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## Interventions for families affected by HIV

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### ABSTRACT

Family-based interventions are efficacious for human immunodeficiency virus (HIV) detection, prevention, and care, but they are not broadly diffused. Understanding intervention adaptation and translation processes can support evidence-based intervention (EBI) diffusion processes. This paper provides a narrative review of a series of EBI for families affected by HIV (FAH) that were adapted across five randomized controlled trials in the US, Thailand, and South Africa over 15 years. The FAH interventions targeted parents living with HIV and their children or caregiver supports. Parents with HIV were primarily mothers infected through sexual transmission. The EBIs for FAH are reviewed with attention to commonalities and variations in risk environments and intervention features. Frameworks for common and robust intervention functions, principles, practice elements, and delivery processes are utilized to highlight commonalities and adaptations for each location, time period, and intervention delivery settings. Health care, housing, food, and financial security vary dramatically in each risk environment. Yet, all FAH face common health, mental health, transmission, and relationship challenges. The EBIs efficaciously addressed these common challenges and were adapted across contexts with fidelity to robust intervention principles, processes, factors, and practices. Intervention adaptation teams have a series of structural decision points: mainstreaming HIV with other local health priorities or not; selecting an optimal delivery site (clinics, homes, community centers); and how to translate intervention protocols to local contexts and cultures. Replication of interventions with fidelity must occur at the level of standardized functions and robust principles, processes, and practices, not manualized protocols. Adopting a continuous quality improvement paradigm will enhance rapid and global diffusion of EBI for FAH.

### Keywords

Family-based interventions, HIV prevention, HIV management, Families affected by HIV, Evidence-based interventions, Behavioral skills, Common elements, Core elements, Replication

### INTRODUCTION

As the global funding for human immunodeficiency virus (HIV) has increased 28-fold in the last 10 years, there has been a parallel demand for accountability [60], specifically by mounting evi-

### Implications

**Practice:** To obtain optimal efficacy, HIV interventions for detection, prevention, and care should occur at the level of function and process not only for the individual but for the entire family.

**Policy:** Resources for HIV interventions should be aimed at those interventions that move beyond scripts and activities and provide practical application for participants.

**Research:** Research on how families affected by HIV can best be supported through local, culturally relevant resources.

dence-based interventions (EBI). Hundreds of EBI have been designed and evaluated [54], yet few are globally diffused. Local organizations, researchers, and service providers in each region assert that the families and communities they serve are unique and that EBI need to be redesigned for their context and populations [5, 24]. Meta-analytic reviews do not typically provide a framework for understanding contextual similarities and differences across studies. This article provides a narrative review of adaptation and translation in family-based interventions for families affected by HIV (FAH) in five randomized trials initiated over a 15-year period across the US, Thailand, and South Africa.

*Families are affected by HIV, not individuals*—The discourse on HIV has concentrated on individuals, not families [80]. Services are typically delivered to individuals in age- and gender-segregated clinics, for example, to pregnant women in well-baby clinics [80]. In many places, HIV care is also “vertically integrated,” being delivered in HIV-identified and categorically funded counseling centers, clinics, and hospitals, which can limit utilization of services due to HIV stigma and, in some cases, can reinforce HIV stigma over time [56]. Even more problematic is that cofactors for risk and comorbid conditions (e.g., alcohol, drug use, tuberculosis [TB], and mental health disorders) are not typically addressed in vertically integrated HIV care settings or by narrowly focused preventive

interventions [95, 102]. Targeting individuals with narrowly focused HIV-identified programs *creates* challenges and stereotypes for FAH [74–77]. There are many examples of unintended iatrogenic consequences as well as opportunities to mitigate these effects, particularly for first-line efforts to intervene with FAH through HIV testing and providing antiretroviral therapies (ART), i.e., “Test and Treat” [22, 53]:

- Antenatal HIV testing has higher penetration rates than testing in the general population in low- and middle-income countries (LMIC) [103]. Pregnant women are then the first family members to get an HIV diagnosis: *first identified is often interpreted as the first infected*. Wives are blamed for bringing HIV to the family and destroying the husband and children [86]. Mothers hide babies’ illnesses from their families, sending children to grandparents in their tribal villages, out of their partner’s sight, or using mixed breastfeeding methods to maintain expectations of extended family members [23].
- After 25 years, 20% of the LMIC’s populations have been tested for HIV [103]. Couples’ testing is often not available in many places and yet has been found to be effective and less stigmatizing than individually targeted testing [100]. Typically, each individual provides voluntary informed consent and receives individual counseling. Husbands do not share their HIV status with their wives and wives have no incentive to disclose to their husbands. Family secrets are created by the health care system, with its focus on individual rights [85].
- Among the five million persons on ART, most are only one of several family members with HIV [4]. The impacts of ART are sometimes diluted by sharing medications among family members when only one family member is engaged in treatment.

HIV testing also provides examples of how family-focused intervention delivery can mitigate the iatrogenic effects outlined above. For example, in Uganda, 96% of a community chooses to be tested for HIV when tests are offered in homes to all family members, far higher than any other HIV testing strategy [100]. Home-based testing has also been demonstrated to significantly increase the detection of HIV [6], including among men who have sex with men (MSM) in the US [98]. Yet, family- and home-based testing is not broadly available. The rates of home-based HIV testing are anticipated to be so much higher than individually delivered voluntary counseling and testing that the United States Centers for Disease Control and Prevention (CDC) is advocating for rapid, consumer-controlled HIV testing in community settings, although it is unclear at this time if home-based testing will be made available [10]. If home-

based HIV testing does become broadly available, not only will overall HIV testing rates be likely to increase but also family-based HIV prevention also becomes much more viable.

