

# Spiraling Upward: The Re-doubling Benefit of Family-centered Care

By Chris Desmond and Furzana Timol



Photo credit: Tash McCarroll

### In Brief

- **Household- and community-level Orphans and Vulnerable Children (OVC) interventions are aimed at directly assisting HIV-affected children. But, they may also be promoting adult treatment uptake and adherence. By highlighting this indirect contribution to adult HIV treatment, we hope to 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.**
- Household- and community-level stresses including financial and time constraints, caregiver mental health, social isolation and stigma, and other similar household- and community-level stresses act as barriers to treatment uptake and good adherence among adults. However, these also increase the risk of negative outcomes for HIV-affected children. For example, poor mental health of HIV-positive caregivers increases the risk that they will have poor adherence, which can compromise the quality of care they are able to provide to their children.
- With the goal of protecting children, many OVC programs providing services at the household and community level have developed, tested, and refined a range of approaches to remove or mitigate the impact of household- and community-level stresses.
- There exists an overlap between the barriers to child development and to adult treatment. Therefore, when OVC programs act to improve child development, they have also likely promoted adult treatment uptake and adherence. For example, improving the financial wellbeing of the household to help keep children in school is also likely to help adults living in that household overcome financial barriers to medical care.
- The impact of OVC programs on adult treatment uptake and adherence will depend on the extent to which child development barriers overlap with adult treatment uptake and adherence barriers. The impact on adult adherence could be strengthened if OVC programs work to identify additional household- and community-level barriers to adult treatment. Once identified, these barriers could be addressed efficiently and effectively given that OVC programs are already working at the household level.
- **The role of OVC programs in supporting adult treatment by addressing household- and community-level barriers should be recognized, evaluated, and strengthened.**
- **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 affected children by improving the health of their caregivers – an important outcome in and of itself.**

*Funding was provided by the United States Agency for International Development (USAID) under Cooperative Agreement AID-OAA-A-11-00015. The contents are the responsibility of the Leadership, Management, and Governance Project and do not necessarily reflect the views of USAID or the United States Government.*

## 1. Introduction: Opportunity in overlap

Many of the household- and community-level stresses which hamper the development of children affected by adult HIV also hinder antiretroviral therapy (ART) uptake and adherence among these adults. For example, stigma, social isolation, and financial and time constraints, which have been identified in the Orphans and Vulnerable Children (OVC) literature as limiting the ability of families to care for and protect their children, have also been identified in the treatment literature as barriers to ART uptake and adherence among adults. Because of this overlap, programs which seek to remove or mitigate these barriers to child development, through household- and community-level interventions could also be indirectly improving treatment uptake and adherence among adults living in these same households.

The role of household- and community-level barriers in hindering treatment uptake and adherence is well known. The work of OVC programs at the household- and community-level is equally well known. Yet, the potential contribution of OVC programs to removing household- and community- barriers to adult testing, treatment initiation, and treatment adherence has gone largely unrecognized. As long as the current contribution of OVC programs goes unrecognized, the potential to strengthen that contribution will be missed.

In this paper, we highlight this potential contribution of OVC programs to the long-term outcomes for both HIV-infected adults and their affected children. We hope that this will open up a discussion on how this important contribution could be strengthened. Because OVC programs are already operating at the household and community level, it is likely that opportunities exist to make small changes to maximize the contribution to adult treatment uptake and adherence, without distracting from the primary responsibility to children. OVC program designers should be encouraged to modify program design to take advantage of these opportunities, because of the dual benefit to both children and their adult caregivers. Clinical staff should be encouraged to view OVC programs as key partners, and to seek ways in which they can support OVC programs in their household- and community-level efforts in order to encourage treatment uptake and adherence.

There are many different types of OVC programs. We are focusing on those providing household-level support. It is the comprehensive nature of these home-based services that places OVC programs in the unique position to improve a wide range of outcomes. These programs visit households regularly; they provide a broad range of services and, thus, are unlikely to be stigmatizing; many of these programs use a case management approach that assesses the range of health and socio-economic issues affecting families, working with local partners to get them the support they need; and, as part of their routine activities, these OVC programs work with all residents of the household, including adults.

### **The downward spiral**

Adult HIV does not inevitably lead to negative consequences for affected children. However, the risk of negative consequences arises when adult caregivers become preoccupied with their diagnosis, compromising the care they provide for their children, or they become ill and physically less able to provide care or earn an income to support their children. When the family does not have the human and

financial resources to shield children from these impacts, children suffer. Children suffer all the more when stresses at home are compounded by stigma, social isolation, and low availability of quality services in the community (Sherr et al., 2014), making them a particularly vulnerable population.

