facilitate support for CLHIV in schools. Ensuring the child's well-being, doing no harm and reducing stigma should be important components of school-related disclosure. Although the decision to inform schools of the child's HIV status should remain a family decision, providers and program managers can facilitate the process and help build family capacity to do this (25).

Disclosure may not always be beneficial, as negative effects may manifest both in the short and longer term, such as precipitated psychiatric issues (28). While it is not clear how much of a challenge this is in SSA, or whether the resulting psychiatric illness is due to HIV or other psychosocial factors, clinicians

need to set up systems to monitor and identify warning signs of psychiatric illness and establish systems for referrals for mental health services (28). Programs that not only address clinical needs of children but also other aspects of child well-being, including psychosocial, life skills, for instance, self-competence, and SRH needs, as well as psychosocial support programs for caregivers are also needed. Programs that adequately address the SRH needs of CLHIV are a clear need from this review, especially as many CLHIV are growing into adolescence and beginning sexual activity. It is critical to reorient health care providers to address their ability and willingness to provide information and services for HIV prevention and contraceptives to CLHIV in a culturally sensitive manner. They also need to emphasize status disclosure, especially in discordant relationships (where one partner is not living with HIV), and encourage consistent condom use to prevent further infection of CLHIV and others (20).

Research Gap

Only five of the 15 studies included in this review were conducted in SSA (none in West Africa), and two of which had very small sample size of 8 and 25 (4, 17) and limited the ability to perform rigorous analyses that would also focus on causality and not just correlations. However, currently 90% of CLHIV live in SSA (21). Clearly, therefore, a major recommendation is the need for more studies on SSA, especially as the different cultural, social, and economic environment in SSA may (or may not) influence health outcomes and HIV disclosure differently. Another recommendation is for more longitudinal studies of larger sample size, to allow more rigorous analyses, such as determining causality—not only in SSA but also in other regions (the US and elsewhere), as nine of the 15 studies reviewed were of sample size 100 or less.

Most studies in this review focused mainly on children infected perinatally. However, it is not clear if there are differences in health and related outcomes between perinatally acquired HIV and non-parental transmission (such as blood transfusion and sexual transmission) and differences in disclosure and health outcomes. Experiences of youth who learn of their status inadvertently (i.e., unintended disclosure) also need to be studied. Programs also need a better understanding of disclosure on school attendance and performance and to study the complex social needs of HIV-positive children in the school environment (25) and how programs can support CLHIV and their parents for disclosure in schools in a sensitive manner and without stigma backlash.

Current studies have limited information on the disclosure process and context. There is need for a better understanding of the appropriate process, context, and child's age for disclosure of status and how these impact on health outcomes (4). The WHO pediatric disclosure guidance also recommends further research on who is best positioned to disclose to the child; and what factors can promote or act as barriers to disclosure (5). Such studies could provide important information for policy development and guidelines on pediatric HIV disclosure. Studies of physical health outcomes also need to include other markers of HIV disease progression, such as viral load, clinical status, and growth velocity (24). Furthermore, more studies adapted

for SSA are needed that use standardized measures to assess emotional health.

Limitations

This review and the interpretation of the findings presented here have several limitations. First, only one database was searched. It is likely that widening the study search to additional databases, such as PubMed, would have yielded other relevant studies. Also, the context of this review required only one reviewer. Thus, the study review process did not benefit from a second opinion where there were uncertainties on whether to include a study or not. The third limitation is the very small sample size of most of the studies. This limited the sophistication of analyses that could be performed by the researchers, including adjusting for confounders. As such, very limited conclusions can be drawn from the studies. Fourth, most of the studies were cross-sectional. Therefore, only correlational inferences between disclosure and health outcomes could be made, without establishing causality.

Fifth, key terms were not defined in most studies. While a few studies used standard tools developed and tested for psychometric studies (26, 28, 31, 32), in majority of the studies, it was up to the investigator to determine how anxiety, depression, and other key terms were defined and conceptualized in the studies. While CD4 count (and percent) was used as a key indicator for disease progression, inclusion of other indicators, such as the number and severity of adverse health events, viral load and growth velocity, as stronger indicators of HIV disease progression, would have made the studies better (24, 34). Finally, most of the studies included in the review were conducted outside SSA. It is not clear if similar findings would be obtained if the studies were repeated within the SSA context. These gaps notwithstanding, the findings reported in this review provide useful information for policy makers in SSA as they explore and develop pediatric

disclosure guidelines. Key factors to consider in adopting these findings will include local culture and family dynamics, country resources, education, and health literacy, which can differ significantly across countries.

CONCLUSION

This review highlights that HIV disclosure to CLHIV does have an effect on health and related outcomes—physical/physiological, psychological, treatment adherence, SRH, and status disclosure to others—albeit the different studies did not always reach the same conclusions, and some studies suggest disclosure may have negative outcomes. There is a very clear need for more studies on SSA, the region where the majority of CLHIV resides, as well as more rigorous and longitudinal studies, with larger study samples that will allow more sophisticated analyses that can establish causality. Information from these studies would also be valuable to countries and program managers to develop HIV disclosure policies and guidelines and programs that improve the well-being of CLHIV and their caregivers.

AUTHOR CONTRIBUTIONS

The author confirms being the sole contributor of this work and approved it for publication.

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