*Diffusion of EBI for families affected by or at-risk for HIV is limited*—HIV prevention programs for families, typically primary prevention interventions for families of unknown or HIV-negative status, have been efficacious when delivered to many different constellations of family members: mothers and daughters [96], mothers and sons [39], mothers and infants [49, 50], fathers and adolescent children [27], and families of runaways [63]. Yet, the diffusion of these family-based programs is limited. The primary dissemination mechanisms for HIV-focused EBI have not included family-based programs; none of the 20+ HIV prevention programs being disseminated by the CDC are family-based [9; <http://www.effectiveinterventions.org>].

EBI for FAH have also demonstrated efficacy over the past 15 years [7]. These interventions are based on the principle that FAH have more positive outcomes when the parents and their children and caregivers are supported to anticipate the HIV-related challenges, build interpersonal skills, and receive support to cope effectively with daily hassles [27, 84]. Similarly, when ART is delivered to HIV-positive adults in the homes and with family support, there is much higher adherence, better health, and fewer mental health symptoms [57, 62]. Thus, HIV detection, prevention, and care are efficacious using family-based approaches, similar to other chronic diseases [55, 94].

*Poorly operationalized EBI “core elements” present a major challenge to diffusion*—An EBI’s “core elements” are those intervention features considered to be primarily responsible for the intervention’s efficacy and, therefore, are intended to serve as anchors for fidelity in adaptation and dissemination processes [45]. Yet, there is little congruency in how core elements are defined and operationalized [74–77]. Previous reviews of EBI have used multiple strategies to elaborate intervention programs and their important elements across EBI. Various researchers have focused on theoretical models [25], physical settings (dedicated meeting space versus shared room), group process factors [38], leadership variables [71], specific competencies addressed [2], and ethnic similarity between facilitators and participants [34]. This is a very diverse list of foci. One of the most highly rigorous model programs for EBI adaptation and diffusion is the US CDC HIV prevention initiative, Diffusing Effective Behavioral Interventions (DEBI) program [9; <http://www.effectiveinterventions.org>]. The DEBI program has relied on the intervention developers to primarily specify their EBI’s core elements, which has resulted in a great diversity in the level at which the core elements are specified [77].

Until recently, there have been no frameworks available to elaborate core elements and guide

intervention adaptation and fidelity monitoring consistently across interventions. Such frameworks can also enable the bridging of training, capacity building, and adaptation experiences across intervention studies. To meet this challenge in the EBI enterprise, a few research groups have begun to elaborate the common and robust features of evidence-based behavioral interventions and psychological treatments from diverse intervention developers [1, 14, 28, 29, 77]. These efforts typically involve mixed methods research on the intervention manuals and materials in which multiple raters code the content and activities of EBI for a problem domain from a range of intervention developers to identify the robust and common intervention elements.

This article describes the *common and unique* challenges faced by FAH across contexts and the *robust* intervention features that our research teams have adapted across five intervention trials in the US, Thailand, and South Africa. Although contextual factors affecting FAH vary across locations and time, there are common functions, principles, processes, and practices across the EBI for FAH. Our aim with these frameworks is to stimulate a discussion about EBI adaptation processes and the robust, shared features of family-based EBI. We conclude with recommendations for future directions for family-based interventions for FAH, specifically that our experiences suggest that a continuous quality improvement (CQI) paradigm be adopted to support more rapid adaptation and diffusion of EBI for FAH.

*Common challenges for FAH*—There are four major domains that affect all people living with HIV: physical health, mental health, transmission, and relationships [92]. Interventions for FAH that have been scaled up to date typically focus only on biomedical treatments, such as HIV testing, provision of ART, postnatal infant polymerase chain reaction testing, and circumcision [74]. The daily routines needed to live with HIV are typically ignored, as are the skills needed to successfully adapt daily routines to new treatments and prevention technologies [101]. The success of biomedical prevention and treatment advances is contingent upon behavioral factors such as adoption, proper utilization, adherence, and not increasing risk behaviors in response to new prevention and treatment tools [101]. Each of the interventions described above address the same content domains: health, mental health, transmission, and social relationships (including parenting). Within each domain, there are challenges about whether when and how to disclose serostatus, cope with stigma and discrimination, and manage HIV as a chronic and infectious disease.

*Maintaining health* today requires that an HIV-positive person get tested for HIV; get lifelong quarterly health checkups; get screened and treated for TB, CD4 counts, and opportunistic infections; adhere to medications and health care regimens; and eat healthy food, routinely sleep 8 h, exercise

daily, and abstain from alcohol, drugs, or smoking cigarettes [90, 104]. There are multiple behavioral challenges, habits that often have to first be acquired and then sustained over time on a daily basis. The ability to monitor TB and CD4 often does not occur at the same clinical site.

*Positive mental health* requires coping with depressed, anxious, and angry feelings about one's HIV status; feeling optimistic about one's life and future; coping effectively with stigma; and problem-solving daily hassles in an efficient and effective fashion.

*Stopping transmission* requires disclosing serostatus to one's sexual partners; encouraging partners to test for HIV; using condoms with serodiscordant partners; and implementing universal precautions daily.

