



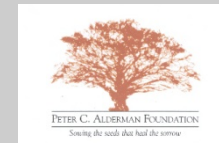
HARVARD
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Family-Based Prevention of Mental Health Problems in Children Affected by HIV/AIDS: An Example from Rwanda



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Overview

- Rwanda – Context
- Mixed Methods Process
- Family Strengthening Intervention (FSI)
- Open Trial Feasibility and Acceptability Study
- Next Steps

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RWANDA

- ★ National capital
- Prefecture capital
- Town, village
- ✈ Airport, airstrip
- International boundary
- - - Prefecture boundary
- Road
- - - Track



Rwinkwavu

Rwanda

- 10.6 million inhabitants – about 50% less than 18 years old (UNICEF, 2011)
- Adult HIV prevalence dropped from 11% to 3% between 2001-2011 (UNAIDS, 2012)
 - **Higher burden among individuals of caregiving age** – 7.9% of women ages 35-49 living with HIV
- **Compound adversities** – 1994 Genocide, HIV/AIDS, extreme poverty – resulting in **83% of children in Rwanda categorized as vulnerable** (MIGEPROF, 2008)
- Rwanda Ministry of Health cognizant of the importance of mental health issues – interested in **improving and decentralizing mental health services, including prevention**



Impact of HIV/AIDS on Families

- HIV-infection is associated with **parental depression, hopelessness, and risk behaviors** such as substance abuse (Rochat et al., 2006; Mellins et al., 2008)
- Disease progression and parental impairment can result in **task-shifting within the family**
 - E.g., children take on adult responsibilities such as caring for younger siblings or dropping out of school to earn money (Cluver & Operario, 2008)
- Increased risk of **family conflict, community stigma, threats to educational attainment, and economic insecurity** which contribute to mental health problems among children (Bauman et al., 2006; Doku, 2009; Lester et al., 2006; Murphy, Greenwell, Mouttapa, Brecht & Schuster, 2006).
- Both **HIV-infected and HIV-affected children are at increased risk for mental health problems** such as depression, anxiety and conduct problems (Orban et al., 2010; Murphy et al., 2000; Fang et al., 2009)

Supporting Children Affected by HIV

- **Positive parent-child relationships, parental monitoring** are associated with resilient outcomes and better coping among HIV-affected children (Dutra et al., 2000; Brook et al., 2002; Mellins et al., 2008)
- Preventive interventions that reduce the risk of mental health problems in children affected by HIV may also **prevent future HIV infection by decreasing HIV risk behavior** (Denison et al., 2009; Biddlecom et al., 2009; Messam et al., 2010; Bell et al., 2008; Coates et al., 2008)

Silo-busting; thinking holistically: the **SAFE** model

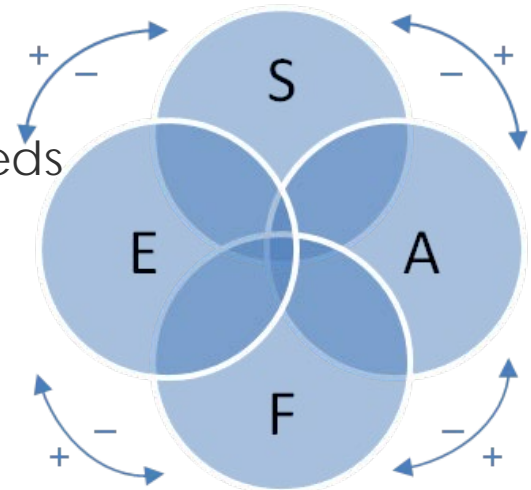
- The SAFE model is a **rights-based, holistic framework** for examining fundamental and interrelated domains of children's security and identifying adaptive and risky survival strategies.

- Interconnected Domains:

