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Saber É Viver: Evidence Based Design

Overview of research and technical strategy that guided the campaign's content design and primary tactics.

March, 2016

Key Objectives Unique & Critical to Changing Mozambique's Current HIV Paradigm

- To build the country's first treatment literacy campaign centered around what is missing most in the HIV stigma paradigm in Mozambique, HIV positive advocates talking openly and unashamed of their HIV status;
- To engage and enlist high level national and provincial leaders, along side influential cultural icons, to kick start a new treatment focused narrative about HIV as a MOTIVATOR for knowing your HIV status;
- To redefine the public image of HIV and AIDS through creative Information, Education and Communication (IEC) techniques
- To inform Mozambicans about the behaviors that lead to a healthy lifestyle for individuals living with HIV;
- To coordinate with provincial implementing partners to leverage all available communication platforms to stimulate debate, discussion and positive action/reaction related to knowledge and stigma around HIV and AIDS;
- Create the awareness and civic participation necessary to double the number of children on HIV treatment;



THE CAMPAIGN ENGAGES LEADERS, INFLUENCERS & MEDIA WITH THIS NEW WAY TO SEE HIV, TEACHING THEM THE IMPORTANCE OF USING POSITIVE MESSAGES TO MOTIVATE THE PUBLIC TO KNOW THEIR STATUS.



The Need for This Campaign

Youth: HIV Stigma & Adherence

According to studies conducted in Mozambique and surrounding countries, early intervention (before age 13) is important to reduce stigma and discrimination among children, in particular changing misconceptions that HIV can be transmitted via casual contact.

- 20% of students in Mozambique would avoid or shun a friend who they thought to be HIV+ and many felt the students shouldn't be allowed to attend school;
- Correct HIV transmission knowledge was significantly associated with fewer discriminatory opinions, and incorrect beliefs about casual contact were strongly associated with discriminatory attitudes.
- 25% thought a person who is HIV+ could be bewitched.
- Being personally acquainted with someone who was HIV positive was associated with having a slightly more discriminatory attitude.

Researches conducting a study in Mozambique and several neighboring countries concluded that youth-friendly interventions may be needed to decrease larger drop-outs amongst youth than general population (17% attrition rate year 1 overall, 27% among youth). These drop outs were more due to loss of follow-up than death, including migration work, lack of belief in benefits, and feeling healthy. Researchers found that young people attending clinics providing sexual and reproductive health services, including condom provision, had significantly lower risk of attrition.

Barriers and Facilitators for Getting Children on Treatment

The issues keeping families from accessing testing and treatment services are complex. Many of them relate to structural barriers such as distance from the health facility, long waiting lines, quality of services provided, and lack of food to take with ARVs each day. PEPFAR is working with the MOH to address many of these issues, but no matter the amount of work we are realistic that there will always be hardships associated with accessing HIV treatment. However, we do know that awareness, understanding and belief in the availability and effectiveness is poor.

Saber é Viver seeks to create deeper understanding, and most importantly BELIEF in HIV treatment with the goal of helping patients become more "resilient." We want individuals and families to believe so strongly in the power of treatment to save the lives of those they love, that they are more

willing to "go the distance" and face whatever hardships they face to ensure they get their ARVs EVERY MONTH, and take their treatment EVERYDAY.

A Mozambique study published in 2014ⁱ, by the Elizabeth Glaser Pediatric AIDS Foundation, provides major insight into barriers and facilitators to getting children tested and on treatment. The campaigns content was created to directly address these issues and opportunities.

