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A PEER-REVIEWED ARTICLE

# Keeping patients in care: A critical component in controlling HIV

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The concept of adherence as it relates to clinical HIV care has expanded from adherence to medications to the critically important issue of adherence to care. This article will cover the evidence that supports the importance of that inclusion as it relates to HIV management and mortality.

Early work on adherence to HIV treatment examined the predictors for appointment attendance (Catz, McClure, Jones, & Brantley, 1999; Israelski, Gore-Felton, Power, Wood, & Koopman, 2001) in clinics in Louisiana and California. Both studies used the number of missed medical appointments as the measure of adherence to care. Consistencies between these studies were that younger individuals, minorities, and those with higher CD4 counts missed significantly more appointments (Catz *et al.*, Israelski *et al.*) (Fig.1). Catz *et al.* noted that perception of lower levels of social support also contributed to non-adherence ($F = 5.29$ $p < .001$), and Israelski *et al.* found that heterosexual orientation ($t = 2.79$, $p < .01$) and lower income ($t = -3.18$, $p < .01$) were also linked to non-adherence. The authors suggested that interventions to support attendance be targeted to these populations.

More recent work, conducted using data on more than 2,000 men from the United States Department of Veterans Affairs (Giordano, Hartman, Gifford, Backus, & Morgan, 2009) and in a large public clinic (Giordano *et al.*, 2005) showed similar findings about predictors of poor retention in care, despite it being a population with almost universal coverage of health care. These studies used the number of quarters of the year where there was an attended clinic appointment as their measure of adherence. In addition to the previously mentioned predictors, they found that the absence of other chronic medical conditions, the presence of Hepatitis C, and substance abuse were further predictors of poor retention in care. An additional finding (Giordano *et al.*, 2007) was the fact that 17% of men in their first year after starting HIV medications attended $\leq$ 2 visits for that year, and that their survival rate was significantly worse than those who attended visits in all four quarters of the year (hazard ratio=1.42 or higher, depending on the number of visits attended, 95% CI, 1.11–1.83 or higher).

The threat of limited retention in care in the first year of HIV care appears to be particularly great, and with outcomes that affect survival. In a large clinic in Alabama, individuals who missed visits in their first year after initiating HIV treatment had a significantly higher rate of mortality (hazard ratio 2.90, 95% CI, 1.28–6.56) (Mugavero *et al.*, 2009), were significantly more likely to delay initiation of antiretroviral therapy (hazard ratio 6.66, adjusted for CD4 < 350, 95% CI, 4.27–10.41) (Ulett *et al.*, 2009) and maintained a higher viral burden (Beta coefficient=0.11 per 10% visit non-adherence, 95% CI, 0.76–0.91) (Mugavero *et al.*, in press), as compared to those with perfect clinic attendance during that year. Poor persistence in HIV care, defined as visits in less than four six-month blocks in the first two years after initiating HIV care, had many of the same predictors as missed visits or retention defined as a visit in four quarters of the year: worse retention/persistence was associated with younger age, substance abuse, and higher CD4 count, though minority status was not significantly associated in this study.

**Retention measurement**

In most of these studies, adherence to care was defined as at least one visit in each quarter of the year. In the literature (Horstmann, Brown, Islam, Buck, & Agins, 2010) there are wide ranges reported in various studies about the extent of non-adherence to care. When measured by missed visits, Horstmann *et al.* report rates ranging from 25% to 35% in general HIV clinics, and 25% to 45% of patients had missed at least one appointment in a defined period of time.

The rate of missed visits for an individual patient does not necessarily translate into lack of continuous HIV care if missed appointments are promptly rescheduled, but it does translate to decreased productivity by clinical providers, and decreased efficiency. When viewing the concept of retention in care as a patient-oriented measure, the number of visits per block of time may be more descriptive. This would assure sufficient appointments to identify complications, to provide important counseling and education, and to provide prescriptions for medications to control viral replication. When measuring patient retention rates as defined by one medical visit every six months, rates have been reported in the literature from 20% to 100%, depending on the clinic and the specific segment of the clinic population (Horstmann, *et al.*, 2010).

The Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB) has a performance measure of at least two primary care visits in a year which are more than three months apart. At least two clinic appointments shows continuity for a particular patient, and having them at least three months apart assures that visits solely during an acute illness will not be confused with retention. Nonetheless, it may not be the best measure of retention in care to reflect persistence or constancy over the long run (Mugavero, Davila, Nevin, & Giordano, 2010). Because of the varied frequencies that are required by individuals at various stages of viral control, using the measure of at least one visit in each half of the year can be a useful measure of constancy that will give accurate results for those in chronic maintenance as well as those in early stages of treatment.

One study (Horstmann, *et al.*, 2010) defined proportions of the clinic population as regular users (at least one complete appointment every six months), sporadic users (those who complete at least one appointment per year but are “no shows” for at least two appointments per year), and non-engagers (those who completed the initial appointment but did not return) This study (Dekker, Relf, & Alampay, 2003) found that 25% of that clinic were found to be regular users, 32% were sporadic users, and 43% were nonengagers.

**Local data collection**

At the University of Mississippi Medical Center (UMMC) Infectious Diseases (ID) Clinic, 28% to 39% of scheduled visits per month were missed in the year from July 2010 through June 2011, with an average of 34% missed appointments per month.

At the UMMC ID clinic, data about patient-level missed visits were much more difficult to obtain than clinic-level data, though theoretically could be obtained from UMMC appointment records or through individual electronic record review. CAREWare, a HRSA-sponsored patient-level reporting database (**http://hab.hrsa.gov/manageyourgrant/careware.html**), utilized primarily by clinics that are funded by the Ryan White Program, can develop reports on visits attended in a particular period of time, but not on missed visits unless this information is entered into CAREWare.

At UMMC, retention in care as defined by the HRSA/HAB performance measure showed that of the 1491 patients who had an appointment with a primary care provider

in the year July 2010 through June 2011, 1150 (77%) had at least two appointments that were at least three months apart. Another analysis showed that 70% had attended at least one appointment in the previous year in each half year (July–December 2010, and January–June 2011), and again, almost all of those (96%) who did not meet that definition had not been formally moved to another place of HIV care.

**Conclusions**

The purpose for data collection regarding retention in care will drive the type of measurement used. For clinic productivity/efficiency, missed visits may be most useful. When trying to understand the characteristics of individuals that are less engaged in care, missed visits and measures of visit constancy would both be useful, as they may point to different aspects of the problem. Missed visits may describe transience and chaotic living situations, and/or system-level changes that need to be instituted by the clinic, such as reminders prior to visits. Visit constancy may describe the extent of full engagement in care on a chronic basis. Discovering the characteristics of patients associated with either of these measures of retention would assist in developing interventions to prevent poor adherence, as these interventions could be targeted to individuals who exhibit those characteristics.

To develop interventions to improve the clinic population's level of retention in care, resources targeted toward specific levels of retention will likely be beneficial in spreading resources to where they are needed. Interventions can be targeted toward a particular category of patient: regular users, sporadic users, or non-engagers. Regular users would be more likely to benefit from reinforcement for their full engagement in care, while assessment of the factors leading to poor retention would result in directed case management for sporadic users and outreach to re-engage non-engagers.

While data systems may not be in place to make the associations between patient characteristics and their retention level, CAREWare or other patient-level databases can be used to identify those individuals who are less engaged in care. A random sample of these individuals interviewed about barriers and facilitators to retention in care may be helpful, potentially by using an instrument such as that used in the CDC Medical Monitoring Project (Division of HIV/AIDS Prevention, 2008). This questionnaire (Fig. 2) is a single question, "What were the reasons you didn't go to your health care provider for the period you were out of care for at least six months?," and is coded by the interviewer using a list of possible categories such as "Felt good and didn't need to go" and "Didn't know where to go." It may then be followed up with the question "Of these reasons, what is the *main* reason that you didn't go to your health care provider?" Using this information, interventions can be developed that address the barriers that are most evident in the sample interviewed.