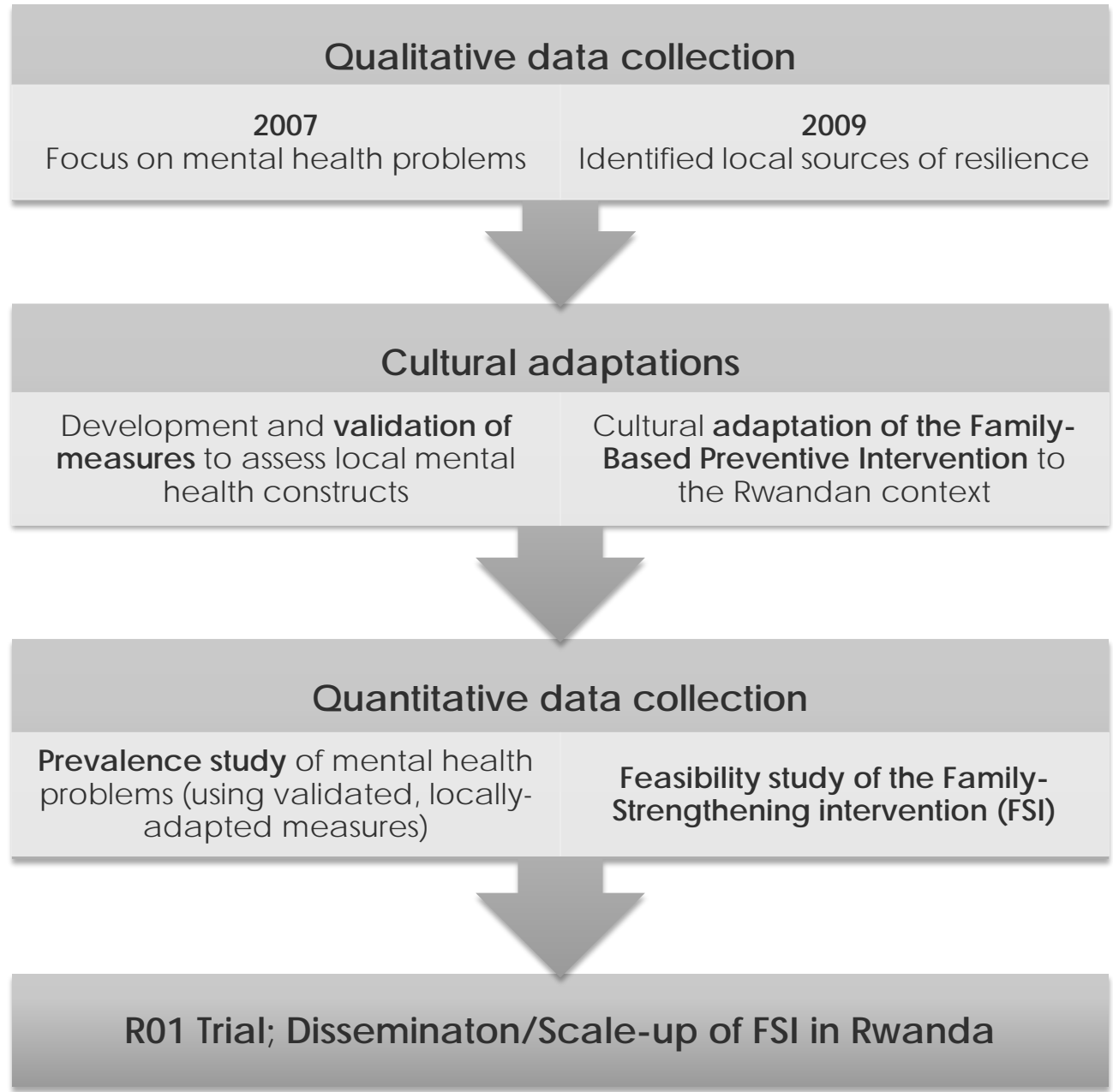
- **S**afety/protection
- **A**ccess to health care and basic physiological needs
- **F**amily/connection to others
- **E**ducation/economic security.