*Relationships*. There are four major types of relationships that are impacted by serostatus: family and partner relationships; relationships with friends and acquaintances; coworker relationships; and relationships with health care personnel. These relationships become much more complex given decisions about whether when, how, and to whom to disclose HIV serostatus. In some circumstances, disclosure is required (e.g., prior to surgery), but disclosure can result in negative outcomes. Relationships are the contexts in which stigma, prejudice, discrimination, and violence emerge. Thus, change and adaptation is required by FAH in each of these roles in life: partners, families, friends, acquaintances, coworkers, and health care providers [85].

*Health risks concurrent with HIV*. Each community, region, or country has an epidemiological profile of its major health risks. In South Africa, alcohol, malnutrition, TB, and violence towards women are concurrent epidemics to HIV ([58, 73]; <http://www.doh.gov.za/facts/>). Furthermore, in relation to antenatal HIV, low birth weights, infant dehydration, diarrheal diseases, and fetal alcohol syndrome are major challenges in South African townships. TB and methamphetamine abuse are associated with HIV risk in Thailand in the major cities. In the US, the primary co-occurring risks for FAH are drug abuse, mental health, and parenting challenges.

Within each domain, there are also highly predictable challenges that are related to families' developmental age, life situation, or phase of disease. For example, pregnant women must adhere to the tasks outlined above, but pregnancy adds the burden to abstain from alcohol and drug use; take ART for a month prior to and following child birth; disclose their serostatus to a provider at the birthing center; take ART within 3 h of childbirth; get their baby tested for HIV at 6 weeks and receive the results as soon as possible; adhere to only one feeding method exclusively (hopefully breastfeeding) for the first 6 months of the baby's life; adhere to regimens for administering antiretroviral (ARV) to the baby starting at 6 weeks until the baby's serostatus is clear; and administer oral hydration, vitamin, and immunization regimens to the baby. In fact, while there are at least 18 different behaviors needed on

an ongoing basis for nonpregnant FAH, HIV-positive pregnant women must engage in a minimum of 8 additional distinct protective health behaviors.

#### Interventions and contextual factors for FAH in the US, Thailand, and South Africa

*New York City, 1994–2000*—In the 1990s, HIV was an epidemic among MSM and injection drug users (IDUs) and their partners, particularly among ethnic minorities in East Coast urban inner cities [9]. On the East Coast, injecting and polydrug use is strongly associated with HIV, especially among African-American and Latino families [72]. In 1994, a representative sample of 303 HIV-positive parents and 420 of their adolescent children in New York City (NYC) were recruited from the major HIV service agency. Most HIV-positive parents were single African-American and Latina (81%) mothers about 37 years of age. Parents had been diagnosed with HIV about 10 years earlier on average. Most parents had histories of polydrug use; many had been jailed and/or treated in inpatient drug rehabilitation facilities. Only about half had a recent sexual partner, 3% had more than one sexual partner, but 50% had bartered sex at some point previously. The parents also had high rates of depression: 84% reported symptom levels consistent with clinically diagnosable levels of depression [21]. About 70% were diagnosed HIV-positive when presenting with an acquired immune deficiency syndrome (AIDS)-defining illness and hospitalized. Parents typically died within 14 months after entering the New York City Division of AIDS Services because ART was not yet available. Thus, preparing for caregiving during illness and custody plans for children was highly relevant at the time.

Families were randomly assigned to an intervention (*Project TALC*) of 24 multifamily group sessions (organized into three modules) or a control condition and followed up for 6 years with 18 assessments and high retention rates (>90% annually). The three modules were: adapting to HIV (coping with negative emotions and disclosure), adjusting to illness (reducing transmission and leaving legacies), and new beginnings (new caregiver relationships and custody plans). Substantial benefits were observed over 6 years for HIV-positive parents, adolescent children, and the grandchildren of the parents living with HIV in the intervention compared to control condition families [78, 79, 81, 83, 84]. Table 1 presents key intervention and population characteristics for the EBI for FAH.

*Los Angeles, 2004–2008*—Ten years later, in 2004, the intervention was adapted in a randomized controlled trial implemented in Los Angeles, CA. There were 339 HIV-positive mothers who had 225 school-age children (Rotheram-Borus et al., in press). Similar to FAH in NYC, FAH were about 40 years old and primarily ethnic minorities; 33% African American and 63% Latina (primarily Mexican

and Central American). Families typically had three children. Most mothers had less than a high school education and were struggling to survive economically. Only one third was employed and about half had health insurance. Even without health insurance, all families were eligible for comprehensive HIV treatment, including ART, provided by the state government. In contrast to New York 10 years earlier, there were few IDUs or polydrug users and there were few sexual transmission acts at recruitment: only 29% had ever had more than one sexual partner; 23% were currently sexually active; 26% had unprotected sex with serodiscordant partners; 27% used alcohol; and 12% used hard drugs. At recruitment, most mothers reported consistent adherence to ART (76%) and 63% had an undetectable viral load. Most mothers had been diagnosed with HIV for about 8 years.

In this randomized controlled trial, half of the FAH received the three-module Project TALC intervention and half were assigned to the delayed control group did not. The intervention was adapted from the NYC intervention focusing on health, mental health, relationship, and transmission challenges, with the main difference being coping with HIV as a chronic versus terminal illness. The intervention was also streamlined during adaptation, based on our experiences in NYC, with the number of sessions reduced from 24 to 16 by cutting activities that were less engaging, less relevant, or that could be done more efficiently and in less time. FAH were followed up for 18 months with high retention (85%). Mothers in the intervention condition were significantly more likely to monitor their own health and their children were more likely to decrease drug use than control FAH [82].