Barriers	Facilitators
 The belief that HIV is a fatal disease with no cure or treatment is a barrier to accessing care reported mainly by participants from the north. HIV is a fatal disease with no cure, and most people in Mozambique witnessed this among their HIV infected family and friends prior to the widespread availability of ART. Being asymptomatic despite having a chronic disease is often thought of as being healthy and not needing care, and thus can affect uptake of and retention in health services. In a national survey on HIV, only 27% of men and 34% of women in the north demonstrated comprehensive knowledge on HIV [19]. 	
Interpersonal	
 Not having any emotional or social support hindered access. Decisions makers in the family are highly influential providers of social support. Caregivers reported that when they do not have sufficient social support, they tend to abandon giving care at health facilities. Fear of disclosure within the family as a barrier to engaging in HIV services was mentioned most frequently in the three southern study sites. Fear of disclosure of women's or child's test result mainly to partner and family. Caregivers who took their children to health facilities risk inadvertent disclosure of their children's status or their own, which may result in their own, which may result in their own, which may result in their own. 	 The presence of family support, for example helping to remind the main caregiver about follow-up visits, was discussed as facilitating access to HIV testing, care and treatment Decisions makers in the family are highly influential providers of social support. In Mozambique these are predominantly the male head of the household who tends to be the father of the child, or the grandmother (in the north this is the mother of the mother and in the south this is the mother of the father) in the absence of the man. All groups except caregivers recruited at facilities reported that in cases where the decision-maker in the family was in favor of getting care at the health facility, caregivers were more open to and likely to visit the health facility for care. Respondents from all groups and all provinces
 abandonment by women's partners or other negative implications. Grandmothers, Health Care Workers (HCW) and caregivers from communities said that caregivers are often obliged to follow instructions given by traditional healers for fear of being abandoned by 	said that when the caregivers felt supported by their family, they were more willing to seek HIV care at health facilities. • While there may be resistance to preventative care, the experience of caregivers witnessing improvements in their children's health once in

Barriers	Facilitators
their partners who oppose and mistrust conventional medicine.	treatment was an important facilitator to remaining in care.
 In the southern study sites, grandmothers described relationship conflict with their daughters-in-law as a barrier to seek care for children at the health facility. 	
 They explained that their in-laws did not discuss their HIV status and their need for care and preferred to avoid health facilities, which hinders grandmothers' ability to provide support. 	
 In the South, Grandmothers/decision makers not supporting care/seeking treatment was a main barrier. 	
Community Level	
 Lack of social support from community members (external to children's families) such as neighbors, influential people in the community. 	 Psychosocial support mainly through community-based support groups was mentioned frequently in all provinces to be a motivator to seek HIV care. The important role
• Fear of disclosure beyond the family were the main barriers to accessing care.	of the community in making referrals to health facilities was highlighted.
• Fear of disclosure of the child's HIV status to family and community members was found to be an influential barrier and is one that has been reported in other studies [9,10,23].	• HCW pointed out that treatment services could be more effective if carried out through support group meetings, but additional incentives, such as refreshments during the group meeting and financial incentives for the counselors, are needed for groups to remain active.
	 According to participants, information and communication materials concerning HIV should include more messages of hope for those infected.

Summary of Barriers & Facilitators

From this study, and other studies from Mozambiqueⁱⁱ and sub-Saharan Africaⁱⁱⁱ ^{iv} this is a summary that all content should be created to address:

Barriers:

- Seeking traditional medicine instead of going to the health facility;
- Belief that diseases have spiritual causes;
- Non-acceptance of the caregiver's HIV status and distrust in HIV tests;
- Lack of hope due to belief that nothing can be done to save life from HIV;
- Fear of stigma and discrimination which deters families from knowing their status, or picking up their medication in fear of being seen;
- Fear of stigma and discrimination that keeps people from telling their family and thus keeps them from getting support;

- Lack of understanding of the difference between HIV and AIDS, and that ARVs can stop HIV from progressing to AIDS $^{\!\nu}$
- Lack of understanding that one can have HIV for years before developing the signs and symptoms of AIDS;
- Male family leaders and fathers are less likely to know their status and female caregivers often hide their status and don't have support at home;
- Lack of support from neighbors and community leaders;
- Hiding of ARVs due to fear of being identified as HIV positive.

Facilitators:

- Visible signs/symptoms of AIDS;
- Belief that the health facility is the best place to get care;
- Having <u>HOPE</u> that those with HIV can live a long healthy life and have a future;
- Seeing people and children who are living healthy with HIV because of treatment;
- Family members know their family members are HIV positive and thus provide support;
- Head of household supportive of getting care from health facility;
- Neighbors and community leaders are accepting and supportive of those with HIV;
- Being able to be seen with ARVs without fear of stigma and discrimination;
- Belief that HIV treatment works and needs to be taken even when a person/child looks healthy.

The Campaign's Design

SEV Primary Objectives

SEV's is designed to start a conversation of HOPE about HIV/AIDS by re-brand HIV as a manageable, chronic illness that does not have to lead to AIDS, sickness and death, IF families and communities support each other and ensure all those with HIV get on, and stay on, treatment.

