results brief

Health and Socioeconomic Well-being of Young People Living with HIV One Year After Implementation of the ZAMFAM Project

Evaluating the ZAMFAM Project

The Government of the Republic of Zambia, in its National Health Research Agenda, 2018–2021, recognizes the importance of implementation science and operations research in responding to the challenge of HIV and AIDS. These tools have become invaluable for guiding policy, strengthening programmatic approaches, determining the effectiveness of interventions, achieving the 90-90-90 targets and the appropriate allocation of resources for HIV prevention, treatment, and care.

In line with the above agenda, the U. S. Agency for International Development (USAID) and U. S. President's Emergency Plan for AIDS Relief (PEPFAR) supported Project SOAR to undertake a prospective cohort study of young people living with HIV (YPLHIV) and their primary caregivers/ guardians to determine the effects of the Zambia Family (ZAMFAM) activity on the well-being of YPLHIV and their households.

ZAMFAM focuses on strengthening comprehensive, integrated service delivery and providing support to children living with, affected by, or vulnerable to HIV and AIDS in Zambia. The goal of the project is to improve the care and resilience of orphaned and other vulnerable children (OVC), YPLHIV, and their households through provision of child- and family-focused services, including community-based child welfare systems.

This brief summarizes findings that compare data from round 1 (R1), which were collected from July to October 2017, to data collected one year later (R2), from July to September 2018. The data come from ZAMFAM participants in Central Province, where Development Aid from People to People (DAPP) is implementing ZAMFAM,[1] and in Eastern Province, the comparison site, where there are no ZAMFAM activities.

KEY MESSAGES

- YPLHIV continued to do well in adhering to treatment and staying in care (above 90 percent in both ZAMFAM and non-ZAMFAM areas).
- Self-reported viral load testing increased in both areas. Nevertheless, further increases in testing are needed to determine whether the 90 percent target of viral suppression is being achieved in this population.
- Access to psychosocial support increased among older YPLHIV in both areas; however, many children are still left out.
- Caregivers in ZAMFAM areas reported significant improvements in financial capacity, joint decision-making, and having help when sick.
- Food insecurity, financial instability, sickness, and school attendance continued to be major problems, with little change between rounds.
- Overall there was little change in the socioeconomic well-being indicators between the two rounds in both areas.

[1]In addition to Central Province, ZAMFAM is being implemented in the Southern Province by DAPP and in the Copperbelt and Lusaka Provinces by Expanded Church Response.

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PROJECT SOAR SUPPORTING OPERATIONAL AIDS RESEARCH

STANDARD/ROUTINE SERVICES

- **"Test and Treat" strategy**: All HIV-positive people are offered treatment immediately after diagnosis.
- **Viral load testing**: Centre for Infectious Disease Research in Zambia has been working with some government health facilities to monitor viral load.
- **Counseling and health education**: Almost all health facilities provide counseling and health education to people living with HIV. World Vision Zambia has been providing limited nutrition support through some government health facilities.
- **Support groups**: The Churches Health Association of Zambia has been working with some government health facilities to help people living with HIV form support groups.
- **Farm inputs**: There is some government and partner agricultural support for local farmers, most of whom practice subsistence farming.

ZAMFAM INTERVENTION SERVICES

- **HIV treatment and care**: DAPP held meetings with health facility staff and community health workers on HIV counseling and testing, and the importance of viral load and CD4 count testing for those in care. Community health workers under the ZAMFAM project were paired with YPLHIV to monitor and support their adherence to treatment and care retention.
- **Child abuse and parenting**: DAPP contracted Young Women's Christian Association (YWCA) to conduct trainings on gender-based violence, child abuse, and parenting for DAPP community staff, who in turn, held meetings with primary caregivers to discuss these issues.


DAPP

- **Food security**: DAPP has been providing farming inputs such as maize seed, legumes, cassava, sweet potatoes, chickens, and goats to households with OVC, including those with YPLHIV.
- **Household finances**: DAPP introduced village savings and loan schemes in each Village Action Group, where the members can borrow money to invest in their small businesses or buy agricultural inputs at low interest rates.
- **Psychosocial support**: DAPP has been implementing a TRIOS innovation, which is a buddy unit consisting of a YPLHIV, guardian/primary caregiver of the child, and a neighbor to support the child in adhering to medications and complying with good health practices. Community counselors and community health workers also have undergone training to improve their counseling skills.
- **HIV index case finding**: Used community volunteers to do HIV index case findings through home-based testing and referral of newly diagnosed individuals for ART and treatment support.
- **Community action group meetings**

METHODS

The study aimed to: 1) Document key child and household well-being indicators among a cohort of YPLHIV and their households; 2) Assess the impact of ZAMFAM on the well-being of YPLHIV beneficiaries and their households; and 3) Assess the impact of ZAMFAM on utilization of care and treatment services among YPLHIV and their households.