- Survival Strategies

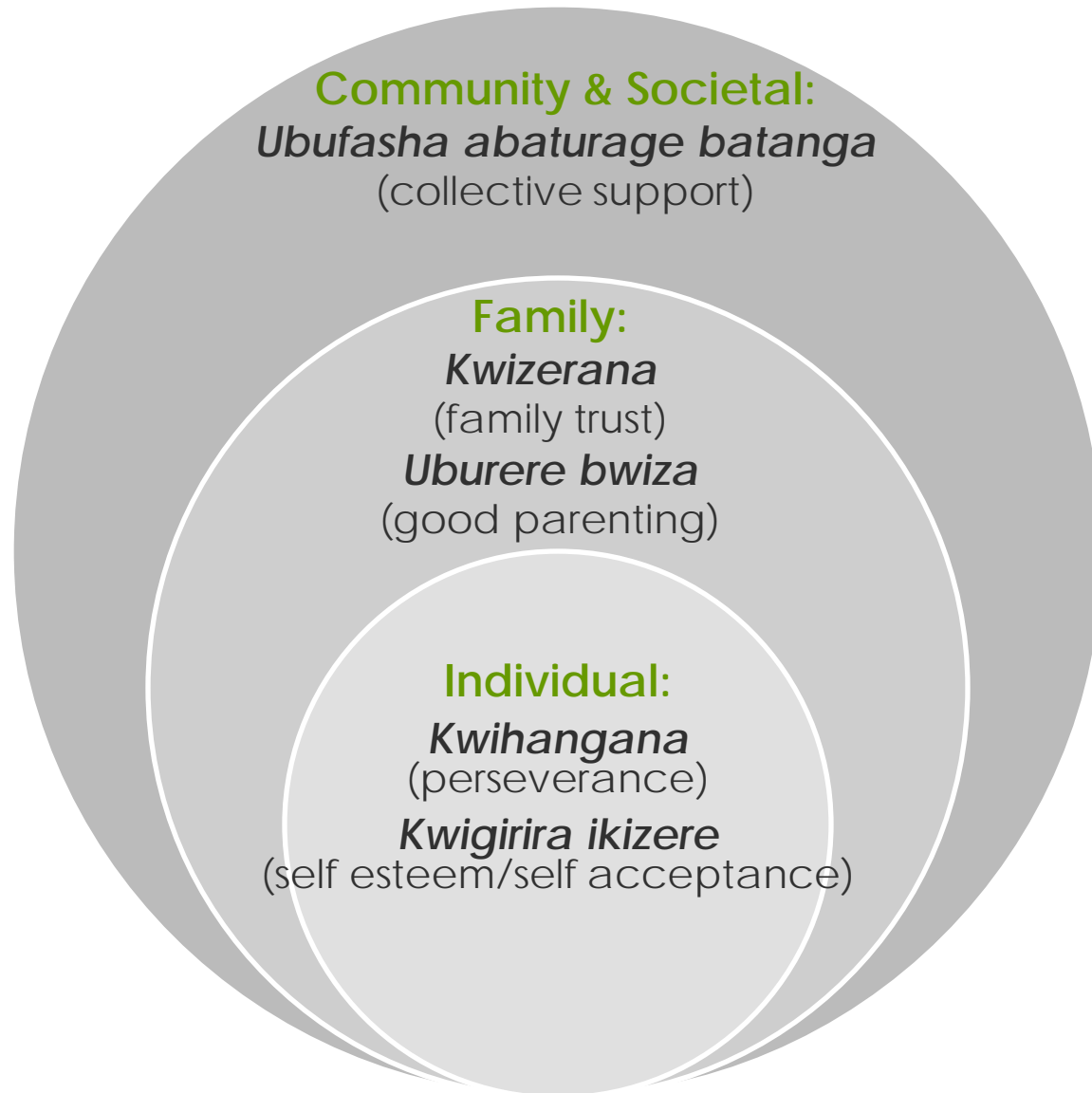
- **interdependence** of children's survival needs; illuminate **survival strategies (dangerous and adaptive) that children and families employ to cope** with deficits in any core domain.



Research Design: Mixed-methods approach



Resilience-related constructs: developmental, ecological view (after Bronfenbrenner, 1979)



