

# Family-based services for HIV: The role of programs for children in improving efficiency of HIV interventions

## Introduction

Household- and community-level Orphans and Vulnerable Children (OVC) interventions are aimed at directly assisting HIV-affected children. However, they may also be promoting adult treatment uptake and adherence. Highlighting this indirect contribution to adult HIV treatment may help spur efforts to identify easy-to-implement modifications to OVC programs. Such modifications could strengthen this contribution – which in turn would help adults to better care for their children. We examine the evidence of household factors which influence adult treatment outcomes and the extent to which these overlap with factors targeted by OVC programs. Moreover, we examine using specially developed models, the importance of adult adherence for developmental outcomes of affected children. We conclude that the role of OVC programs in supporting adult treatment by addressing household- and community-level barriers should be recognized, evaluated, and strengthened. This would lead to a win-win: Identifying opportunities to strengthen the contribution of OVC programs to treatment uptake and adherence in adults (critical factors in reaching the 90-90-90 treatment target) will improve outcomes for HIV affected children by improving the health of their caregivers – an important outcome in and of itself.

## Objective

To identify extent to which programs to support the families of children affected by HIV are already improving outcomes for adults on treatment and the potential for this benefit to be magnified.

## Methodology

To examine the importance of family strengthening in improving adult HIV treatment adherence, we reviewed the literature on the determinants of adherence to antiretroviral drugs. We compared this to the household factors which are addressed in programs designed to improve the lives of children affected by HIV.

To examine the importance of adult adherence for child outcomes, we used a previously developed model. As part of a President's Emergency Plan for AIDS Relief (PEPFAR)/USAID-funded project, we developed a model to predict the impact of adult (in the first instance, maternal) HIV on affected children. The design of the model is described by Desmond et al. (2014). To demonstrate the importance of treatment adherence, we used this model to examine what the 90-90-90 target (UNAIDS, 2014) would mean over the long term for adult women and for their children. The target implies the following: 90% diagnosis, 90% on treatment, and 90% with viral suppression. To model the 90-90-90 target, we assume that for a population with 90% viral suppression, the HIV-related mortality rate will be 3% per annum and that a further 3% will be lost to follow up per annum (an optimistic assumption recognizing that we were modelling a highly effective service).<sup>1</sup> Mortality rates will remain high among those who do not achieve viral suppression and even people who have achieved viral suppression may subsequently be lost to

## Results

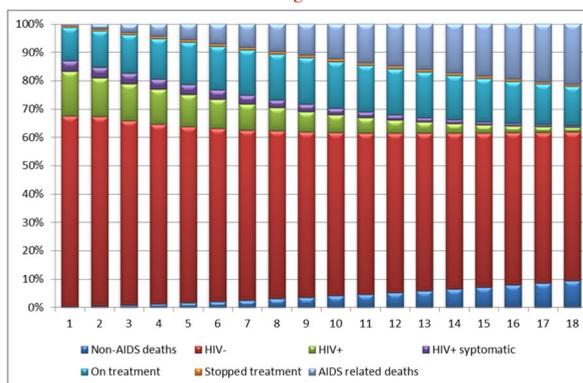
Table 1 summarizes the results of the literature review on determinants of adult adherence. A number of barriers to adherence are specific to treatment: knowledge of treatment options, difficulty understanding treatment regimens and pill burden (both of which are becoming less serious as treatment regimens become ever simpler), dietary restrictions, side effects and forgetting to take medication/go to the clinic, for example. A number of other barriers to do with the health system: distance to treatment sites, long waiting times, and drug stock outs, among others. A number of important barriers are, however, not specific to treatment, but are barriers that affect many aspects of an individual's life and, critically, the life of their family, including their dependent children. Examples include financial constraints, food security, lack of family/social support, social isolation, and stigma. Programs for