A second comparison sample of families without HIV (seronegative mothers) was recruited from the same neighborhoods and compared on similar measures over the same 18-month period. HIV-positive mothers reported lower rates of alcohol use and family conflict than HIV-seronegative mothers in the same neighborhoods. HIV-positive mothers were significantly less depressed and less anxious than HIV-negative neighbors over 18 months, which may have been a result of the safety net of services made available to people living with HIV. However, the levels of baseline risks (i.e., sexual risks, drug use, depression/anxiety) were lower in the LA cohort compared to NYC. Thus, the intervention outcomes were not as dramatic as those observed 10 years earlier; HIV had reached less risky populations, though still socioeconomically vulnerable, while HIV had simultaneously become a chronic disease in the US.

*Thailand, 2007–2010*—Over 610,000 Thais are living with HIV; most are adults older than 15 years and 41% are women. About 80% of HIV infections in Thailand occur through heterosexual sex and injecting drug use [67, 93]. Since 2000, the government has provided ART to HIV-positive people in Thailand through more than 900 public hospitals

and clinics [70]. While fewer than 2% nationally are HIV-seropositive, 13% of grandparents over the age of 50 years will experience the HIV-related death of an adult child. About one in four grandparents will have custody of an AIDS orphan [99]. Similar to other countries, older adult Thais expect to be cared for by their children. In contrast to this expectation, the parents of adult parents living with HIV (or other family caregivers) confront lengthy caregiving of their adult children and grandchildren through severe periods of illness, disability, and premature deaths; reduced financial and material support; increased emotional distress and community stigma [8, 47, 65]; and decreased support in old age [97].

In Thailand, regional hospitals provide care to people living with HIV. Therefore, we adapted and implemented the intervention within hospital primary care clinic settings. At two hospitals in Korat and two in Chang Rai, Thailand, we recruited 409 HIV-positive parents with a respective family member. Korat is a rural farming region in the northeast; Chang Rai is a small town of about 61,000 persons at the site of the Golden Triangle, the intersection of Thailand, Laos, and Cambodia. FAH in the study had an average of 1.4 children, about half of the parents were married or living with their partners, and on average, the parents with HIV were about 38 years old. Most parents with HIV were female (67.2%) and most had less than a high school education (85%). Almost all (93.7%) reported getting the HIV infection via heterosexual intercourse; substance use was low.

FAH were randomized to an intervention consisting of multifamily group sessions (with the parent with HIV and one family member) or to a standard care condition and were followed up for 2 years. The intervention was adapted from the US *Project TALC* intervention for FAH, using the common factors, processes, principles, and practices frameworks (described in more detail below), as opposed to adapting the intervention manuals directly. The intervention was streamlined from 24 sessions to 13 sessions in four modules (sound body, sound mind, healthy family, and healthy community). The intervention content and framing was adapted to resonate with Buddhist values and idioms around “sound body and sound mind,” as well as Thai values around the importance of family and community in health and well-being. FAH in the intervention condition reported significantly greater improvements in their physical health, mental health, and quality of life compared to FAH in the standard care condition [52].

*South Africa, 2008–2012*—South Africa has the highest number of people living with HIV (5.7 million), with HIV prevalence stabilizing at around 11% [87]. From 20% to 40% of pregnant women are young mothers living with HIV [46]. Given that ART can reduce HIV transmission rates to < 2% at childbirth [18] and exclusive breastfeeding for 6 months also reduces transmission [36, 48], pregnant women in South Africa are in need of programs to prevent

mother-to-child transmission. HIV testing is broadly available, especially to pregnant women. However, clinic disorganization can be associated with up to 50% of pregnant women not being tested for HIV or returning for their test results [64]. Furthermore, there is a shortage of trained health care workers to deliver interventions, and so community health workers (CHWs) are needed to deliver preventive interventions.

We are currently evaluating two different strategies for supporting pregnant HIV-positive mothers: a clinic-based strategy and a home-based strategy. We adapted the core intervention functions/factors, principles, processes, and practices of the original US FAH intervention for the South African context for the specific target population of pregnant women with HIV. Adaptation also included integration into existing health care services and delivery by peer CHWs labeled “mentor mothers.” In Kwa Zulu Natal, a clinic-based delivery strategy has HIV-positive mentor mothers deliver intervention over eight sessions, four antenatal and four during the postnatal periods. In Cape Town, we are evaluating a home-visiting strategy compared to a clinic-based standard care and whether township “mentor mothers” (both HIV-positive and HIV-negative) can effectively deliver support and problem solving for families with a pregnant woman during home visits that integrate HIV and substance abuse prevention with an existing maternal and child health nutrition program. When township mothers are making home visits, they are addressing the challenges of malnutrition, alcohol, and HIV, which are the major health threats in Cape Town.

Table 1 outlines the key attributes and population characteristics of five family-based interventions for FAH designed and implemented by our teams over the last 15 years.

*Analyses across programs for FAH*—The authors and colleagues from each of the three countries designed and adapted these programs. We outline below the common challenges and common intervention theory, principles, processes, practices, and standardized functions across all programs, highlighting the adaptation processes led by the local leaders and researchers to ensure cultural competence and responsiveness to the context of FAH in the local region.