Measuring Syndromes and Protective Resources

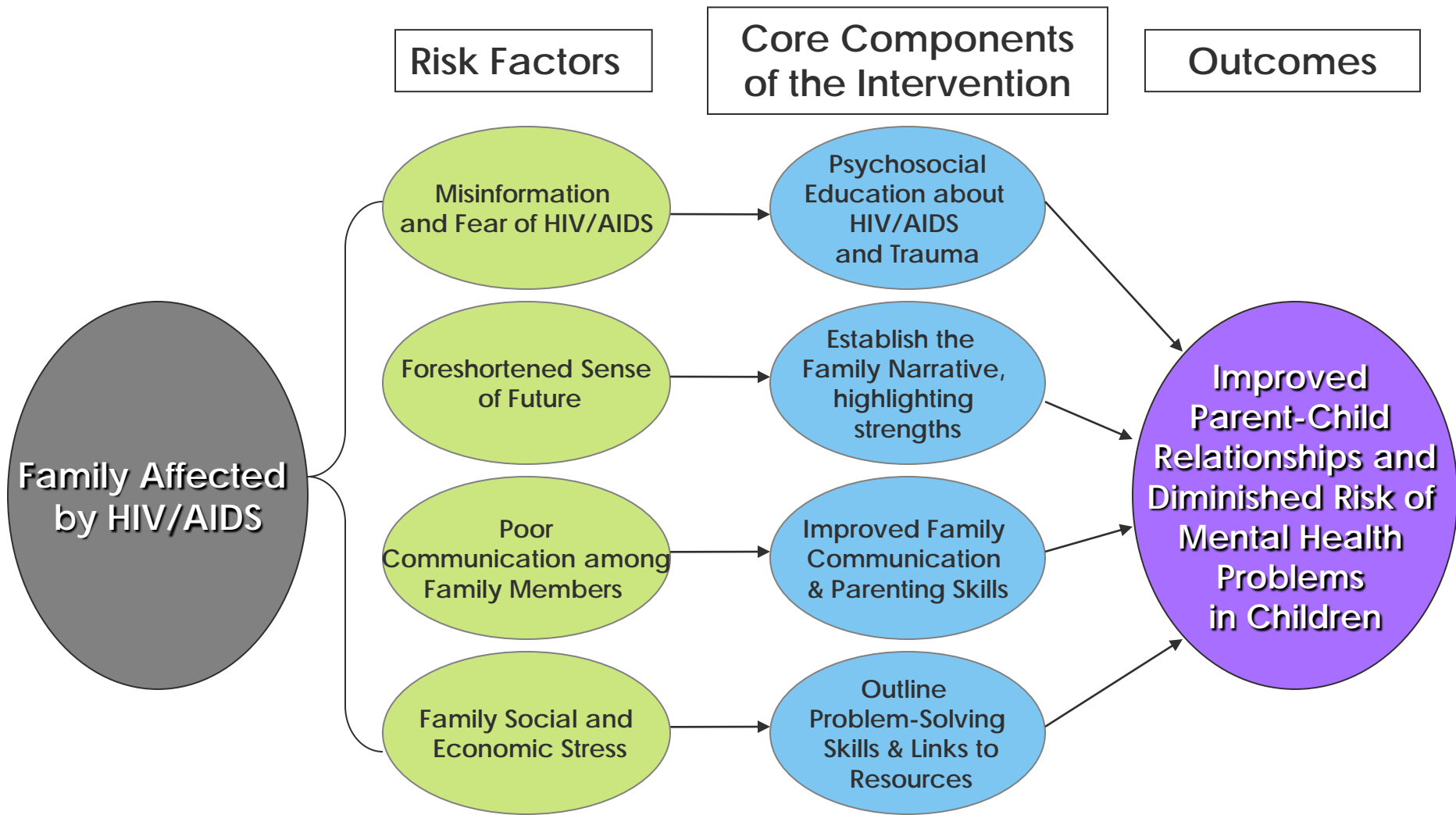
Construct	Measure	Description
Depression-- <i>Agahinda kenshi/Kwiheba</i>	Adapted Center for Epidemiological Studies Depression Scale for Children (CES-DC) ¹	<ul style="list-style-type: none"> • 30 items • 4-point Likert scale <i>Never, A little, Sometimes, Often</i>
Internalizing-- <i>Guhangayika</i>	Adapted Youth Self Report (YSR) (internalizing subscale) ²	<ul style="list-style-type: none"> • 38 items • 3-point Likert scale <i>Not at all true, Sometimes true, Always true</i>
Irritability-- <i>Umushiha</i>	Adapted Irritability Questionnaire (IRQ) ³	<ul style="list-style-type: none"> • 27 items • 4-point Likert scale <i>Never, A little, Moderately, Very much so</i>
Conduct problems/externalizing-- <i>Uburara</i>	Locally-derived	<ul style="list-style-type: none"> • 16 items • 4-point Likert scale based on the CES-DC response options
Perseverance-- <i>Kwihangana/Kwigirira ikizere</i>	Adapted Connor-Davidson Resilience Scale for Children (CD-RISC) ⁴	<ul style="list-style-type: none"> • 34 items • 5-point Likert scale <i>Not true at all, Rarely true, Sometimes true, Often true, True nearly all the time</i>
Family trust/unity-- <i>Kwizerana</i>	Locally-derived	<ul style="list-style-type: none"> • 17 items • 4-point Likert scale based on the CES-DC
Good parenting-- <i>Uburere bwiza</i>	Locally-derived	<ul style="list-style-type: none"> • 14 items • 4-point Likert scale based on the CES-DC
Collective support-- <i>Ubufasha abaturage batanga</i>	Adapted Inventory of Socially Supportive Behaviors (ISSB) ^{5, 6}	<ul style="list-style-type: none"> • 33 items • 5-point Likert scale <i>Never, Once or twice in the last month, About once a week, Many times a week, Almost every</i>



