Bridging practice and research: A Survey of evidence-based practices used in HIV Care for linkage, retention and adherence support

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No conflicts of interest
After well over a decade of targeted efforts, and marked successes in public and individual health, HIV treatment remains limited in impact by:

- Delays in entry into care post diagnosis
- Cyclical use/discontinuation of HIV-care
- Sub-optimal adherence to or non-persistence with ART
While local and international ART treatment guidelines have recommended the monitoring of and intervention with adherence for several years, recommendations for how to do so have been limited.
In an effort to facilitate the identification of evidence based monitoring and support strategies for both engagement in HIV-care (linkage and retention) and adherence, **CLINICAL GUIDELINES** were recently released.
Clinical Guidelines

Guidelines for Improving Entry Into and Retention in Care and Antiretroviral Adherence for Persons With HIV: Evidence-Based Recommendations From an International Association of Physicians in AIDS Care Panel

Melanie A. Thompson, MD; Michael J. Mugavero, MD, MHSc; K. Rivet Amico, PhD; Victoria A. Cargill, MD, MSCE; Larry W. Chang, MD, MPH; Robert Gross, MD, MSCE; Catherine Orrell, MBChB, MSc, MMed; Frederick L. Altice, MD; David R. Bangsberg, MD, MPH; John G. Bartlett, MD; Curt G. Beckwith, MD; Nadia Dowshen, MD; Christopher M. Gordon, PhD; Tim Horn, MS; Princy Kumar, MD; James D. Scott, PharmD, MEd; Michael J. Stirratt, PhD; Robert H. Remien, PhD; Jane M. Simoni, PhD; and Jean B. Nachega, MD, PhD

Systematic review of the international literature since 1996 culling across 46,000 citations producing over 300 studies in the evidence base

- Entry and retention in HIV care
- Monitoring ART adherence
- Interventions to improve ART Adherence
- Adherence tools for patients
- Education and counseling interventions
- Health system and service delivery interventions
- Special populations
GUIDELINES FOR IMPROVING ENTRY INTO AND RETENTION IN CARE AND ANTIRETROVIRAL ADHERENCE FOR PERSONS WITH HIV

<table>
<thead>
<tr>
<th>Quality</th>
<th>Interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent (I)</td>
<td>RCT evidence without important limitations</td>
</tr>
<tr>
<td></td>
<td>Overwhelming evidence from observational studies</td>
</tr>
<tr>
<td>High (II)</td>
<td>Strong evidence with important limitations</td>
</tr>
<tr>
<td></td>
<td>Strong evidence from observational studies</td>
</tr>
<tr>
<td>Medium (III)</td>
<td>RCT evidence with critical limitations</td>
</tr>
<tr>
<td></td>
<td>Observational study evidence without important limitations</td>
</tr>
<tr>
<td>Low (IV)</td>
<td>Observational study evidence with important or critical limitations</td>
</tr>
</tbody>
</table>

TOTAL OF 12 RECS FOR MOST/ALL FOR GENERAL POPULATION

<table>
<thead>
<tr>
<th>Strength</th>
<th>Interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strong (A)</td>
<td>Almost all patients should receive the recommended course of action</td>
</tr>
<tr>
<td>Moderate (B)</td>
<td>Most patients should receive the recommended course of action. However, other choices may be appropriate for some patients</td>
</tr>
<tr>
<td>Optional (C)</td>
<td>There may be consideration for this recommendation on the basis of individual circumstances. Not recommended routinely</td>
</tr>
</tbody>
</table>
How do these recommendations map onto current practice?

• OBJECTIVE:
  – Characterize clinics/providers in terms of use/offering the recommended monitoring and support strategies for linkage, retention and adherence.
  – Characterize other aspects of “commonly provided” adherence support.
Characterizing Standard of Care in relation to these guidelines

• METHOD:
  – We surveyed providers of HIV-care on the use of various recommended retention and adherence monitoring and support strategies from the guidelines and from our experiences with standard of care offerings
Characterizing Standard of Care in relation to these guidelines

**METHOD:**
- E-blast to 1,500 IAPAC members w/ two reminder blasts (Jan 2012)
- Link to survey (40 item measure on web)
- Surveys completed between Jan 2012 and May 2012 compiled and analyzed
Approach

• Characterize monitoring and support strategies (generally and in relation to guidelines where applicable)
  – Proportion reporting a strategy used with or offered to most or all patients/clients

• Evaluate potential differences in strategy use between groups of respondents
RESULTS- Respondents

• A total of **395** surveys were partially (n=65) or entirely (n=330) completed.