At the UMMC ID clinic, assessments have been conducted in a variety of ways. In 2008, focus groups were conducted (Williams, Amico, & Konkle-Parker, 2010) that described barriers and facilitators to retention in HIV care (Fig. 3). Participants described clinic-level barriers like fragmentation of the system of care, and personal-level barriers like competing demands, stigma, negative affect, and a sense of HIV care not being important as having impact on their retention in care.

In addition, a qualitative/quantitative assessment of barriers to retention in care was conducted in 2007 (Konkle-Parker, Amico, & Henderson, 2011) among those who reported at least one gap of six months in HIV care (n=94). The most frequent responses given were they felt good and didn't feel they needed to go to the clinic (21% gave this as a barrier, 13% as the main barrier), they were not in town at the time of the appointment (21% a barrier, 8% main barrier), they were unable to get transportation (20% a barrier,

13% main barrier), or it was due to drinking or using drugs (14% a barrier, 11% main barrier).

Clinic-based interventions might center on: a) developing coordination between various health care settings and supporting increased levels of privacy, b) providing education about the importance of routine clinical care, and c) encouraging active engagement in care and increased support through support groups, Consumer Advisory Boards, and/or other projects that allow patients to become more active in the clinic. Other education may center on resources available for transportation, or encouragement to attend drug or alcohol treatment. Targeting interventions to barriers identified in the particular clinic allows for a greater likelihood of effectiveness, and thus increased retention in care.❖

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**Figure 1**

**Differences in number of missed appointments**

Younger age: Catz *et al* $r = -.21$, $p<.01$;
Israelski *et al* $t = -4.28$, $p<.001$

Minority status: Catz *et al* $F = 11.35$, $p<.001$;
Israelski *et al* $t = 3.87$, $p<.0001$

Higher CD4 counts: Catz *et al* $r = .18$, $p<.05$;
Israelski *et al* $t = -3.01$, $p<.0001$

## Figure 2

**What were the reasons you didn't go to your health care provider for the period you were out of care for at least six months? [Check all that apply.]**

Felt good, didn't need to go ..... ❑ 01
Didn't like the clinic ..... ❑ 01a
Didn't like the doctor or NP ..... ❑ 01b
Forgot to go ..... ❑ 02
Missed my appointment(s) ..... ❑ 03
Too busy to go ..... ❑ 04
Moved or out of town ..... ❑ 05
Didn't want to think about being HIV positive ..... ❑ 06
Didn't believe test result ..... ❑ 07
Unable to get transportation ..... ❑ 08
Unable to get childcare ..... ❑ 09
Inconvenient (locations, hours, time, etc.) ..... ❑ 10
Didn't know where to go ..... ❑ 11
Hard to find right doctor or good doctor for me ..... ❑ 12
Initial CD4 count and viral load were good ..... ❑ 13
Drinking or using drugs ..... ❑ 14
Living on the street ..... ❑ 15
Didn't have money ..... ❑ 16
Didn't have insurance ..... ❑ 17
Unable to get earlier appointment ..... ❑ 18
Incarcerated ..... ❑ 19
Was worried about my privacy ..... ❑ 19a
Other ..... ❑ 20
(Specify:_____)
(Specify:_____)
(Specify:_____)
(Specify:_____)
Refused to answer ..... ❑ 77
Don't know ..... ❑ 99

**Figure 3**

**Barriers to and Facilitators for Attending Regularly Scheduled Medical Care Visits**

BARRIERS
1. Competing demands
2. System of care
3. Stigma
4. Negative affect
5. Beliefs about HIV health care not being important

FACILITATORS
1. Support
2. Active engagement in care
3. Positive aspects of health care visit
4. Perceived vulnerability to negative consequences