The Adherence Protocol is an individual intervention designed to actively engage a person living with HIV and his or her HIV treatment specialist in a clinical relationship based on a client centered/patient centered treatment approach. The key characteristics of the Adherence Protocol are: the person living with HIV manages the treatment process through an oral and written agreement; the clinician and patient learn to work together adhering to the patient’s treatment choices; and the treatment planning process teaches the patient to be fully in charge of his or her care and teaches the HIV specialist the true meaning of client-centered/patient-centered care.

I. Description

OBJECTIVES

- To improve the adherence to medications, making therapy more successful
- To encourage self-management of medications
- To foster honest communication between patient and provider
- To respect the patient’s choices and decision-making related to their HIV related medical care

TARGET AUDIENCE

- Any HIV+ person who is taking or contemplating HIV related medications
- HIV+ people from the Hispanic/Latino, African American, Alaska Native, Asian/Pacific Islander, and white communities
- HIV+ people with high “mobility” or transient living patterns who move back and forth between “active” to “inactive” patient status

ACTIVITY DESCRIPTION

An “adherence protocol” is an HIV treatment relationship tool based on honest communication between HIV+ clients and their health care providers. It can be an important ingredient for establishing the trust necessary in a relationship to help patients navigate the situations in their lives when faced with the complexity of HIV therapy. Through the use of an adherence protocol, the patients participate in HIV related medical services at their own pace. The patients feel welcome at the clinic and are able to reconnect with care even after a lapse in treatment.
The adherence protocol is both oral and written and follows a series of steps:

- The clinician meets with the patients and recommends a treatment regimen. Then patients make an appointment with the case manager for the first steps in the “adherence protocol” process.
- The case manager reviews the patient’s case with the clinician to gain a clinical perspective before the patient returns for the appointment.
- The case manager meets with the patient for an intake session. From the very beginning, the case manager, dedicated to the adherence protocol, clearly affirms that the patients are at the “center of their treatment regimen,” and that the health care professionals are there to help them make a choice that will positively affect their health.
- After a thorough discussion about treatment options, the case manager communicates support for the patient’s decision even if they do not “agree” with it based on health care criteria.
- The case manager gives patients a pre-treatment questionnaire to ascertain their “readiness” to begin therapy. This gives patients the option to say they are “not ready.” If patients say they are not ready, the case manager encourages patients to discuss fears or concerns about taking the medications.
- When patients are not ready to begin medications, the case manager respects their decision and offers to “revisit the medication question in the future.” Before finishing the session, the provider offers additional services, including testing and lab work.
- Each patient’s decision is recorded in the electronic medical records system and is flagged for review in 3 months to continue the conversation with the patient.
- If the patients choose to start medications, the case manager provides both oral and written educational material to prepare the patients for taking them. The pharmacist also spends time explaining the details of treatment when patients first pick up medications.
- The case manager follows up with patients who elect to undergo therapy by telephoning a few days after their scheduled start date. The case manager inquires after them, asks if they have begun taking the medication, and asks how the first few days have gone. The case manager may use language like: “what is the ‘real’ situation now that you are at home with the pills?” Often, the situation of being at home with the medication is more difficult than expected, and the case manager can offer assistance negotiating treatment and strategizing the practical realities of their care. Questions like: “What would work for you?” and “Can I call you back to talk about this?” foster respect for patients, who are then more likely to share frankly the difficulties of integrating their health care needs into their lifestyle.
- With patient consent, the case manager repeats the follow-up phone call in a few weeks and again at one month from the start of treatment, encouraging the patient to call with any questions.
- Patients complete an adherence questionnaire every 6 months following the initiation of treatment.
- As part of monitoring adherence, the clinic pharmacist reports if patients are not picking up their medications to the case manager.
- If patients miss appointments or drop out of treatment, the case manager calls to ascertain the situation. The case manager tries to keep in touch with the patients.
- If there is a change in medication, the adherence protocol process starts over from the beginning.

PROMOTION OF ACTIVITY

None
II. Logistics

STAFF REQUIRED

- Two case managers
- Quality improvement coordinators (nurse) – to track patient appointments and follow-up time
- HIV clinician/primary care doctor

TRAINING & SKILLS

- Registered nurse with good communication and listening skills who understands case management
- Case manager with HIV counseling skills

PLACE OF ACTIVITY

Primarily in the office or exam room; occasionally at patients’ homes or other off-site locations

FREQUENCY OF ACTIVITY

Every six months or upon change in medications

OUTSIDE CONSULTANTS

None

SUPPORT SERVICES

Taxi vouchers, bus passes, translation service by staff member (Spanish to English)

CONDITIONS NECESSARY FOR IMPLEMENTATION

Discussed within the description

III. Strengths and Difficulties

STRENGTHS

The staff

WEAKNESSES

Lack of racial diversity in the current staff

DIFFICULTIES FOR CLIENTS

- Patients do not want to disappoint their provider. The challenge is to make it okay for them to say "no" or "I can’t do this" to an authority figure.
- Often the patients who have been at the clinic longest get more staff time while much less time is spent developing the relationships with newer patients.

DIFFICULTIES FOR STAFF

Limited time to do home visits
OBSTACLES FOR IMPLEMENTATION

None

NON-APPROPRIATE CLIENTS

None

IV. Outcomes

EVIDENCE OF SUCCESS

- The program monitors lab results to evaluate the success of the self-management goals.
- The program consults a consumer advisory board for input. Patients rate the adherence protocol program as very good.
- Patients do return to the clinic to resume treatment after becoming “inactive.”

UNANTICIPATED BENEFITS

- For everyone, staff and clients, the adherence protocol keeps the communication open, both inside the clinic and within the community.

“CONNECTING TO CARE” ELEMENT OF ACTIVITY

Patients really know they have choices: to engage or not engage, to adhere or not adhere, to come to the clinic and remain in care or not, to take medications or not.

EVALUATION

- Yearly report to HRSA
- The activity receives input from consumers

KEEP IN MIND...

- Structure the schedule to facilitate more one-on-one interaction.
- Pay attention to the fact that the issues around care and adherence extend beyond the therapy itself.