• Response rate based on estimated number of e-blast recipients = 26.3%

• Completion rate = 84%

![Graph showing regional distribution](image1)

![Graph showing professional distribution](image2)
RESULTS- CLINICS/CARE SITES

- 70% of respondents reported working with medium to large (>200 to >1000) clinic populations

- Cumulative estimated number of patients represented by respondents:
  - 170,866 to 279,807 patients

- Most patients on ART (77%)

- Diverse subgroups within treatment populations
Porportion of respondents reporting clinic populations that included...

- PLWH with comorbid medical conditions: 79.7%
- PLWH with Mental Health Concerns: 75.4%
- PLWH who live in poverty: 74.9%
- Pregnant Women: 73.2%
- PLWH with Substance Abuse Problems: 62.8%
- PLWH who are homeless: 58.2%
- Children: 53.7%
- PLWH transitioning out of incarceration: 49.6%
- PLWH in methadone maintenance: 48.1%
- PLWH who are incarcerated: 47.6%
RESULTS - Estimates from Respondents

What percentage of your HIV-positive patients, once diagnosed, is typically lost-to-follow-up after their first clinic visit?

- Most (over half): 5.9%
- About half: 22.6%
- Some (1 to 25%): 28.5%
- Lost: 71.5%

What percentage of your HIV-positive patients, once linked to care and prescribed an ART regimen, is typically lost?

- Most (over half): 1.1%
- About half: 5.6%
- Some (1 to 25%): 6.7%
- Lost: 93.3%

Of those HIV-positive patients currently on ART at your clinic, what percentage do you estimate are suboptimal adherers (meaning they miss more than three prescribed doses/month)?

- Most (over half): 12.9%
- About half: 10.5%
- Some (1 to 25%): 89.5%
- Optimal: 76.6%
REPORTED STRATEGY USE

• Over all respondents and specific to grouped respondents
  – Size of clinic population
  – Reporting from a site inside or outside of the US
  – Reporting from a site inside or outside of Africa

LARGE (~240) vs SMALLER (~92) CLINICS
US (~185) vs OUTSIDE OF US (~179) CLINICS
AFRICA (~74) vs OUTSIDE OF AFRICA (~291)
RESULTS - RET MONITORING (N 365)

Documentation of frequency of visits
- None/Not Used or Not Avail: 6.3%
- Some/As Needed: 9.6%
- All/Most patients: 84.1%

Documentation of linkage to care/treatment initiation
- None/Not Used or Not Avail: 12.3%
- Some/As Needed: 13.2%
- All/Most patients: 74.5%

Standardized linkage to care protocol
- None/Not Used or Not Avail: 18.4%
- Some/As Needed: 11.5%
- All/Most patients: 70.1%

Standardized retention in care monitoring
- None/Not Used or Not Avail: 21.6%
- Some/As Needed: 14.0%
- All/Most patients: 64.4%

Integrated data sources to enhance patient linkage to care and retention in care monitoring (medical records,...
- None/Not Used or Not Avail: 23.6%
- Some/As Needed: 15.3%
- All/Most patients: 61.1%
**RESULTS - RET SUPPORT (N 365)**