Mental, physical, and financial strain in an environment characterized by stigma, social isolation, and poor services hinder adults' access to ART and reduce the likelihood of high levels of adherence even when treatment is accessed. In this situation, families may find themselves in a downward spiral resulting in mental, physical, and financial strain; poor outcomes for children and adults; poor treatment uptake and adherence; greater financial stress; further stigma and social isolation; and even poorer outcomes for children and adults. The worst outcomes for children and adults occur when this spiral goes unchecked.

### **Reversing the spiral**

OVC programs provide effective support at the household and community level, targeting the mechanisms through which adult HIV can result in hardships for children, including financial stress, poor adult mental health, and stigma and social isolation, among other things. These stresses also serve as pathways to poor adult ART treatment and adherence. As a result, OVC programs are addressing issues relevant to both children and adults, and thus are likely already playing an important role in preventing the downward spiral for families dealing with HIV.

If OVC programs are already indirectly playing a role in improving adult treatment outcomes, it is likely that there are opportunities to make adjustments to current programs that would strengthen the contribution to adult populations. Regular contact with households and an overarching concern for all household members, combined with the possibility of linking households to other services, places OVC programs in a unique position to provide additional support to all members of the household. For example, programs could complement existing psychosocial activities at the household level with counseling and support for adult adherence, highlighting the benefits for adults and their children. Knowledge of HIV status, treatment uptake, adherence, or loss to follow up of adult caregivers could be monitored and used to identify families in difficulty, triggering proactive intervention. By doing what they currently do and adding in one or two additional activities, programs designed to protect children can help reverse the downward spiral for adults as well. Improvements in adult health, in turn, can improve the care environment, thereby producing direct benefits for children.

## **2. Delaying or preventing the loss of a parent**

Programs providing HIV treatment for adults have an opportunity, perhaps even a responsibility, to protect affected children until they reach at least 18 years of age. To realize this opportunity these programs (in partnership with others) will have to place greater emphasis on adherence and retention. For example, consider how long a woman infected with HIV must live with the virus to see all her children reach their 18<sup>th</sup> birthday. The majority of women who are infected with HIV are infected before the age of 25. Many women have their first child during this same period, but often go on to have additional children well into their 30s. If a woman is infected at age 17, has her first child at 20, and her second at 25, she must survive 26 years with HIV to see both her children reach 18 years of age.

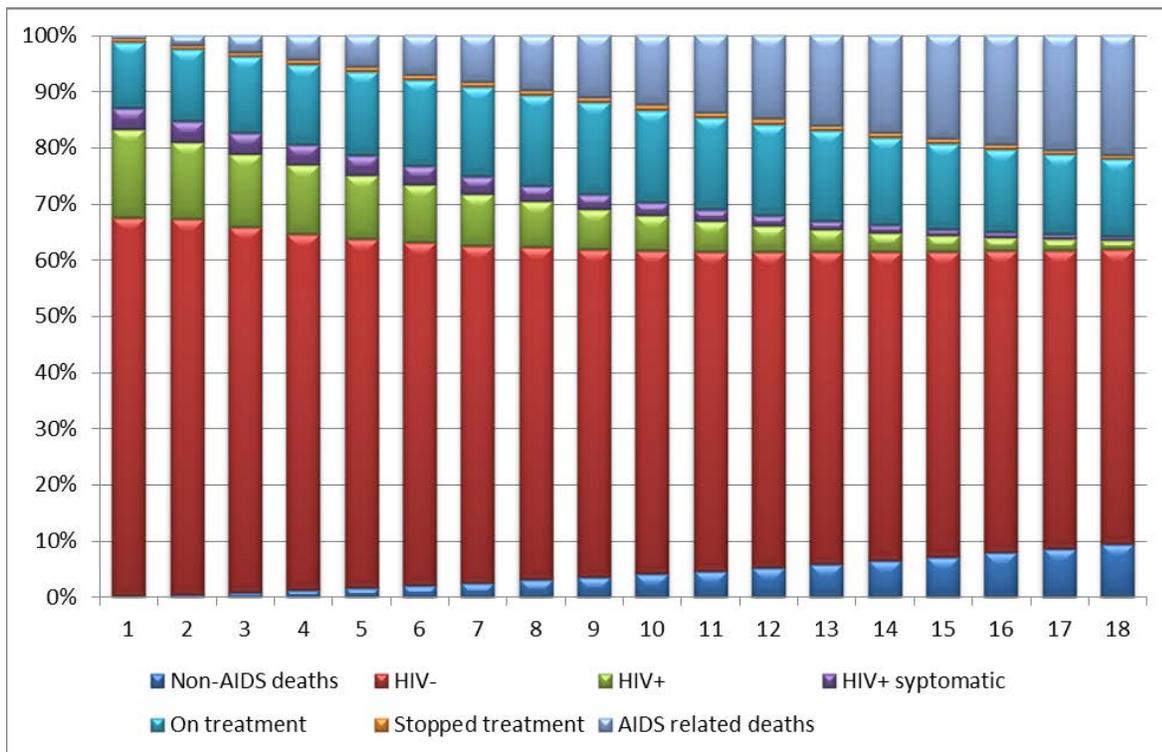
Advances in ART now mean that living 20, 30, and even 40 or more years with HIV is a real possibility. This, however, requires treatment to be started at the proper time and high levels of adherence to treatment regimens.

