BLOOD:WATER

Blood: Water Technical eUpdate Vol. 16 – Pitfalls and Opportunities for Improving Long Term Treatment Adherence

Dear Partners,

This month's edition of the eUpdate explores the necessity of treatment adherence support as a part of community based HIV-responses. Working with communities infected and affected by HIV will undoubtedly bring you into the realm of **Antiretroviral Therapy (ART),** the course of treatment available for HIV. Supporting people living with HIV who are on treatment is a very critical component of the philosophy of positive living, as well integral to home-based palliative care activities. This is especially important given the sensitive nature of the therapy and the way that it works to suppress the HIV-virus in the body.

The guidelines for Antiretroviral Therapy, also commonly referred to as Highly-Active Antiretroviral Therapy (HAART) is a combination of 3 or more antiretroviral medications to be taken together. The goal of this course of treatment is to achieve maximal and durable suppression of the virus replication in the body. This in turn reduces the destruction of CD4 cells, reduces immune suppression and slows disease progression. Success with ART can be seen in rising CD4 cell counts, undetectable viral loads and clinical improvement in patients. Recent studies affirm that by achieving undetectable viral loads are equal to becoming un-infectious, which is now a huge area of focus under the global 90-90-90 strategy in order to turn the tide on new infections each year.

Adherence is defined as 'the act or quality of sticking to something—to adhere to something'. In the context of treatment with medications, adherence means to take doses according to their prescribed dosages through the full length of the course. An Individual's adherence practices is an essential component of their treatment success. Research supports that greater than 95% adherence, the equivalent of missing less than 3 doses per month, is needed in order to maximize the benefits of ART on clinical and immunological outcomes. Poor adherence practices are also associated with increased risk of developing drug-resistant viral strains and subsequent treatment failure.

The Changing Nature of Defaulting Treatment

And as much as adherence counseling is a standard part of treatment preparation, we are learning that this is not enough to support staying on this **life-long** therapy. Studies now affirm that the longer a person is on treatment, the higher the likelihood of defaulting, with a critical point of defaulting being after 5 years, where newly initiated individuals adhere well. The reasons that cause individuals to stop taking their medications are dynamic and change and ***this is where our call to action lays.*** Consider the following top causes experienced today by programs that monitor causes for defaulting treatment[1]:

- Cost barriers to attending clinic to pick their medications. This includes the cost of transport as well as lost income from having to take off from work.
- Difficulty or inconvenience around getting to the clinic. Non-cost challenges in transportation including distance and limited availability of options in some areas.
- Feeling well! Believe it or not, and this is why the default rate increases after 5 years.
- Stigma: Fear of inadvertent disclosure when going to pick medications at the clinic.
- Spending too much time at the clinic waiting

[1] Sikazwe et al. IAS 2017 Abstract TUPED 1291

- Moving: relocation either planned or unplanned often results in large numbers of people falling out of care.
- Lack of understanding between the relationship between viral load suppression (high CD4 count) and ongoing ART treatment. Achieving this is not a once-and-for-all goal, but needs to be maintained.
- Fearing being scolded or ridiculed by the health care providers for having missed medications. This fear causes clients to hide their missed treatments or fall out of programs completely.
- Lack of ongoing support. Reinforcing adherence and information that empowers successful health management is a never-ending need, particularly as life changes affect an individuals' ability or priority to maintain adherence to treatment and medical follow-up

Transforming Programmatic Pitfalls to Opportunities for Effective Adherence support:
Adherence support takes on different forms and, similar to other types of interventions, needs to be sensitive to the individually specific needs or challenges that are experienced. Most if not all programs talk about providing adherence support, but few approach support provision based on active barrier reduction or addressing the root causes linked to missing medication. Linking support activities to individual and ongoing client needs is the primary pitfall for having an impact on treatment adherence. Here are some tips on how to change your programmatic approach of adherence support.

1. **Supporting adherence by understanding and affecting change on individual barriers:**

   Adherence should be assessed at **every point of contact**, and ideally also at the time of pharmacy refills, in all PLHIV on ART and/or other medications, including cotrimoxazole and TB treatment. Remember, ***poor adherence to ART predicts disease progression, emergence of drug-resistance and treatment failure.***

2. **Reinforce treatment success with routine test results:**

   This is a new strategy to support long-term clients on treatment. Continuously linking a person's health status with their treatment is powerful and empowering. Creating deliberate conversations whenever lab results are received that demonstrate the relationship between achieving low or undetectable viral load and high CD4 tests with treatment success is important. Reinforcing this relationship as being connected will address the misconception that improved health outcomes can be sustained without continued treatment.