• Increase Awareness & Understanding

- The difference between HIV and AIDS; HIV leads to AIDS overtime if not treated;
- $\circ\;$ Those with HIV can live long healthy lives IF they get on treatment and stay on treatment;
- \circ $\:$ It is better to know you have HIV early, BEFORE signs of AIDS;
- Free treatment at the health facility is the ONLY way to stop HIV from creating sickness and death.
- Increase Belief
 - That HIV treatment WORKS and can keep children healthy and alive;
 - $\circ~$ Belief that there is HOPE for children and families with HIV and the key is taking treatment EVERYDAY;
 - $\circ~$ That everyone in the family and community is responsible for keeping children with HIV alive;
 - That a strong community leader, and a good father, is one that knows his HIV status and encourages families to go to health facility for care;
 - The ARV bottle is a sign of power and hope and those with it should be seen as heroes who are stopping AIDS, sickness and death.

The Campaign Tone & Approach Seeks to Create:

- Hope that they, and those they love, can live a healthy, long, life with HIV;
- **Excitement** about participating in the SEV campaigns and taking its messages to all those they love to stop AIDS deaths in Mozambique;

- **Trust** in the services provided at the health facility, and trust HIV treatment works;
- **Ownership** that every member of the community is responsible for each other alive and healthy;
- **Resilience** to find the strength within oneself to face all the obstacles to getting and staying on treatment because they know that it has the power to keep them alive;

The Campaign Message Platform:



To Know Is To Live: What Does It Mean?

To know you are HIV positive is LITERALLY the essential first step to getting on treatment that will keep you alive. Just about every Mozambican knows about HIV/AIDS, yet fear and stigma is a major reason why three out of five people currently with HIV keep from getting tested. It's estimated that it takes 10 years^{vi} for the average young adult for HIV to progress to AIDS and many people wait until AIDS causes sickness to get tested, if at all. And studies show, that once you get sick, its much harder to get you fully healthy again. Thus, to KNOW your status is the only way to keep someone from dying of AIDS related illnesses. And just as important, once you get HIV, the sooner you know, the better the treatment works to keep you alive and healthy. Unfortunately, a majority of Mozambican's don't understand that HIV and AIDS are not the same thing. A study^v conducted in rural Mozambique showed that only 47% of Portuguese speaking women accurately understood the difference.

Pediatric experts in Mozambique report that families and communities don't realize children can have HIV, and even when their child is sick, HIV stigma often creates a state of denial. Families would rather believe their child's illness is due to supernatural causes such as "spirits" or assume their child is sick with malaria, or ANY disease other than HIV. Families often take their child to natural healers first, and delay taking their child to the health clinic until the child is very ill. And once a child has AIDS and is severely ill, it is very difficult to get them healthy again.

A core goal of this campaign is to REVERSE how people perceive HIV. SEV is about giving Mozambicans HOPE by increasing understanding that HIV and AIDS are NOT the same thing. And that because of treatment, HIV does not need to progress to AIDS and death. Thus instead of being scared to know

you are HIV positive, you should be more scared that you have HIV and don't know it. We need to reverse the public's thinking. Knowing you have HIV no longer means you will soon die.



Why Our Primary Message Is "Know Your Status" Instead of "Get Tested Now"

Unfortunately, there is not enough test kits or human resources to flood the healthy facilities with everyone getting tested. The reason we use the broad statement of "know your status" is that there are certain target groups that need to get tested now and the remaining population should "know their status" by ensuring they get tested when they fall into one of those groups.

Vital Importance of <u>SHOWING</u> Treatment.

What it all comes down to is promoting broad public awareness and belief in ARVs. ONLY they can stop AIDS. Only that pill a day keeps someone with HIV alive and healthy. FREE ARVs are now available at 930+ health sites across the country. Public health experts have often assumed that if you scale-up treatment this will automatically get rid of HIV/AIDS stigma because when people stop dying of AIDS, communities will stop fearing HIV.

But here's the problem: Stigma is so strong those on treatment and living healthy normal lives HIDE their status and HIDE their treatment bottles. So the examples of HIV that the community is aware of continues to be the negative ones: the people sick and dying because HIV progressed to AIDS. Even when the community has seen someone sick of AIDS regain their health because of treatment, they at times think, "well that person must not really have had AIDS." Further because almost half of people that start treatment stop taking it within two years, communities have seen countless people get treatment from the health facility, and still get sick again, and some eventually dying. What the community doesn't know is that the person stopped taking ARVs. Studies continue to show that a major barrier to keeping people on treatment is that they fear that during their monthly trip to the health facility to pick up their bottles that they will be seen by someone they know and their community will learn their status. Often patients will take the treatment until they are no longer visibly sick and then stop to reduce their chances of being seen at the facility or with a bottle of ARVs.