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. The model demonstrated that, even if this goal is reached, we will have to continue to strengthen efforts to support good adherence.

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 follow up.

The model maps maternal health according to the age of their children. Figure 1 presents the results for a cohort of women born into a high prevalence context.

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

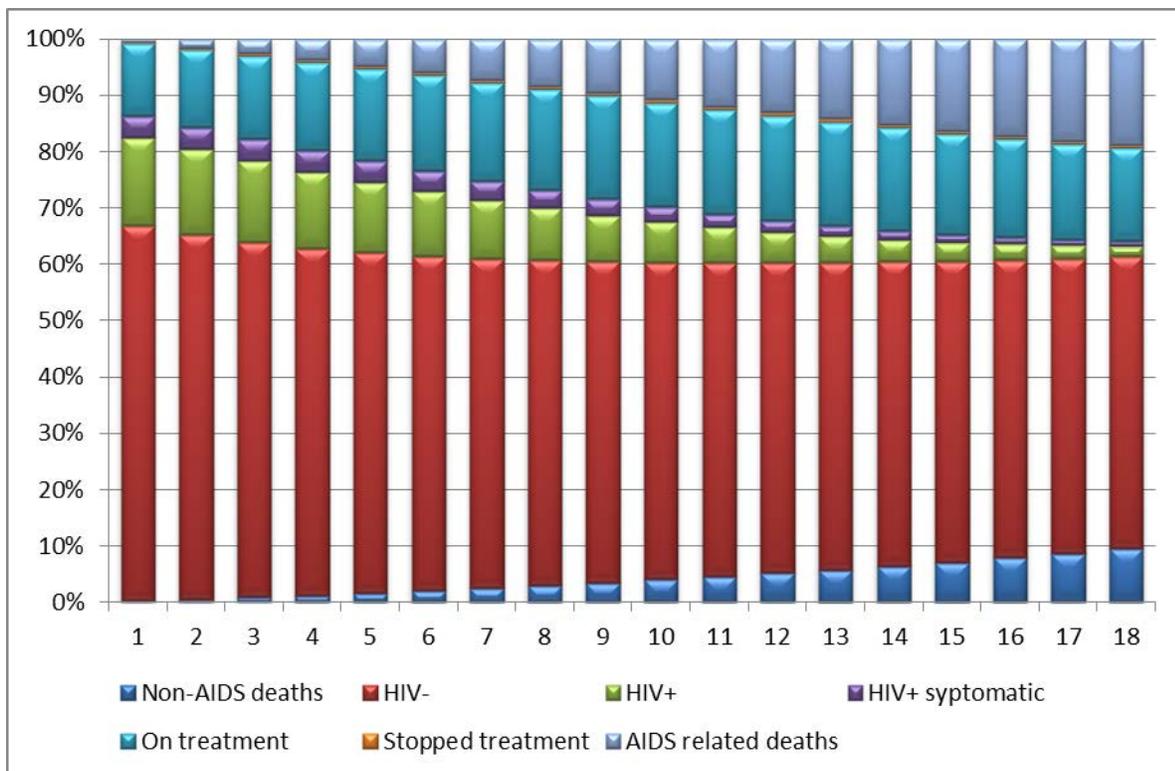


<sup>1</sup> Using the approach taken in the Actuarial Society of South Africa (ASSA) model, we assume higher mortality and attrition in the first six months of treatment, 6.6% and 4% respectively.

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%<sup>2</sup> 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, as shown in Figure 2, would increase the proportion of HIV-affected mothers living to see all their children reach 18 years to 51%.