*Common factors, principles, processes, and practices*—One theory guided each adaptation for FAH across the five interventions: *people change slowly over time within relationships with opportunities to take small steps that are rewarded*; we see this as the essential and common theoretical premise of all evidence-based behavior change theories. Each intervention systematically addressed the predictable HIV-related challenges by identifying the topical issues and offering opportunities to set realistic goals to practice novel behaviors. The robust intervention elements can be understood in terms of common factors, principles, processes, and practices identified in analyses of EBI

Table 1 | Characteristics of EBIs for FAH

Program	Risk factors	Population priorities <sup>a</sup>	Settings	Delivered by	Format	Sessions	Positive intervention impacts
NYC Project TALC 1994–2000	Sexual transmission; polydrug use, IDU or partners of IDU	Preparing for death, custody plans, caregiving by child, substance use	ASO run by local government	Masters level psychologists or trainees	Mother groups, adolescent groups, family sessions	24 at 1.5–2 h weekly or 12 half-day weekend sessions	6-year follow-up; substance use, sex risks, and mental health symptoms for parents and adolescents; adolescent school graduation, employment, pregnancies, and coping with parentification; grandchildren's home environments
LA Project TALC 2004–2008	Sexual transmission; partner risks unknown	Managing HIV as chronic illness, family functioning	HIV clinics, ASOs, CBOs	Masters level psychologists or trainees	Mother groups, adolescent groups, family sessions	16 at 1.5–2 h weekly	18-month follow-up; mother self-monitoring health status, children reduce substance use (less mental health symptoms for HIV-positive compared to HIV-negative neighborhood family comparison sample)
Thailand Family to Family 2007–2010	Sexual transmission, IDU	Multigenerational caregiving, impact on parent of adult PLH	Primary care clinics in hospitals	Clinic staff	Parent and family member multifamily groups	12 at 1.5–2 h weekly	12-month follow-up; general health, physical health, mental health, quality of life
South Africa Mentor Mothers Clinic-Based 2008–2011	Pregnant women in high prevalence area	PMTCT, alcohol, nutrition, child development	Primary care clinic	Mentor mothers (peer CHW)	Small groups of mothers	8 at 1.5 h	12-month follow-up; disclosure at hospital, postpartum depression, child grant registration, health quality of life, well-baby checkups, developmental milestones, infant single feeding methods, HIV prevention knowledge, condom use
South Africa Mentor Mothers Home Visits 2008–2012	Pregnant women in high prevalence area (includes HIV-positive and at-risk)	PMTCT, alcohol, nutrition, child development	Home visits (for MCH)	Mentor mothers (peer CHW)	Mother and family	8 at ~40 min	18-month follow-up; only baseline data is completed at time of this publication; follow-up data collection is ongoing

IDU injection drug user, ASO AIDS services organization, CBO community-based organization, PLH parent living with HIV, PMTCT prevention of mother-to-child transmission of HIV, MCH maternal and child health, CHW community health worker

<sup>a</sup>All program populations had participants faced with common challenges of coping with stigma, disclosure, mental health symptoms, and sexual transmission risks

manuals for HIV prevention. At the broadest level, common factors describe the standardized functions of the interventions, that is, the proximate goals of the intervention [75]. The intervention messages and framing can be understood as a set of common principles identified across EBI [76]. Intervention delivery characteristics can also be understood as a set of common processes identified across EBI [37]. Finally, common practice elements are the therapeutic tools embedded in the interventions [14].

#### Common factors

1. *Frame the meaning of the desired behavior change.* Each FAH program asserted that families *live* with HIV and are not dying. HIV is seen as an opportunity to be “your best self” or “your highest self.” Rather than feeling helpless to control your life, HIV becomes an impetus to focus on the important values in your life. Rather than being overwhelmed by feelings of despair, depression, anger, revenge, and hurt at having acquired HIV, all country programs focused on how to identify the strengths and good aspects of one’s life. We created metaphors for the training that were not symbolic of “counseling,” but attempted to invoke high status roles for participants. Each FAH was portrayed as a health advocate in their country, a person who can help others overcome feelings of stigma and stopping discrimination. We identified FAH as leaders of social change.

We also framed our intervention for FAH in terms of “family wellness” as opposed to “HIV prevention” to help participants overcome the stigma and marginalization of parents living with HIV. We supported families in addressing common developmental challenges and environmental barriers that drive risks for HIV infection, and other diseases as well as life challenges. In Thailand, for example, the Family to Family program was framed as a support program for persons with chronic illness. We framed the problem (living with HIV) by “normalizing” the types of challenges that all families coping with illnesses experience.

2. *Provide information in a manner that allows individuals to apply it to their lives.* FAH’s ability to navigate institutional systems is a critical determinant of the quality and length of life [85]. Self-management of daily health routines requires good knowledge of HIV as well as general lifestyle management. Yet, knowledge of optimal HIV-related health behaviors is useless unless it is applied to the lives of the FAH. Therefore, strategies were established in each country’s program to communicate emerging guidelines of HIV care as well as problem-solving ways that FAH can apply the information into their daily lives.

Our adaptations of the EBI for FAH in South Africa demonstrate the ways information is pro-

vided that can be applied in participant’s lives: (1) showing how an egg poaches in alcohol to demonstrate the impact of drinking on an unborn child’s brain development; (2) having a small jar with two different colors of jelly beans in a ratio that reflects the percentage of persons with HIV in the community; (3) showing pictures of women with HIV prior to and following ARV (Lazarus effect); (4) a doll with brown skin that has fetal alcohol syndrome; (5) a normal-sized baby doll with brown skin (highly realistic); and (5) a workbook that summarizes the mother’s experience.

3. *Build cognitive, affective, and behavioral skills.* We used a Feel–Think–Do (FTD) model in all of our EBI for HIV prevention, which is a colloquial presentation of cognitive–behavioral theory that is based on the idea that our feelings (i.e., physiological responses to events) influence our thoughts and, in turn, our behaviors. The underlying change strategy implied in this model is that we can change the way we think and feel by managing our internal thoughts (through positive self-talk or “replacement”) as well as our physiological responses (through relaxation and awareness building), in order to think more clearly and behave more in accordance with our intentions.