THE FAMILY STRENGTHENING INTERVENTION: *helping children & families thrive*

The FSI for Rwanda: An adaptation of the Family-Based Preventive Intervention

- **Evidence-based intervention** (National Registry of Effective Programs & Practices) originally developed for children of depressed caregivers by Dr. William Beardslee
- Designed to be administered by a **wide range of providers**
- As a family-based preventive model, it **proactively focuses on identifying and enhancing resilience and communication in families** who are managing stressors due to parental illness *before* mental health problems develop
- Good “fit” for the setting and context of HIV in Rwandan families
 - Strengths-based approach **benefits all members of the family** by emphasizing family resilience and connections to resources available in the local community



Core Components of the Family Strengthening Intervention for Rwanda

Main Features of the Family Strengthening Intervention

- **Brief, strengths-based approach**
 - Targets protective resources
 - **Manualized protocol**
- **Weekly, home-based sessions** between family and interventionist –
- 6 core modules + pre and post session
 - Sessions last **60-90 minutes**, on average
 - **Separate sessions** for school-aged children and caregivers
 - Module 6 convenes all family members for a **family meeting**



The Intervention Modules

Pre-Session

- Describe the intervention
- Obtain consent and assent

Module 1 *Caregiver Session*

- Establishing the family narrative with a focus on experiences of HIV/AIDS in the family,

Module 2 *Caregiver Session*

- Continuing the family narrative; focus on parenting and communication skills

Module 3 *Child Session*

- Develop the family narrative from the children's perspective
- Psychoeducation on HIV/AIDS

Module 4 *Caregiver Session*

- Identify sources of resilience in the family
- Prepare caregivers for the family meeting

Module 5 *Child Session*

- Identify sources of resilience from the children's perspective
- Prepare the children for the family meeting

Module 6 *Family Meeting*

- Family meeting of children and caregivers
- Discuss the family narrative, family challenges, and family goals

Family Meeting Review & Follow-up Meeting

- Review what was discussed in the family meeting
- Check in with family about current functioning

Themes of Intervention Modules

Key Themes drawn from Rwandan culture

- **Abashize hamwe ntakibananira**
Nothing can defeat combined hands
- **Umuryango utazimuye urazima**
A family will not break as long as there are no secrets in it
- **Abana mibo Rwanda rw'ejo**
Children are the future of Rwanda
- **Utaganariye na se ntamenya ioyo sekuru yasize ayuze**
If someone doesn't spend enough time with his father, he will never know what his grandfather said

Psychoeducation Materials



**Iyo Umwe Mu Bo Mu Muryango Abana na
Virusi Itera SIDA**

When someone in the family has HIV

By Theresa Betancourt, Morris Munyanah, and Felix Rwabukwisi Cyamatare

Illustrations by Morris Munyanah



**Rimwe na rimwe twese dukenera umuntu
twabwira ibyacu**

We all need someone to talk to sometimes

By Theresa Betancourt, Morris Munyanah, and Felix Rwabukwisi Cyamatare

Illustrations by Morris Munyanah

HIV and AIDS

Psychoeducation: Basic facts, cartoon-based materials, and illustrated psychoeducational books are all included.

Trauma Psychoeducation: Discussion Topics and Activities that can be useful for talking about the traumatic effects of illness and loss on the family.

Open Trial

- Open trial of the Family Strengthening Intervention is complete, and 6-month follow-up assessments are ongoing

- N=20 families in Nyamirama Sector, Kayonza District
 - At least one HIV+ caregiver
 - At least one School-aged child (between 7 and 17)
 - Caregiver willingness to discuss HIV status with children

- Aims:
 - Test intervention feasibility and acceptability when delivered by bachelor level psychologists
 - Make necessary modifications before follow on stages

Open Trial Demographics

Family Demographics	
Single Caregiver Families	11
Dual Caregiver Families	9
Mean Age of Enrolled Children	13 years (46% female)
Mean Age of Caregivers	43 years
Mean Family Size	5.9 people
Mean Number of Children aged 7-17 per Family	2
Number of families completing FSI and Pre-Post Assessments	18

Results: Acceptability and Feasibility

- **Participant Satisfaction** with FSI: **90%** highly satisfied

I can compare our family like someone who has a long journey while traveling. He gets tired so he decides to sit and take a break in order to relax. Then after feeling relaxed, he continues his journey comfortably. FSI was our relaxer.