**Figure 2: Maternal state by children’s age, assuming 90-90-90 and low loss to follow up**



The results of the model indicate that, even if the 90-90-90 target is reached, unless loss to follow up is kept to below 1.5% per annum, less than half of HIV-positive mothers will live to see their children reach 18 years of age. That is to say, if the high adherence necessary for viral suppression is not complemented by high retention rates, the benefits will be eroded over time. If this is to become a reality, the barriers to good adherence and retention must be addressed. When you consider how far

<sup>2</sup> The 44% is calculated by summing all the HIV states of mothers when their children are 18 to get an estimate of the number of HIV-positive mothers alive when their children reach 18, and then dividing this number by itself plus the number who have died from HIV: (number of HIV+ mothers alive when child reaches 18)/(number of mothers ever infected) X 100

we still are from the 90-90-90 target, the need to address barriers not only to adherence, but also uptake, becomes even clearer.

### 3. Causes of poor adherence: The overlap

People living with HIV and their healthcare providers in resource-limited settings often face challenges in ensuring good adherence due to personal as well as social- and system-level barriers. Some barriers are more prominent in resource-limited settings, while many occur across settings (Scanlon & Vreeman, 2013). Poor adherence and, at the extreme, loss to follow up greatly reduce the benefits of treatment and may lead to public health challenges associated with resistance. Table 1 summarizes the finding of six systematic reviews on barriers to adherence.

**Table 1: Summary of selected barriers to adherence review articles**

Author (year)	Review studies						
	Patel et al. (2010)	Scanlon and Vreeman (2013)	Vitalis (2013)	Sandelowski, Voils, and Lee (2009)	Mills, Nachega, Bangsberg, et al. (2006)	Langebeek et al. (2014)	Gourlay, Birdthistle, Mburu, Iorpenda, and Wringe (2013) <sup>3,4</sup>
<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	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	
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

<sup>3</sup> Studies focused on HIV-positive, pregnant, and post-partum women.

<sup>4</sup> This study looked at uptake comprised of access, initiation, and adherence.

Review studies							
Author (year)	Patel et al. (2010)	Scanlon and Vreeman (2013)	Vitalis (2013)	Sandelowski, Voils, and Lee (2009)	Mills, Nachega, Bangsberg, et al. (2006)	Langebeek et al. (2014)	Gourlay, Birdthistle, Mburu, Iorpenda, and Wringe (2013) <sup>3,4</sup>
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
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

The barriers to adherence once reversed can become drivers of adherence. Factors such as social support (Gourlay et al., 2013; Sandelowski et al., 2009; Vitalis, 2013), concern for others (Gourlay et al., 2013; Mills, Nachega, Bangsberg, et al., 2006; Vitalis, 2013), belief in the effectiveness of treatment (Mills, Nachega, Bangsberg, et al., 2006; Sandelowski et al., 2009), self-efficacy/self-worth (Mills, Nachega, Bangsberg, et al., 2006) easier medical regimens (Mills, Nachega, Bangsberg, et al., 2006; Sandelowski et al., 2009), patient counselling and education (Haynes, Ackloo, Sahota, McDonald, & Yao, 2008) and positive relationship with healthcare provider (Gourlay et al., 2013; Mills, Nachega, Bangsberg, et al., 2006; Sandelowski et al., 2009) are some of the factors which facilitate retention and 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 have 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 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.

## 4. Evidence for household- and community-based interventions to improve adherence

A recent review examined the literature on the benefits of community health workers, community care coordinators, peer health workers, field officers, health extension workers, peer HIV lay counsellors, directly observed therapy (DOT) for ART, adherence supporters, and home-based care volunteers to support the delivery of ART in resource-limited countries (Wouters et al., 2012). The authors conclude that community-based support services can have a favorable impact on a number of aspects related to ART programs, including adherence and patient retention levels, virological outcomes, and survival rates. Others have similarly found there to be potential to significantly increase adherence levels, including with cognitive behavior therapy, education programs, community-based workers, DOT, and active reminder devices (Chaiyachati et al., 2014). Although not all community- and household-based services have proven successful, many have, providing evidence for the potential positive impact of well-designed and well-implemented household- and community-based services. OVC programs should take note of the practices of those home- and community-based adherence support programs which have proven successful. This will assist with identifying potential modifications to OVC programs that would ensure that the most is made of the opportunities to support adult adherence. Similarly, lessons can be learned from unsuccessful adherence interventions, so that OVC programs can avoid previous mistakes.

If the most is made out of the opportunities provided by OVC programs, they may well prove more successful than standalone home- and community-based adherence support. Unlike standalone adherence programs, OVC programs are likely to be more intensive, address a broader set of household difficulties, and be less stigmatizing. Evaluating the possibility of family-centered care, built around OVC programs, to improve child and adult outcomes should be a priority.