Central and Eastern Provinces were matched based on HIV prevalence estimates of children aged 0–14 years, by using 2016–2017 Health Management Information System records of new HIV infections and geographical positioning of selected districts along thoroughfares. ***The comparison districts in Eastern Province had no ongoing interventions similar or comparable to ZAMFAM at the time of enrollment.***

In the ZAMFAM areas, a two-stage sampling procedure, stratified by urban and rural, was implemented to select wards proportional to the size of the estimated YPLHIV population and a fixed number of 30 households were randomly selected in each ward.

Since the number of eligible children in non-ZAMFAM areas was too few to form a sampling frame, all YPLHIV meeting the eligibility criteria were recruited until a sample size threshold of 272 primary caregivers and children aged 5–17 years old was reached.

One child and her/his primary caregiver/guardian was selected per household. After providing informed consent, the primary caregivers/guardians were interviewed on mainly household indicators and about themselves, but they also provided detailed information on the YPLHIV aged 5–9 years. For YPLHIV 10–17 years of age, an interview was conducted directly with the child, after obtaining permission from the primary caregiver/guardian and the child.

The information collected in the study focused on key thematic areas that ZAMFAM aims to improve, including health and nutrition, food security, shelter, schooling, child protection, psychosocial status, and HIV care and treatment.

At baseline (R1), 544 YPLHIV, aged 5–17 years, and their primary caregivers /guardians (272 in each of the two provinces) were recruited into the cohort and interviewed.

In R2, a total of 494 YPLHIV and their primary caregivers/guardians (253 in ZAMFAM areas and 241 in non-ZAMFAM areas) were successfully interviewed, yielding a 91 percent response rate. Twelve deaths of YPLHIV were recorded in the year following the baseline study (10 in non-ZAMFAM areas and 2 in ZAMFAM areas).

WHO ARE THE STUDY SUBJECTS AT ROUND 2?

 Caregivers (n=494)	 YLPHIV 6–9 years old (n=164)	 YPLHIV 10–18 years old (n=330)
86% female	52% female	59% female
Median age: 44 years	Median age: 8 years	Median age: 14 years
Marital status: 54% married or in union, 25% widowed	Enrolled in school (ages 7–9*): 78% females, 59% males	Enrolled in school: 75% females, 85% males
	*Children in Zambia start school at age 7 so only those older than 7 were included in this analysis	

There were no significant differences between R1 and R2, except for each group being a year older.

KEY FINDINGS

Health indicators

- At R1, about a third of younger and older YPLHIV in both study areas were too sick to participate in daily activities in the past two weeks. Sickness prevented a smaller percentage of children in both age groups and provinces from participating in daily activities at R2, but the differences were not statistically significant (Table 1).
- Testing for viral load significantly improved for children in both age groups and in both provinces. About half of younger and older participants in the study areas had not received a viral load test in the past six months at R1. This decreased by 12 to 20 percentage points, depending on age group and province (Table 1). Additionally, a greater proportion of older boys (64 percent) than older girls (43 percent) in ZAMFAM areas were tested for viral load in (R2) and this difference was statistically significant.
- Care retention among all groups of YPLHIV was almost universal at R1 and remained so at R2 (Table 1).
- There was little change in reported ART adherence, except among older YPLHIV in non-ZAMFAM areas where there was a significant decrease in the proportion of participants reporting inconsistent ART uptake in the last month. Still, it remained somewhat more of a problem among older YPLHIV than younger PLHIV (Table 1).
- Access to psychosocial support significantly improved among older YPLHIV in both provinces, but the proportion of all children not receiving psychosocial support remains high, particularly in non-ZAMFAM areas (Table 1).