FAH in each country initially lacked a vocabulary to label and to assess the intensity of their feelings. Knowing one’s feelings was basic to recognizing dysfunctional, habitual ways of talking to oneself that elicits negative feelings over time. These processes were universal across countries. We developed a set of tools that were tailored across countries. To monitor feelings, a feeling thermometer was used in American trials to verbally express the dimension and the intensity of uncomfortable feelings. Feeling cups were useful in South Africa and Thailand. In Thailand, the FTD model was framed within the context of Buddhist belief in self-awareness and the positive cycle of cause and effect. Each FAH was taught a model that what they felt and thought influenced their ability to engage in health protective behaviors.

Role-plays were also used in all countries to practice new behaviors prior to being in a real-world setting; role-plays were highly popular in South Africa and Thailand. Initially, FAH in the US were more reticent; however, with support, role-plays became increasingly accepted. “Pair shares,” linking two participants in pairs to practice and role-play new behaviors, was used in each of the LMIC. Few participants could initially identify their thoughts. Habitual thinking styles become automatic in stressful situations.

4. *Establish sustained social support.* The mode of intervention delivery, typically multifamily groups, was utilized in order to ensure that there is a source of ongoing social support. Furthermore, the interventions also aimed to build



**Table 2** | Common factors and practice elements in family-based interventions for HIV-affected families in Thailand

Common factors	
Establish a framework to understand behavior change	“Normalize” challenges facing HIV-affected families
Convey issue-specific and population-specific information	Address four domains
	Maintaining healthy mind
	Maintaining healthy body
	Maintaining healthy family relations
Improve social and community integration	Improving social and community integration
Build cognitive, affective, and behavioral self-management skills	Rehearse and practice identifying and self-regulating feelings in HIV-related situations, thinking patterns in difficult situations, and social skills
Address environmental barriers to implementing health behaviors	Access to ongoing health care
	Access to transportation
Provide tools to develop ongoing social and community support	Interventions designed as drop-in sessions
	District hospitals’ monthly support groups for HIV-affected families
Common practice elements	
Relaxation and ice breaking activities	Meditation, singing, and dancing
Feeling thermometer	Tied to Buddhism advocating self-awareness
	Effective tool to understand current state (feelings)
Feel–Think–Do (FTD) model	Promoting positive cycle of cause and effect
	Buddhist philosophy of linking feelings, thoughts, and actions
Tokens (rewards)	Yellow color represents loyalty and respect to the king
	Stars represent culturally accepted symbol for rewards
	Facilitate expression of kindness and joy
Role-playing in pair sharing	Practice challenging hypothetical scenarios
	Effective dyadic exercise to act out situational challenges
	Rehearse a variety of problem-solving scenarios with different participants

sources of support from family, friends, and service providers. Disclosure of HIV-positive status is a key topic in each intervention, with the aim being to disclose in situations that will result in increased social support but not result in serious negative consequences such as social rejection, stigma, or violence.

5. *Addresses environmental barriers.* Each country has its own challenges for FAH to adopt the new routines promoted in EBI. Access to condoms, sexually transmitted infection screening, and ARV medications is achievable by the intervention team facilitating access to local resources. However, employment was a common challenge that was not solved by our intervention programs. In high-income countries, such as the US, public safety nets provide income, health care, medications, and shelter as basic rights. However, LMIC often do not have the same level of these supports [35]. Maintaining income while ill is a problem for all illnesses, not just HIV. None of the interventions that we mounted directly addressed survival needs and economic vulner-

ability, for example, though microfinance programs [105]. However, our interventions do provide linkages to government and nongovernment organizations that provided access to resources for education, welfare services (e.g., child grants in South Africa), vocational training (cellphone repair, hair braiding), or entrepreneurial/microenterprise programs. Thus, while behaviorally focused EBI do not typically directly address environmental barriers to change, they can provide participants with information on available resources and ways to problem-solve broader structural barriers to their health and well-being.

#### Common principles

A set of *principles* or rules characterize each of the five interventions for FAH. *Principles* reflect the stated goals and anticipated lessons learned in implementing an activity during an EBI. The principles also reflect a set of guiding rules for living healthy lives embedded in each intervention’s activities. Ten common principles were identified

in content analyses of EBI for HIV prevention developed by five different researchers [76]:

1. Believe in your own worth and right to a happy future;
2. Distinguish fact from myth (inaccurate beliefs about HIV);
3. Evaluate options and consequences;
4. Commit to change;
5. Plan ahead and be prepared (with condoms, ARV medications);
6. Practice self-control;
7. Know pleasurable alternatives to high-risk activities;
8. Negotiate verbally, not nonverbally (talking makes a negotiation possible);
9. Choose to limit your own freedom (delay gratification for lower-risk behaviors).
10. Act to help others protect themselves.

Each of the EBI for FAH has multiple activities designed to identify, practice, and support these principles in families' daily routines. The principles are translated into culturally and linguistically relevant language, idioms, and concrete activities. For example, to demonstrate "distinguish fact from myth" for local HIV prevalence in South Africa, we found that percentages, pie charts, and bar graphs were not familiar to the population and were not easily understood. Instead, we use a jar filled with jelly beans with one color representing HIV-positive individuals in order to demonstrate the high local HIV prevalence and the high likelihood that participants will have contact with people living with HIV in their daily lives.