**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.



**UGANDA PEPFAR/USAID SCORE Project**

According to Jonathan (front), a primary motivator for participating in the savings group and engaging in income generating activities is that it has enabled the family to save enough to buy additional crops and livestock, and sell surplus in local markets.

## 5. Summary: The win-win and win-again of household and community services for HIV-affected children

There is evidence that household and community programs can improve adherence to ART treatment. 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 programs will improve adult treatment outcomes (via improved uptake, adherence, and retention):

- **Win:** Community and household services for children affected by HIV benefit children directly
- **Win-win:** Adapting these programs to make the most of the overlap with adherence barriers can benefit HIV-positive household members (both adults and children)
- **And win-again:** Improved uptake and adherence to treatment among adults will improve the care environment for children, providing further benefits for affected children

## References

- Chaiyachati, K. H., Ogbuonji, O., Price, M., Suthar, A. B., Negussie, E. K., & Bärnighausen, T. (2014). Interventions to improve adherence to antiretroviral therapy: a rapid systematic review. *AIDS*, 28, S187-S204.
- Desmond, C., Bruce, F., Tomlinson, M., Marlow, M. B., Aber, J. L., Ouifki R., & Welte, A. (2014). Modelling the long-term impacts on affected children of adult HIV: benefits, challenges and a possible approach. *AIDS*, 28(suppl 3):S269-S275.
- Gourlay, A., Birdthistle, I., Mburu, G., Iorpenda, K., & Wringe, A. (2013). Barriers and facilitating factors to the uptake of antiretroviral drugs for prevention of mother-to-child transmission of HIV in sub-Saharan Africa: a systematic review. *J Int AIDS Soc*, 16(1), 18588. doi: 10.7448/ias.16.1.18588
- Haynes, R. B., Ackloo, E., Sahota, N., McDonald, H. P., & Yao, X. (2008). Interventions for enhancing medication adherence. *Cochrane Database Syst Rev*(2), CD000011. doi: 10.1002/14651858.CD000011.pub3
- Mills, E. J., Nachega, J. B., Buchan, I., Orbinski, J., Attaran, A., Singh, S., Rachlis, B., Wu, P., Cooper, C.,

Thabane, L., Wilson, K., Guyatt, G. H., & Bangsberg, D. R. (2006). Adherence to antiretroviral therapy in sub-Saharan Africa and North America: a meta-analysis. *JAMA*, 296(6), 679-690. doi: 10.1001/jama.296.6.679

Mills, E. J., Nachega, J. B., Bangsberg, D. R., Singh, S., Rachlis, B., Wu, P., Wilson, K., Buchan, I., Gill, C. J., & Cooper, C. (2006). Adherence to HAART: A systematic review of developed and developing nation patient-reported barriers and facilitators. *PLoS Med*, 3(11), e438. doi: 10.1371/journal.pmed.0030438

Patel, A., Hirschhorn, L., Fullem, A., Ojikutu, B., & Oser, R. (2010). Adult adherence to treatment and retention in care. AIDSTAR-One, Task Order 1. (pp. 1). Arlington, VA: USAID.

PEPFAR. (2012). Guidance For Orphans And Vulnerable Children Programming. Washington, DC: PEPFAR.

Sandelowski, M., Voils, C. I., & Lee, E. J. (2009). A systematic review comparing antiretroviral adherence descriptive and intervention studies. *AIDS Care*, 21(8), 953-966.

Scanlon, M. L., & Vreeman, R. C. (2013). Current strategies for improving access and adherence to antiretroviral therapies in resource-limited settings. *HIV AIDS (Auckl)*, 5, 1-17. doi: 10.2147/hiv.s28912

Sherr L, Cluver LD, Betancourt TS, Kellerman SE, Richter LM. & Desmond C. 2014. Evidence of impact: health, psychological and social effects of adult HIV on children. *AIDS*. 28 (suppl 3):S251-S259.

UNAIDS. (2014). 90-90-90: An ambitious treatment target to help end the AIDS epidemic. UNAIDS, Geneva.

Vitalis, D. (2013). Factors affecting antiretroviral therapy adherence among HIV-positive pregnant and postpartum women: an adapted systematic review. *Int J STD AIDS*, 24(6), 427-432. doi: 10.1177/0956462412472807

Wouters, E., Van Damme, W., van Rensburg, D., Masquillier, C., & Meulemans, H. (2012). Impact of community-based support services on antiretroviral treatment programme delivery and outcomes in resource-limited countries: a synthetic review. *BMC Health Serv Res*, 12, 194. doi: 10.1186/1472-6963-12-194