3. **Support retention in care:**

   Implementation of an appointment system and a method to track individuals that are enrolled in care. Extra attention may be needed for those at high risk of loss to follow up because of the barriers identified. This can include sms or phone call reminders of appointments, accompanied visits where there are people with physical or other challenges. Subsidizing transportation costs or creating other incentives to the household.

4. **Create community structures that work with the clinic:**

   Utilization of community- based groups of patients for ART refills and adherence assessments has also been shown to increase retention. This is an innovation in the concept around support groups that is being hailed as a true marker of success in supporting long-term treatment adherence by decentralizing aspects of treatment monitoring and delivery into communities.

To help your programs actualize the above, please take some time to read and evaluate the following resources. Download them and share with your teams for discussion on where opportunities lay for innovation, modifying your programmatic approaches or forging more effective linkages with other service providers to solve the challenges around adherence.

Enhanced Adherence Plan Tool: Developed by Columbia University ICAP, this tools is intended for point-of-contact assessment of adherence. The tool is very well developed to guide client sessions through areas of discussion that get to some specific root causes of challenges to treatment adherence. Adopting this tool for your programs as you support households and individuals is the first step to getting to the root cause of defaulting treatment. **Click the following link or see the PDF Attached:**
http://files.icap.columbia.edu/files/uploads/Enhanced_Adherence_Plan_Tool.pdf

The Viral Load Toolkit: Also developed by Columbia University ICAP the following is a full toolkit to support programs to use lab testing and results to reinforce ongoing adherence counseling. The flipcharts were developed for a range of health care workers (e.g., adherence counselors and community health workers included). There are three versions of the flipchart: one for adult (non-pregnant nor breastfeeding) patients, one for adolescent patients, and one for infants and children. Each flipchart is available in English, Swahili, Portuguese, and French, and PowerPoint versions are provided to facilitate adaptation. **Click the following link to download: http://www.icap.columbia.edu/resources/detail/viral-load-toolkit-flipcharts**

ART Adherence Clubs Model and Toolkit: The ART Adherence Clubs were initiated by Medecins Sans Frontieres in 2007 with the support of the Western Cape Department of Health and the Treatment Action Campaign in Khayelitsha at the Ubuntu Clinic to address this challenge. The ART clubs decentralize the provision of treatment to patients' local communities with an added incentive of social support as stigma is still a challenge faced by many people infected with HIV in South Africa. The ART clubs are a long term retention model of care catering for stable ART patients where 30 stable patients meet and are facilitated by lay healthcare workers who provide a quick clinical assessment, referral where necessary, peer support and distribution of pre-packed ART every 2 months. The goals of the ART Clubs are two-fold, for both patients and health facilities:

Health Facility and system

- Decentralize provision of ARTs from mainstream care to communities alleviating volume of patients in public clinics.
- Therefore, allowing nurses and other health providers to see more patients and effectively manage those who default on treatment.
- Reduce load on pharmacies by using a central dispensing service for pre-packing.
- Monitoring of patient outcomes.

Patients in ART clubs

- Provide ARTs at convenient locations.

- Offer peer support and a platform for patients to share experiences with other community members facing similar challenges.
- Improve retention and virological outcomes.
- Empower patients to manage their own health.

ART Adherence Clubs are proving to give stable adherent HIV patients easier access to their treatment, while unclogging clinics and freeing up scarce nurses and doctors to manage new or at-risk HIV patients. **Click the following link or see the PDF Attached: https://www.msf.org.za/system/tdf/art_adherence-club_report_toolkit.pdf?file=1&type=node&id=3126**

ART Adherence Club SOP: Also issued by MSF, in support of other programs replicating this model, the following resource is the actual standard operating procedures (SOP) applied to the ART Adherence Clubs. You will see from the document that these are NOT the same as psychosocial support groups and so this SOP document will serve as an effective way to ensure alignment with the intention of the ART club goals and objectives for ART adherence: **Click the following link or see the MS Word file Attached: https://www.msf.org.za/sites/default/files/publication/documents/Club-SOP.pdf**

Implementation of community-based adherence clubs for stable antiretroviral therapy patients in Cape Town, South Africa: A true innovation in the area of decentralizing care and increasing community capacity for HIV/AIDS support is this concept of ART Clubs. To better orient you with this concept and provide the available evidence of its success the following is a research article published in the Journal of the International AIDS society on applying this model in the South African context. This provides the preliminary findings and document the areas of consideration which need more research. It is an important read as you consider taking on this new model and using additional resources provided in this update. **To read, see the attached PDF**