Socioeconomic well-being indicators

- There were no significant changes in socioeconomic well-being indicators (Table 2).
- The challenges of school attendance are still prominent at R2 among YPLHIV in both age groups and areas. Being too sick to participate

Table 1 Health indicators for YLPHIV at Rounds 1 and 2

Indicator	ZAMFAM (%)				Non-ZAMFAM (%)			
	Younger PLHIV†		Older PLHIV‡		Younger PLHIV†		Older PLHIV‡	
	R1	R2	R1	R2	R1	R2	R1	R2
Too sick to participate in daily activities	32	27	34	30	30	23	31	22
Not tested for viral load in the past 6 months	51	39**	51	39**	51	34*	48	28**
Retained in care past 12 months	99	97	95	96	96	99	94	92
Not consistently taking ART in last 1 month	10	6	12	10	3	5	20	14*
No psychosocial support	57	51	60	43**	91	89	88	79*

†At R1 and R2, this group was 6–9 years old. ‡At R1, this group was 10–17 years old and at R2, 10–18 years old.
*p<0.05; **p<0.01

Table 2 Socioeconomic well-being indicators for YLPHIV at Rounds 1 and 2

Indicator	ZAMFAM (%)				Non-ZAMFAM (%)			
	Younger PLHIV†		Older PLHIV‡		Younger PLHIV†		Older PLHIV‡	
	R1	R2	R1	R2	R1	R2	R1	R2
Schooling								
Missed school at least once last week	46	41	32	26	36	30	28	32
Did not progress last school year	24	33	3	3	22	16	9	9
Food intake (in the past 4 weeks)								
Lacked food for a whole day and night	18	11	17	16	12	13	8	6
Slept hungry at night	37	35	37	33	22	23	14	15

†At R1 and R2, this group was 6–9 years old. ‡At R1, this group was 10–17 years old and at R2, 10–18 years old.

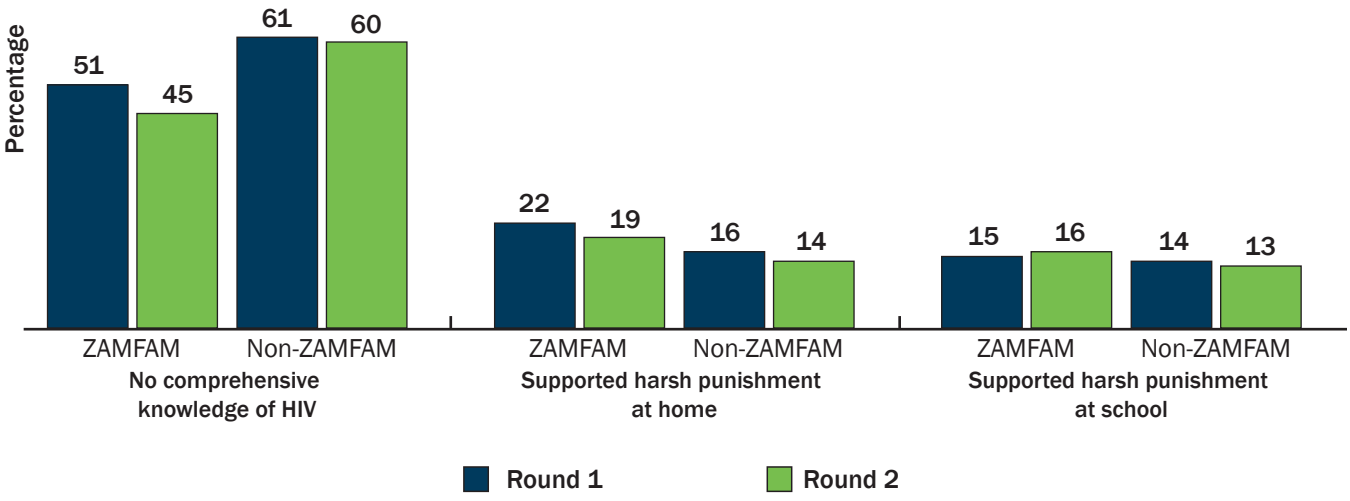
in daily activities was the most frequently reported reason for missing school and this may have influenced school progression as well among younger YPLHIV, particularly in ZAMFAM areas.

- A notable number of YPLHIV lived in financially unstable and food insecure households in ZAMFAM and non-ZAMFAM areas at both points in time (Table 2).

Caregivers and the household environment

- Most caregivers lacked comprehensive knowledge of HIV at R1. The proportion lacking HIV knowledge decreased only slightly, indicating a remaining gap in information among many caregivers (Figure 1).
- Between 14 and 22 percent of caregivers in both areas supported harsh physical punishment either at school or at home at R1, and there was little change at R2 (Figure 1).