Table 1: Determinants of adult ART adherence

Author (year)	Review studies						
	Patel et al. (2010)	Scanlon and Freeman (2013)	Vitalis (2013)	Sandelowski, Voils, and Lee (2009)	Mills, Nachega, Bangsberg, et al. (2006)	Langebeek et al. (2014)	Gourlay, Birthistle, Mburu, Jorpenda, and Wringe (2013)
<b>Intrapersonal</b>							
Knowledge of treatment options		X	X	X	X		X
Difficulty understanding/managing treatment		X			X		X
Medication factors (Complicated regimens, pill burden, dietary restrictions, side effects)		X	X	X	X	X	X
Forgetting to take medication/go to the clinic		X			X		X
Emotional distress/Depression	X	X	X		X	X	X
Self-worth/efficacy				X	X	X	
Perceptions of health/illness		X	X		X		X
Perceptions of treatment		X	X		X	X	X
Substance/alcohol abuse	X	X	X	X	X	X	X
Financial constraints	X	X	X		X	X	
Food security		X					
Lower literacy	X						X
Younger age	X		X				X
Gender	X						
Prior/current medical comorbidities/conditions	X		X		X		X
Alternate/traditional treatments		X	X				X
<b>Interpersonal/Social</b>							
Lack of family/social support	X	X			X	X	X
Social isolation					X		
Dependency on partners for financial support		X	X				
Stigma	X	X	X	X	X	X	X
Fear of disclosure/non-disclosure	X	X	X		X		X
Fear of violence/abandonment	X	X	X		X		X
Provider relationship	X	X	X	X	X	X	X
Lack of community involvement in ART programs		X					
<b>System factors</b>							
Cost of transportation	X	X	X		X		X
Access: Distance	X	X	X		X		X
Access: Long waiting times	X	X	X				X
Cost of care and treatment	X	X					X
Drug shortages	X	X			X		X

1 Studies focused on HIV-positive, pregnant, and post-partum women.  
2 This study looked at uptake comprised of access, initiation, and adherence.

Figure 1: Maternal state by children's age, assuming 90-90-90 treatment targets



children affected by HIV have developed, tested, and refined approaches to supporting families dealing with these issues and are further exploring opportunities to incorporate interventions addressing emotional distress/depression and substance abuse. They have done so to improve outcomes for children, such as keeping children in school and protecting them from abuse. However, given that these are established determinants of adherence, it is likely that, in supporting children and families in this way, these programs have also indirectly improved adult treatment outcomes. This conclusion is supported by the evidence that similar household and community programs have been effective at improving adult treatment adherence.

If the 90-90-90 target is reached, 73% (90% x 90% x 90%) of mothers will achieve viral suppression. This will lead to a large decline in mortality in the short run. However, high mortality among the 27% who do not achieve viral suppression and residual excess mortality among those who do, combined with even a small drop-out rate, will, over time, erode this success at the population level. In the modeled scenario, only 44% of HIV-positive mothers will be alive when their children reach 18 years of age, a 13 percentage point (40%) increase compared to the percentage in a no-treatment scenario. A major improvement, but a long way from the little over 90% of mothers who would live to see all their children reach 18 year of age in the absence of HIV. Halving loss to follow up, not shown, would increase the proportion of HIV-affected mothers living to see all their children reach 18 years to 51%.

The results suggest that adult adherence is affected by household factors and that adult adherence is important if we want to prevent, as opposed to delay, orphaning. When you consider that programs for children are already working at the household level, the potential for improving both adult and child outcomes by adapting these programs to explicitly address adult adherence is clear.

## Lessons

## Learnt and

## Policy

## Recommendations

There is evidence that household and community programs can improve adherence to ART treatment (Wouters et al., 2012; Chaiyachati et al., 2014). Programs directed at affected children are, in fact, already working at the household and community level in a way that indirectly addresses the factors associated with poor adult treatment outcomes, including family economic well-being, mental health, social isolation, and stigma.

Efforts should be made to identify opportunities to build on this existing connection between child and caregiver health. One way to ensure that such efforts are made is to make adult (and child) treatment uptake and adherence the secondary goals of programs directed at affected children. Adult focused goals are unlikely to distract OVC programs from achieving their primary task of supporting children (given common barriers), and could lead to a range of benefits, for both adults and children. To make the most of the opportunity, changes would be necessary on the side of treatment programs. It would require treatment programs to collaborate with, refer to, and support the training of these household- and community-based programs in order for them to play this essential role. In this way, treatment programs will help improve OVC outcomes (via improved caregiver health) and OVC



Community and household services for children affected by HIV benefit



Adapting these programs to make the most of the overlap with adherence barriers can benefit HIV-positive household members (both adults and children).



Improved uptake and adherence to treatment among adults will improve the care environment for children, providing further benefits for affected children.

## UGANDA PEPFAR/USAID SCORE Project

Jonathan (far right) stands in front of his house with his wife and three children. With support from the USAID-funded Sustainable Comprehensive Responses (SCORE) for Vulnerable Children and their Families Project in Uganda, the family has received training in farming techniques and financial literacy. Through their involvement in a village savings group, Jonathan and his wife were able to take out a loan to buy additional livestock. Having started treatment in 2005, Jonathan volunteers in his community to educate others about HIV and how to live positively.



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## References

Chris Desmond and Furzana Timol,  
Human Sciences Research Council

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Contact Information

Chris Desmond, cdesmond@hsrc.ac.za; Furzana Timol, ftimol@hsrc.ac.za

