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Measuring and Supporting Adherence to Antiretroviral Therapy

Adherence to antiretroviral therapy (ART) is fundamental to treatment success in patients living with HIV. Good adherence has been strongly correlated with viral suppression, reduced rates of resistance, increased survival, and improved quality of life (Chesney 2006, WHO 2003). Because adherence is so critical to treatment success, measuring adherence is a barometer of quality of care at individual and programmatic levels.

Despite evidence that high levels of adherence to treatment are possible, adherence is a dynamic phenomenon affected by patient, provider, and systems factors (Castro 2005). Patient adherence tends to decline with the length of time enrolled in treatment, a phenomenon often referred to as “pill fatigue” or “treatment fatigue” (Oyugi 2004). Poor adherence has been associated with a number of factors, including treatment side effects, complex regimens, lack of social support, and feeling depressed or overwhelmed (Mills 2006).

In clinical settings, adherence data are seldom collected in a systematic manner. A cross-sectional survey of 24 systems of care in five East African countries showed that less than half of the facilities routinely measured patient level adherence, and less than a quarter attempted to estimate adherence levels for their clinic populations (Chalker 2008). However, in order to optimize the quality of care provided for patients on ART, it is vital to

institute systems that regularly assess adherence.

Although there is no gold standard, there are many validated tools and strategies that can be used to assess adherence. Several practical and effective methods for use in clinic settings are described below. Clinic staff should commit to a measure or combination of measures, and then use these measures to assess adherence for every patient at every visit,

and document the results in a standardized fashion. The results can then be used to manage and support individual patients and to assess and improve how the clinic as a whole is performing with regard to this critical aspect of care. While providers should encourage patients to adhere as closely as possible to their prescribed regimen, when assessing

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Box 1: Sample Quantitative Measures to Assess Adherence

Adult 30-Day Visual Analog Scale:

Below is a generic 30-day visual analog scale (VAS). The VAS is not meant to imply that the medication is in cups, but to provide a visual representation of how much or how little medication has been taken overall.

Circle the object that best represents the number of doses you took in the last 30 days:



Pediatric 7-Day Structured Survey:

Which doses were you not able to give in the last seven days?

a. Write in days of the week for the last seven days, and mark an “X” for missed morning and/or evening doses.

| Day | | | | | | | |
|---------|--|--|--|--|--|--|--|
| Morning | | | | | | | |
| Evening | | | | | | | |

b. Check the option below that captures the level of adherence in the last seven days:

Low (5 or more missed) Medium (3 or 4 missed) High (0-2 missed)

What was the main reason that each dose was missed?

A full version of both tools, as well as other tools and resources for adherence in adult and pediatric patients, can be found on the ICAP Clinical Unit WIKI: <http://www.socialtext.net/icap-clinical/index.cgi?icapam>.

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adherence, it is important to involve patients in a discussion, using non-judgmental language that normalizes less-than-perfect adherence. For example, a clinician can start by acknowledging how difficult it is to take medicines regularly, and how easy it is to miss doses. Having multiple members of the health care team asking about adherence can facilitate this dynamic. Finally, the ultimate goal of adherence assessment is to support the patient. Assessment allows staff to determine which specific types of support are most appropriate for each individual patient.

Quantitative Measures

Patient recall methods, including structured self-report and visual analog scales (see examples in box 1), are valid measures of patient adherence and correlate well with objective and clinical measures of adherence. A systematic review of 77 studies confirms that patient recall methods are valid and reliable (Simoni 2006). A small study in Kampala found that patient recall methods (3-day self report and 30-day visual analog scale) were closely correlated with objective measures of adherence (electronic medication event monitoring, and unannounced home pill count) as well as therapeutic impact (viral load) (Oyugi 2004). Patient recall methods tend to overestimate adherence, due to patients

inaccurately recalling or reporting missed doses, often because patients may view adherence as 'socially desirable.' Clinicians and counselors can attempt to address these biases by emphasizing to patients that missing doses is normal for all patients at some point in their treatment.

Pill counts and pharmacy records of medication refills can also be used to assess adherence. Pill counts can be performed by clinicians or counselors. These data should be collected using a standardized tool, and the results converted into a percentage for a given time period (e.g. 85% of pills taken over last 30 days), so that they are readily understood. Pharmacy refill data are also correlated with objective and clinical measures of adherence (Bisson 2008; Saberi 2008), are simple to interpret, and easy to collect. These data can also be used to assess how well clinic patients are adhering as a whole, which may inform changes in a clinic's approach to adherence support (Grossberg 2007).

Qualitative Measures

All patients should be asked a general qualitative question about adherence, even if they have not reported missing any doses. For example, the question "What have you found difficult about adhering to your medicine this month?" can strengthen patient engagement in care by allowing the patient to discuss his or her story, and enable providers to tailor support interventions to patient needs.

Qualitative measures can be open-ended and include multiple questions on barriers and facilitators to patient adherence, such as "What problems have you had taking your medications in the past month?" and "What has helped you to take your medications in the past month?" Asking these questions enables providers to link patients with support interventions that address specific barriers and strengthen facilitators to promote high adherence levels over time. Tools and resources on assessing barriers to adherence can be found at <http://www.socialtext.net/icap-clinical/index.cgi?icapam>.

Programmatic Considerations

As mentioned, adherence must be assessed for every patient at every visit. The programmatic challenge is to balance the time needed to complete these assessments against the reality that assessment is complex, sensitive, and may provoke intense emotions. The balance will be different for every clinic setting, but the following parameters should guide choice of methodology.