Figure 1 Caregiver knowledge and attitudes

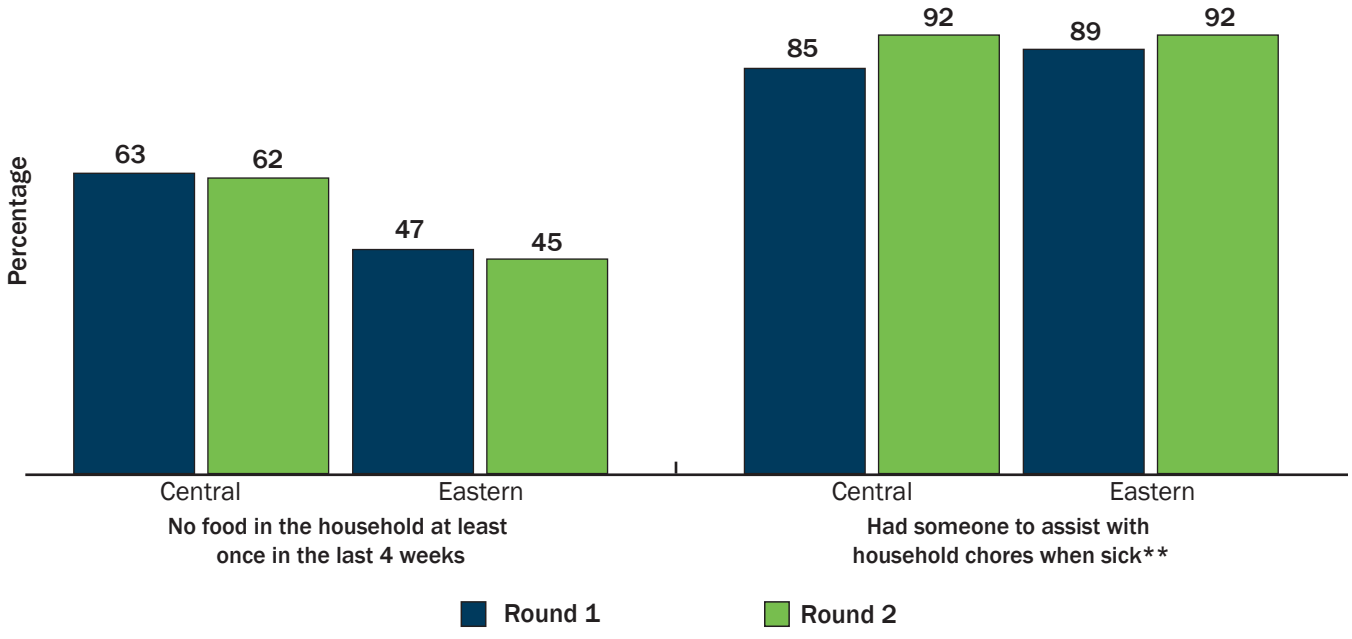


DAPP

Through ZAMFAM, DAPP organizes village savings and loan groups where members can borrow money to invest in their businesses or buy agricultural inputs at low interest rates.