#### Common processes

Each program for FAH also shared a set of common delivery *processes* that were highly similar to common processes identified in analysis of small group format adolescent HIV prevention programs [37]. There was a repetitive pattern to the sequence of meeting activities. Strategies for managing group processes were similar, with ground rules for confidentiality within the group and respect for other opinions and feelings. Each session also had goals and agendas, even if the goals were quite different in each country. In each country, there was also ritual opening and closing activities. For example, in Thailand, participants meditated, while in South Africa, a song and a prayer opened and closed each session; in the US, participants shared compliments with each other. All interventions also opened with reviewing goals set at the previous session, problem-solving barriers, and then set a new goal by the end of each session.

#### Common practices

Mental health services researchers, building on the common factors movement in psychotherapy, have also conducted content analyses of EBI manuals in conjunction with expert rating and confirmation

focused on child and family evidence-based mental health treatments [13, 14, 29, 43]. The work of Chorpita and colleagues is a strong example, having reviewed over 300 randomized trials (over 600 treatment protocols or manuals) to identify and synthesize about 30 common "practice" elements at the level of specific therapeutic techniques or procedures [12]. Examples of practice elements include assertiveness training, communication skills, goal setting, modeling, monitoring, antecedent-behavior-consequences identification, praise, problem solving, relaxation, self-monitoring, self-reward, self-talk, and rewards. In reviewing this list, our group found that all of these practice elements are embedded in our EBI for FAH. Chorpita and colleagues have recently completed a large randomized dissemination trial examining the effects of training and support for providers using standard evidence-based treatment manuals compared to training and support built around the 30 practice elements embedded across treatment manuals, finding that the common elements approach resulted in higher provider adoption and satisfaction as well as improved child mental health outcomes [11]. This provides a model example of how EBI for FAH can be translated and disseminated across diverse contexts.

Our experience in adapting the EBI for FAH in South Africa provides concrete examples of adaptation and translation of common practice elements. To increase awareness and skills to regulate emotions, women are taught to use feeling cups to calibrate their feelings, which is an adaptation of the commonly used "feeling thermometer" in the US. A clear glass is filled with different levels of water, depending on their degree of uncomfortable (full) feelings. Tokens are small chips that are not cashed in for any tangible reward; however, they are exchanged during intervention sessions between participants to indicate that the mentor mother has a positive feeling towards the mother and her participation. Mothers are provided with an empty jar to count the number of times they adhere to their goals, which is an adaptation of self-monitoring diaries used in the US.

As a country deeply rooted in Buddhism, meditation emerged as a highly relevant and applicable relaxation activity in Thailand [15]. Therefore, meditation was employed throughout the pilot sessions as a relaxation activity. In addition, meditation was applied as a stress management tool in several of the intervention sessions. Singing and dancing were incorporated as ice breaking activities; these were relevant and appropriate in Thai culture, thus promoting group cohesiveness and supportive environment. We used yellow tokens (small squares of construction paper) with a star, color and symbol accepted by the Thai population, as value-free rewards that are exchanged between group participants and intervention facilitators to acknowledge and encourage participation. Stars in Thailand are culturally accepted symbol for rewards; the color yellow represents loyalty and respect to the king of Thailand. In addition, the use of tokens facilitated the

expression of kindness and joy, which is closely related to the Buddhist principles of Phrom Viharn 4 in Thailand [69]. Table 2 shows the examples of adaptation of common factors and practice elements for the Thailand intervention trial.

#### Disclosure of HIV status as a prototype issue of adaptation

We use our experience with disclosure to demonstrate how an approach to common factors, principles, processes, and practices could facilitate cultural adaptation processes. Disclosure of HIV status is a process that evolves over time and continues across the lifespan of FAH. There are always novel situations and new relationships for FAH to decide if, when, who, what, and how to disclose about their serostatus [66, 88]. For the person living with HIV, there are a range of benefits from disclosure of serostatus, primarily emotional and instrumental support, caretaking, empathy, and acceptance [20, 30, 41, 89, 106] that result in higher adherence to medications, fewer mental health symptoms, higher self-esteem, and less internalized stigma for FAH [66]. Disclosure is desirable, if there is acceptance following. However, disclosure to others can result in violence, isolation, discrimination, rejection, depression, and lower immune functioning and lower self-esteem for the HIV-positive parent [42, 44, 68]. Thus, the benefits and costs of disclosure may be about equal, on average, for the HIV-positive person when negative consequences are likely [19].

Rates of HIV disclosure among FAH vary within and between countries, for example, from about 50% in South Africa to 100% in the US [3, 51]. In Thailand, disclosure was 90% to at least one family member in one rural setting and only 30% in another region [52]. Anxiety about disclosure is high when newly diagnosed, but as increasing numbers of friends and relatives are accepting of one's serostatus, the anxiety recedes [66]. Those who do not disclose are much more likely to be those who engage in a cluster of negative behaviors: multiple partners, alcohol/drug use, and sexual risk behaviors [40].