So even though treatment is now more available than ever, fear and stigma continue to create a cycle that keeps feeding the very same, bad, behaviors that continue to lead to AIDS related death and sickness, and in turn, keeps the fear and stigma going! And even though there are now over 850,000 people on treatment, the ones taking it everyday are healthy and normal so they are completely invisible.



Importance of Knowing Your Status

A study done in the Mozambique's five neighboring countries compared a group of HIV patients not on treatment to a group of patients that were on treatment.^{vii} Guess who reported more stigma and discrimination? THE PEOPLE ON TREATMENT. Why? Because the ARV bottle becomes a symbol of HIV/AIDS, and the community attaches to it all of the fear and negative misperceptions it holds towards AIDS.

Thus, this campaign was designed to help break this cycles of misunderstanding and stigma. We must teach the public the difference between HIV and AIDS, and teach them that treatment is the ONE THING that keeps HIV from becoming AIDS. Rebranding HIV can only be done if we create a strong positive brand for ARVs. And just like any brand or product, we MUST show the product, to sell the product. We must show strong, positive, beautiful of those living positively because of consuming it. The campaigns visuals were designed to do exactly this, and brings the ARV bottles and pills out of the shadows, and boldly, unapologetically and beautifully into the public's attention. Core to everything we do is creating public awareness that ARV bottles represent hope, life, strength, freedom, and happiness. Essentially, we want to help make ARVs a source of celebration for communities.

But this simple concept is met with resistance. As you read this you may too feel that resistance. That's your own fear and stigma now surfacing. You've been programmed for decades to believe that only by fearing HIV can we stop HIV because it's been touted that only by fearing HIV can we get

people to stop having risky sex. That was true 10 years ago when condoms were about the only thing that could stop transmission. But now this isn't so. Multiple studies now prove that once someone is on treatment their viral load goes down to what is termed "undetectable." This means it's so low lab tests can't detect it. When this happens risk of transmitting HIV to another person, even without condoms, goes down to less than 96% each year^{viii}. In fact, a study published last year found not a single HIV+ person with an undetectable viral load, transmitted the virus to their HIV negative partner. This study followed 760+ couples who reported over 30,000 acts of non-protected sex without having a single case of transmission between the person living with HIV and his/her partner^{ix}. Countries around the world are now promoting this new information. Mozambique is not yet promoting this understanding, but this has major positive implications for Mozambique. This means that if reducing fear and stigma associated with HIV facilitates more people getting tested and on treatment, then not only does this stop that person from getting AIDS, IT STOPS the person from transmitting the virus that could lead to AIDS in someone else.



Someday, hopefully soon, when a community sees one of their members with an ARV bottle, they shouldn't simply be happy that person will stay healthy, they should CELEBRATE that person for stopping HIV from spreading further. Studies show that to stop the Global HIV epidemic we must get 90% of people with HIV to know their status, 90% of them on treatment, and 90% of them to have an undetectable viral load^x. PEPFAR and the MOH are currently working to scale-up Test and START, which means as soon as someone is positive they will be put on treatment. And they have been rapidly expanding new lab equipment across the country so that in the near future, instead of telling patients their CD4 count, all patients will instead be told their viral load and the goal will be to help every patient get to undetectable. One of the key activities within the campaign events is the *TARV vs Viral Load Battle! which* demonstrates in a simple visual way how ARVs keep one healthy by fighting the viral load within the body.



Although this campaign is not going to focus on teaching people about reduced risk of transmission, it is important to note a recent study^{xi} in Malawi that shows how teaching this information lessens stigma and increases voluntary testing and counseling. "A large randomized trial of communities in rural Malawi shows that a single community meeting providing information on how antiretroviral therapy makes people less infectious can have a significant impact both on HIV stigma and HIV testing. The results were presented to the Eighth International AIDS Society Conference on HIV Pathogenesis, Treatment and Prevention (IAS 2015) in Vancouver this week" (AIDSmap.org).

We Must Start Breaking the Stigma Cycle...