Child, age 8

- **Interventionist Satisfaction** with FSI: **100%** highly satisfied
- Interventionist **Fidelity** to Core Components: **90%**

“Fit” of the intervention to context

- **50% of families** mentioned **the Rwandan Genocide** as a major event in their family narrative
 - Family identity as “survivors” and the factors that helped them make it through that time are processes
 - Trauma psychoeducation is also provided (book and discussion)
 - Supplemental trauma Module includes skills building for coping, relaxation skills and cognitive exercises to emphasize safety, stability
 - Referral to mental health services for PTSD etc.

Other lessons learned

- **28% of caregivers had not disclosed their HIV status** to some, or all, of their children
 - Role play to support developmentally appropriate and supportive disclosure to children
 - HIV/AIDS psychoeducation for children and caregivers ensuring accurate information about HIV

*It is important to disclose to your children so that they do not learn about your HIV status outside the family. If they learn it from outside, it decreases trust, respect, and the child may react badly. However, **I feel helpless. I do not know what I can say.***

Mother, age 50, during caregiver session

Case 1

Caregivers: 1
Eligible children: 3

HIV Status:
Mother is HIV+,
all children are negative



P01

35 years



C01

15 years



C02

12 years



C03

9 years



C04

7 years
(nephew)



C05

3 years
(lives with
father)

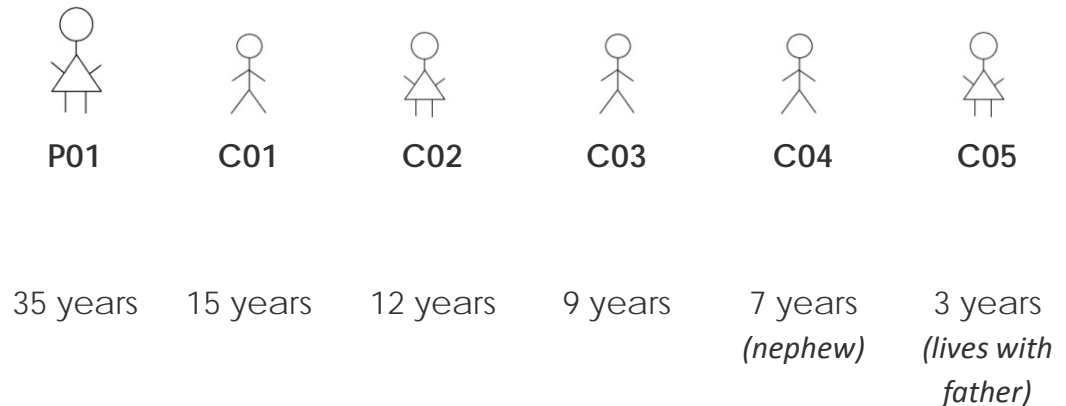
Family History

- Mother devastated when she first learned she was HIV positive (2003).
- The children's father separated from their mother and remarried. This has created a burden on the mother to work and support her children.
- Poverty is a major concern of the single mother and her children who talked about how it is difficult for them as they often must go without food.
- 15-year old boy who is deaf and mute dropped out of school; 12-year old girl and 9-year old boy remain in school.
- Strengths: Children are very helpful to their mother; have good relationships with each other and their peers.

Case 1

Caregivers: 1
Eligible children: 3

HIV Status:
Mother is HIV+,
all children are negative



Course of Intervention

- The 9-year old boy often cried and struggled with the idea that his mother would die soon. The family worried he might have *agahinda kenshi*, or depression.
- The mother was provided with support, encouragement and role play to help her communicate information to her children in a reassuring manner; she educated her children about HIV in the family meeting.
- In the post-assessment, the family noted that they were able to discuss HIV more freely and work through problems together. The 9-year old boy is feeling greater reassurance less sadness. Referral was made to Mental Health services, if needed.
- Referrals were also made for the 15 year old boy who is deaf/mute and now excelling at a special school.

FSI helped me to feel better about the illness because FSI taught us about HIV. Now I know HIV is the long life illness like diabetes, so I don't fear my future life because my mommy can live a long life as long as she is taking medicines."