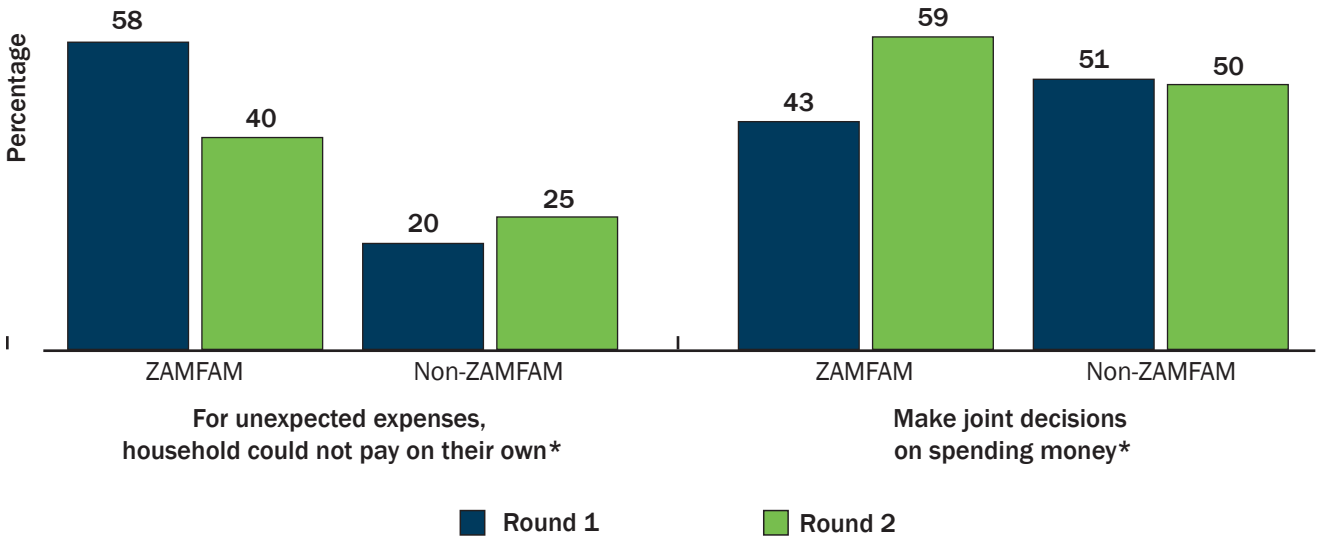
- There was no change in food insecurity among caregivers in both areas, with about one half to two-thirds reporting no food in the household in the last 4 weeks at R1 and R2 (Figure 2).
- Most caregivers in both areas reported that they had someone to assist with household chores when they were sick. But significantly more caregivers in ZAMFAM areas indicated they had help at R2 compared to R1 (Figure 2).
- A significantly greater percentage of caregivers in ZAMFAM areas said they could pay an unexpected expense at R2 compared to R1, yet overall, caregivers in ZAMFAM areas were worse off than those in non-ZAMFAM areas (Figure 3).
- Significantly more married or in-union caregivers in ZAMFAM areas reported joint decision-making at R2 compared to R1, whereas there was no change in non-ZAMFAM areas (Figure 3).

Figure 2 Food insecurity and household assistance



**p≤0.01

Figure 3 Financial matters



*p≤0.05

CONCLUSIONS AND RECOMMENDATIONS

Our findings show a number of significant positive changes from R1 to R2 that are summarized in Figure 4. Overall, YPLHIV continued to do well in adhering to treatment (with a boost among older YPLHIV in non-ZAMFAM areas) and staying in care (above 90 percent in both areas). Self-reported viral load testing increased in both areas. Nevertheless, further increases in testing are needed to determine whether the 90 percent target of viral suppression is being achieved in this population. While access to psychosocial support improved among older YPLHIV in both provinces, many children are still left out. Caregivers in Central Province where ZAMFAM is being implemented reported significant improvements in financial capacity, joint decision-making and having help when sick. Food insecurity, sickness, and school attendance, however, continued to be major problems affecting YPLHIV, with little change between rounds.

Many of our recommendations from R1 remain important in light of data from R2. Therefore, we recommend that ZAMFAM continues to:

Figure 4 Summary of positive changes from R1 to R2

	ZAMFAM		Non-ZAMFAM	
	Younger YPLHIV	Older YPLHIV	Younger YPLHIV	Older YPLHIV
Viral load testing	✓	✓	✓	✓
ART adherence				✓
Psychosocial support		✓		✓
	Caregivers		Caregivers	
Pay unexpected expense on their own	✓			
Joint decision-making about money	✓			
Assistance with chores when sick	✓			

✓ = statistically significant change

- Strengthen community outreach activities by community health workers and counselors to further improve psychosocial and health support to YPLHIV and their households, especially when YPLHIV are sick and not adhering to HIV medication.
- Sensitize primary caregivers and community health workers on the importance of viral load testing for YPLHIV to ascertain whether they are virally suppressed.
- Enhance the capacities of caregivers to care for YPLHIV and seek timely care for them at health facilities.
- Reinforce comprehensive knowledge of HIV, and HIV care and treatment among primary caregivers and YPLHIV.
- Strengthen community strategies to enhance financial and food security in the most vulnerable households.

Given the difficulty of measuring the impact of ZAMFAM after only 12 months, we recommend a third round of data collection after two years of ZAMFAM implementation.

LIMITATIONS OF THE STUDY

- The one-year time frame between R1 and R2 may have been too short to see any significant change, particularly in socioeconomic indicators.
- The different sampling procedures might have yielded different comparison groups. Whereas the ZAMFAM sample was from a population deemed vulnerable, the non-ZAMFAM sample was recruited based on their HIV status only. This might explain socioeconomic differences observed among study participants in ZAMFAM and non-ZAMFAM areas.
- There might have been social desirability bias, such as underreporting adverse economic and social outcomes, or exaggerating financial information among participants in ZAMFAM areas where they are receiving services.

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