The Saber É Viver campaign won't solve the entrenched country wide HIV stigma overnight immediately, nor on its own, but if FCM and collaborating partners can start decreasing fear and stigma enough for more patients living with HIV to live openly and unashamed or their daily ARVs, then we will start breaking the stigma cycle, and this will continue to grow as more and more people begin to feel safe to live openly with HIV, their example thus encouraging others to know their status and get on treatment. The SEV campaign seeks to start breaking this stifling stigma cycle with the vision and hope we will achieve a time, hopefully soon, where thousands of people on treatment start living openly and Mozambicans truly live by the motto—Saber É Viver. A day when families and communities actively take up their duty in helping all those with HIV to get on, and STAY on, treatment.



All key influencers were strategically recruited to widen the impact of the messages and to give relevance to the validity of the information conveyed.

ⁱ De Schacht et al. "Access to HIV prevention and care for HIV-exposed and HIV-infected children: a qualitative study in rural and urban Mozambique. BMC Public Health 2014 14:1240. doi:10.1186/1471-2458-14-1240. Article Link: <u>http://b.3cdn.net/glaser/035d5a48a077ce35a1_9vm6i26fi.pdf</u>

ⁱⁱ Cook, Rebecca E. et al. "Predictors of Successful Early Infant Diagnosis of HIV in a Rural District Hospital in Zambézia, Mozambique." *Journal of acquired immune deficiency syndromes (1999)* 56.4 (2011): e104– e109. *PMC*. Web. 24 Mar. 2016. Article Link: <u>http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3073723/</u>

^{III} Cohen M D et al. *Prevention of HIV-1 Infection with Early Antiretroviral Therapy.* N Engl J Med, 365:493-505, 2011. Article Link summarizing this study and similar research: <u>http://www.aidsalliance.org/assets/000/000/737/90670-Addressing-PMTCT-uptake_original.pdf?1406299595</u>

^{iv} Ngozi C. Mbonu, Bart van den Borne, and Nanne K. De Vries, "Stigma of People with HIV/AIDS in Sub-Saharan Africa: A Literature Review," Journal of Tropical Medicine, vol. 2009, Article ID 145891, 14 pages, 2009. doi:10.1155/2009/145891. Article Link: <u>http://www.hindawi.com/journals/jtm/2009/145891/</u>

^v Ciampa PJ, Skinner SL, Patricio SR, Rothman RL, Vermund SH, et al. (2012) Comprehensive Knowledge of HIV among Women in Rural Mozambique: Development and Validation of the HIV Knowledge 27 Scale. PLoS ONE 7(10): e48676. doi: 10.1371/journal.pone.0048676. Article Link: <u>http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0048676</u>

^{vi} "Stages of HIV Infection," www.AIDS.gov. Article Link: <u>https://www.aids.gov/hiv-aids-basics/just-diagnosed-with-hiv-aids/hiv-in-your-body/stages-of-hiv/</u>

^{vii} Makoae, Lucy N. et al. "The Impact of Taking or Not Taking ARVs on HIV Stigma as Reported by Persons Living with HIV Infection in Five African Countries." *AIDS care* 21.11 (2009): 1357–1362. *PMC*. Web. 24 Mar. 2016. Article Link: <u>http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2797125/</u>

viii Cohen M D et al. Prevention of HIV-1 Infection with Early Antiretroviral Therapy. N Engl J Med, 365:493-505, 2011. Article Link: <u>http://www.aidsmap.com/Treatment-and-heterosexual-transmission-risk/page/1322858/</u>

^{ix}Rodger A et al. *HIV transmission risk through condomless sex if HIV+ partner on suppressive ART: PARTNER study.* 21st Conference on Retroviruses and Opportunistic Infections, Boston, abstract 153LB, 2014. Article link: <u>http://www.aidsmap.com/No-one-with-an-undetectable-viral-load-gay-or-</u> <u>heterosexual-transmits-HIV-in-first-two-years-of-PARTNER-study/page/2832748</u> [×] UNAIDS. 90-90-90 An ambitious treatment target to help end the AIDS epidemic. Geneva, Switzerland: UNAIDS; 2014. JC2684. Article Link: <u>http://www.unaids.org/sites/default/files/media_asset/90-90-</u> <u>90_en_0.pdf</u>

^{xi} Derksen L et al. *Reducing stigma and increasing HIV testing with a health information intervention, a cluster-randomized trial from Malawi*. Eighth International AIDS Society Conference on HIV Pathogenesis, Treatment, and Prevention (IAS 2015), Vancouver, abstract MOPDC0102, 2015. Article Link: <u>http://www.aidsmap.com/Giving-people-information-about-HIV-treatment-as-prevention-lessens-stigma-and-increases-testing-rates/page/2987768/</u>