--12 year old girl

"I learned that I can change those repercussions [of HIV] if I can stay positive and patient ...work hard despite my illness."

-- Mother

Facilitators of Change

- Strong connection to the interventionist
- Repeat processing/integration of psychoeducation
- Encouraging stronger communication, building parent-child relationships, attention to each child; disclosure
- Connection to informal and formal supports

In the beginning it was very hard for me to ...explain to them my problems but with the help of the FSI team, I changed the way I think about my children ... after having the FSI sessions, I no longer fear to talk to my children because they now know almost everything about me, about my sickness and HIV in general. I now know my children can be whatever they want to be, and am proud of my children.

Single mother, age 51

Challenges

- Persistent material needs (managing expectations); opportunity costs of participating
- Families in “crisis” may benefit less or need a higher level of care
- Importance of functioning health system (i.e. access to ART, mental health, social services)
- Prevention takes time, longer follow up horizon needed
- Funding each phase of the research (expanding as NIH is contracting; sequestration)

Current Activities

- 80 families enrolled in a randomized feasibility pilot (NIMH R34)
 - 40 families receiving FSI
 - 40 families receiving “care as usual” via community health center-based social work
- Initial results are promising; process indicators show very high satisfaction, retention

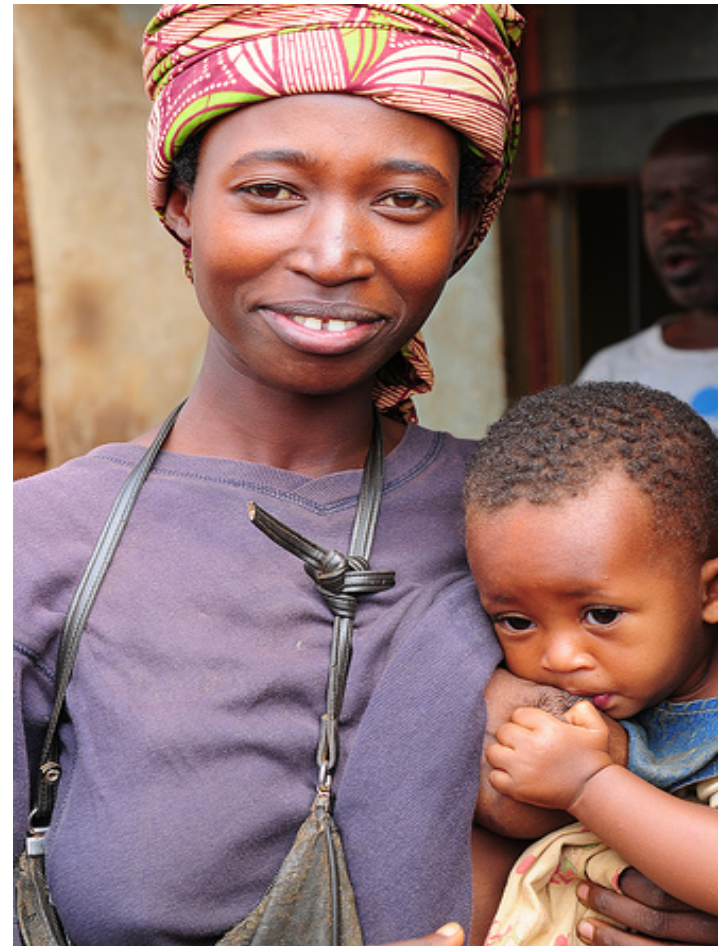


Future Directions

- Effectiveness trial with FSI **delivery within the existing health system** (R01) that also examines cost-effectiveness for future scale up in low-resource settings
- **Integration** of the FSI **within the standard package of services** for HIV/AIDS-affected families
 - **Early intervention opportunity** through initiation during routine testing and care
 - Potential **delivery channels at various levels of the health system** (e.g., social workers or community health workers)
- Expansion of the FSI parenting components to include a focus on **early childhood development** (ages 0-6)

In Summary

- Strengthening families has the potential for both **early and broad impact**
- Data on cost and effectiveness needed for **informing scale up** efforts
- Model has potential to be **adapted to other forms of adversity**



Icyizere (hope)

"we sometimes thought: after all, what is the point of living? ...conversations with [the intervention team] helped us... to have hope...I am grateful that we have people like you who give us morale to live again."

--HIV + Father

Thank you! (murakoze cyane!)