The EBI for FAH addresses the issues surrounding disclosure as a major component. The national and regional scientists, health providers, CHWs, and HIV advocates are those initially best informed to anticipate disclosure issues in and adapt EBI for FAH their community. A recognition of the tension points in the local community that can be shifted to avoid potential negative consequences of disclosure are the most important, *robust*, processes to adapt to address disclosure issues among FAH. In most of our EBI for FAH, participants learn to problem-solve disclosure decisions and practice disclosure conversations in role-plays. However, structural alternatives to disclosure of one person to another are also useful in avoiding negative consequences of disclosure. For example, to increase disclosure and partner testing in the South Africa EBI for FAH,

physician letters are provided to pregnant women to take to their partners and families that do not disclose HIV status but rather encourage the couple or family to go together to get tested for HIV. Stigma and backlash to the mother with HIV from a personal disclosure are avoided since couple- and family-based HIV testing sidesteps the need for disclosure of serostatus by one partner to another [59, 91]. In South Africa, HIV-positive pregnant women also find it hard to disclose their serostatus to nurses, so cards are given out to provide to the sister (nurse) at childbirth that says "I am HIV+, please make sure that I get NVP," helping the woman communicate her HIV status without verbal disclosure.

#### Delivery vehicles and service systems as a point of adaptation

*Decision to mainstream HIV into community life or not*—In each of these programs, a series of decisions were made about how to adapt or tailor their FAH programs. One of the primary decisions was whether or not to mainstream HIV into community life or not and through which service systems. Families varied across countries on whether they wanted to receive HIV care in their neighborhood or not. Across countries, however, all families wanted to receive health care in settings that were not HIV-identified, at least to most outside observers. In the US, FAH were already receiving existing safety net services at HIV clinics, AIDS service organizations, and community-based organizations that typically provide confidential access to their services in ways that are not HIV-identified while also having staff that are highly sensitive to HIV and HIV-related stigma. Thus, FAH preferred to receive services in their usual HIV-focused, but not necessarily HIV-identified, service settings. The large urban contexts of the US interventions also enabled FAH to utilize these services with some degree of privacy. In Thailand, families *prefer* both testing and care to be localized in the primary health care system that also provides their HIV care. Similar to the US, the HIV-focused services and intervention in Thailand make keen efforts to not explicitly identify services with HIV and to protect the confidentiality of FAH.

In South Africa, FAH also report preferring testing and care to be integrated into mainstream community services such as primary care clinics or a home-visiting program for maternal and child health. Since South Africa is a country with a generalized epidemic that extends into small communities and rural areas, HIV-related stigma and confidentiality are particularly challenging for individuals as well as for service organizations and interventions. The HIV epidemic in Sub-Saharan Africa has motivated significant scale up of health care infrastructure, but unfortunately, this has resulted in vertically integrated HIV-specific services that distort health care priorities and personnel

resources [33]. Stigma associated with HIV and HIV-identified services is a significant barrier to engaging in HIV prevention and care [56]. Thus, our two EBI for FAH in South Africa are testing two different potential strengths of family-based intervention delivery vehicles. The clinic-based strategy optimizes potential intervention impact by using HIV-positive “mentor mother” role models to deliver the intervention within non-HIV-identified primary care clinics. The mentor mothers provide immediate hope to the HIV-positive mother, on the day she tests positive, that she too can have a good life. Alternatively, the home-visiting strategy has the advantages of being embedded in families’ daily lives and less stigmatizing as the program is identified as a nutrition intervention, not for HIV or alcohol, and serves all families in each community, not HIV-positive only. Both programs have similar impacts, but the home-visiting program has significantly higher follow-up and retention rates, over 85% compared to about 70% in the clinic-based program. The home-visiting program is more directly integrated into the daily lives and communities of the FAH and families at-risk of HIV infection. The potentially higher costs of home-visiting relative to centralized clinic-based delivery may be outweighed by the benefits in intervention reach, engagement, and the ability to tailor intervention delivery and content to the needs of individual families.

## CONCLUSION

Family-based psychoeducational groups have been repeatedly demonstrated to help families coping with chronic medical and psychiatric illnesses [61] and increase families’ capacity to manage transitions between illness phases and enhance problem-solving strategies [32]. The EBI for FAH reviewed in this paper are highly similar to these programs. The predictable challenges for FAH [85] are addressed by robust intervention functions, principles, and processes that are likely to be common across interventions for a variety of health challenges.

Yet, the availability of EBI for FAH does not guarantee their adoption or utilization by service systems and providers [81]. The norm to *replicate programs with fidelity* [26, 45] is a significant barrier to broad diffusion of interventions [31]. *Replication with fidelity* is not feasible when “replicability” refers to the set of sequenced activities and scripts in manuals [24]. Communities typically do not implement EBI with fidelity to intervention manual scripts and activities, even after receiving substantial training in specific EBI [16, 17, 34]. Often, communities and service systems and providers *cannot* or *will not* implement with fidelity to EBI manuals given resource constraints, lack of leadership or staff buy-in, and lack of applicability to local contexts and population characteristics [24, 28]. When communities *do* adopt an EBI, there are no clear guidelines

on how to adapt EBI [24, 28, 71]. Community providers will inevitably adapt, tailor, and reinvent EBI.

As a result of our experiences in adapting and implementing EBI for FAH, we advocate a norm towards *CQI* of interventions, using routinely collected monitoring and evaluation data [83]. Our experience over 15 years has ultimately taken a *CQI* approach, albeit on much longer timelines, through refinements and streamlining of the interventions at each time and place of implementation. With each new adaptation, the number and duration of intervention sessions are reduced and streamlined as our teams of researchers and local collaborators learn which intervention activities and priorities are salient for FAH and their risk environments. However, a true *CQI* approach would iterate and streamline on much faster timeline cycles rather than only between each randomized trial. In order to more rapidly and broadly diffuse EBI globally, scientific norms for standards of evidence and implementation with fidelity will need to shift to support a *CQI* approach to EBI adaptation that also explicitly provides opportunities and pathways for adaptation and tailoring by local communities.

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