- **Multiple methods should be utilized** whenever possible. For example, a patient recall method such as 3-day structured survey can be combined with review of pharmacy refill data.
- Multiple providers should participate in adherence assessment and support for each patient. Patients reveal different things to different providers. **The multidisciplinary team approach**, involving counselors, peer educators, clinicians, and pharmacists, should facilitate the collaboration necessary to support adherence, and will maximize the useful information emerging from interactions with patients.
- Self-monitoring and participation in care are the goals of adherence assessment. Adherence assessment should be **participatory and interactive, rather than a "report"**, allowing patients to actively track and improve their own adherence.
- Adherence assessment should be **situated within both clinical and counseling frameworks**. A supportive, multi-dimensional, setting will increase the likelihood of eliciting accurate,

Box 2: Key Steps in Conducting Patient-Centered Adherence Measurement

1. Introduce the process of adherence measurement: acknowledge that medications are difficult to take for most patients at sometime during their treatment. Reassure patients that the following assessment is meant to help improve treatment, and that they can be open about reporting missed doses, as the results will be kept private and confidential within the multidisciplinary healthcare team.
2. Confirm the medication regimen: ask patients what pills they are taking to treat their HIV, how many pills they take each day, and when they take them. If patients have their medications on hand, ask to see them. If patients are not sure, confirm the regimen in their medical record. Then, review the details of how to take the medications.
3. Measure, interpret, and document adherence: complete the assessment with patients and help them interpret the results. Document the result in a systematic fashion.
4. Ask about challenges: even if a patient has not reported missed doses, ask what challenges or barriers to adherence he/she has experienced. If patients don't identify any challenges, prompt with a list of common challenges to see if any apply.
5. Plan for maintenance and improvement: develop a plan to sustain high adherence and improve upon low levels of adherence that accounts for specific challenges, strengths, and available support interventions. This process of adherence assessment, counseling, and support will occur at each visit, and will include the participation of the multidisciplinary team.

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- complete, and actionable information.
- Adherence assessment should be **sensitive to staffing and time constraints**. A measure that takes a shorter time to complete may be most appropriate for busy clinical settings. It is most important that the assessment be done on a regular basis using the same methodology.
- Adherence assessment is the beginning of further conversation and patient engagement; it must be **linked to appropriate adherence support interventions**. In order to achieve high levels of adherence sustainably, the results of adherence assessments must be used to improve adherence and for continuous quality improvement in adherence support interventions.

Importance of Dedicated Programmatic Initiatives

Adherence, and most adherence support, occurs in the home, with patients visiting the clinic relatively infrequently – at most once per month. Nonetheless, these clinic visits are critical in assuring that patients receive the support and skills they need for successful adherence, are able to voice any issues or concerns, and receive appropriate adherence interventions when necessary.

References

1. Bisson GP, Gross R, Bellamy S, et al. (2008). Pharmacy refill adherence compared with CD4 count changes for monitoring HIV-infected adults on antiretroviral therapy. *PLoS Med*, 5(5), e109.
2. Castro A. (2005). Adherence to Antiretroviral Therapy: Merging the Clinical and Social Course of AIDS. *PLoS Medicine*, 2(12), e338.
3. Chalker J, Andualem T, Minzi O, et al. (2008). Monitoring adherence and defaulting for antiretroviral therapy in 5 East African countries: an urgent need for standards. *J Int Assoc Physicians AIDS Care (Chic Ill)*, 7(4), 193-199.
4. Chesney MA (2006). The elusive gold standard. Future perspectives for HIV adherence assessment and intervention. *J Acquir Immune Defic Syndr*, 43 (Suppl 1):S149-155.
5. Grossberg R, Gross R. (2007). Use of pharmacy refill data as a measure of antiretroviral adherence. *Curr HIV/AIDS Rep*, 4(4), 187-191.
6. Mills EJ, Nachega J B, Bangsberg DR, et al. (2006). Adherence to HAART: a systematic review of developed and developing nation patient-reported barriers and facilitators. *PLoS Med*, 3(11), e438.
7. Nachega, JB, Mills, E J, & Schechter, M (2010). Antiretroviral therapy adherence and retention in care in middle-income and low-income countries: current status of knowledge and research priorities. *Curr Opin HIV/AIDS*, 5(1), 70-77.
8. Oyugi JH, Byakika-Tusiime J, Charlebois ED, et al. (2004). Multiple validated measures of adherence indicate high levels of adherence to generic HIV antiretroviral therapy in a resource-limited setting. *J Acquir Immune Defic Syndr*, 36(5), 1100-1102.
9. Saberi P, Caswell N, Amodio-Groton M, Alpert P. (2008). Pharmacy-refill measure of adherence to efavirenz can predict maintenance of HIV viral suppression. *AIDS Care*, 20(6), 741-745.
10. Simoni J M, Kurth AE, Pearson CR, Pantalone DW, Merrill JO, Frick PA. (2006). Self-report measures of antiretroviral therapy adherence: A review with recommendations for HIV research and clinical management. *AIDS Behav*, 10(3), 227-245.
11. World Health Organization (2003). Adherence to long term therapies—evidence for action. www.who.int/chp/knowledge/publications/adherence_report.



Peer support groups are one strategy for assisting patients with ART adherence.

In the clinic setting, multiple strategies have been employed to assist and support patients in the difficult work of adherence to HIV care and treatment. Functional appointment and associated patient contact systems are fundamental to structuring timely clinic attendance and patient follow-up and outreach when necessary. Social networks are critical to the maintenance of adherence (Nachega 2010). In the clinic setting, peer educators and peer support groups may play

this role. Peer educators are patients who have been trained in HIV education and counseling and can suggest adherence strategies based on their own experiences. Support groups offer similar benefits, allowing patients to share difficulties and successes from their own process of adhering to treatment. Implementation materials for both of these strategies can be found on the ICAP website: <http://www.columbia-icap.org/resources>.