- **Case management for newly diagnosed patients**: 78.6%
  - None/Not Used or Not Avail: 0.0%
  - Some/As Needed: 10.0%
  - All/Most patients: 80.0%
- **Identification of patients out of care for 6 months or more to providers or care team**: 58.4%
  - None/Not Used or Not Avail: 0.0%
  - Some/As Needed: 18.0%
  - All/Most patients: 82.0%
- **Phone or text contact for patient not returning to care for a defined period**: 51.8%
  - None/Not Used or Not Avail: 0.0%
  - Some/As Needed: 22.0%
  - All/Most patients: 78.0%
- **Phone or text contact for missed visits**: 51.0%
  - None/Not Used or Not Avail: 0.0%
  - Some/As Needed: 22.0%
  - All/Most patients: 78.0%
- **Phone or text reminder of upcoming appointment**: 49.9%
  - None/Not Used or Not Avail: 0.0%
  - Some/As Needed: 22.0%
  - All/Most patients: 78.0%
- **Link to peer navigators, advocates or community workers on entry into care**: 34.2%
  - None/Not Used or Not Avail: 0.0%
  - Some/As Needed: 22.0%
  - All/Most patients: 78.0%
- **Link to peer navigators, advocates or community workers when out of care for a defined period of time**: 28.8%
  - None/Not Used or Not Avail: 0.0%
  - Some/As Needed: 22.0%
  - All/Most patients: 78.0%
- **Going to home or residence when patient has not returned to care as expected**: 21.4%
  - None/Not Used or Not Avail: 0.0%
  - Some/As Needed: 22.0%
  - All/Most patients: 78.0%

**Comparison:**
- US vs Not:
  - Case management: 74% vs 84%
  - Identification: 73% vs 26%
  - Phone or text for missed visits: 73% vs 26%
  - Phone or text reminder: 73% vs 26%
  - Link to peer navigation on entry: 73% vs 26%
  - Link to peer navigation when out of care: 73% vs 26%
  - Going home/residence: 12% vs 31%
RESULTS - RET SUPPORT (N 365)

- Case management for newly diagnosed patients: 78.6%
- Identification of patients out of care for 6 months or more to providers or care team: 58.4%
- Phone or text contact for patient not returning to care for a defined period: 51.8%
- Phone or text contact for missed visits: 51.0%
- Phone or text reminder of upcoming appointment: 49.9%
- Link to peer navigators, advocates or community workers on entry into care: 34.2%
- Link to peer navigators, advocates or community workers when out of care for a defined period of time: 28.8%
- Going to home or residence when patient has not returned to care as expected: 21.4%

% Africa vs Not:
- 19% vs 56%
- 39% vs 54%
- 47% vs 31%
- 39% vs 17%
RESULTS - ADH MONITORING (N 367)

- Ask about adherence during check-up/check-in
  - 93.5%

- Use a self-reported measure of adherence
  - Africa 74% vs Not 59%
  - Africa 58% vs Not 52%
  - Africa 49% vs Not 13%

- Review pharmacy refill data
  - 61.9%

- Perform pill counts of returned medication
  - 45.5%

- Use drug concentration analyses
  - 44.7%

- Use electronic monitoring device for opening of pill case or pill bottle
  - 91.6%

- Use electronic monitoring device for opening of pill case or pill bottle
  - US 0% vs Not 4%

- Review pharmacy refill data
  - 78.2%

- Perform pill counts of returned medication
  - 35.4%

- Use drug concentration analyses
  - 16.1%

- Use a self-reported measure of adherence
  - 20.7%

- Ask about adherence during check-up/check-in
  - 1.6%
Current regimen contained a fixed-dose combination (FDC) ARV drug

First-line regimen is once daily dosed for treatment-naive patients

Treatment-experienced patients are reviewed for potential switch to simplified regimens

- None/Not Used or Not Avail
- Some/As Needed
- All/Most patients

US 79% vs Not 50%
US 69% vs Not 43%
Africa 64% vs Not 76%
Africa 44% vs Not 70%
Africa 45% vs Not 60%
RESULTS - ADH TOOLS (N 366)

Provide pill case or other organization tools (diary)

Provide a device for reminders/dose-time alerts or assist in programming cell phones for alerts

Send text messages that are motivational to promote adherence

Send text messages for reminder or dose-times

- None/Not Used or Not Avail
- Some/As Needed
- All/Most patients

US 44% vs Not 23%
Africa 19% vs Not 37%
Small 10% vs Larger 4%
80.3%
RESULTS - GEN ADH STRATS (N 356-357)

One-on-one education about ART and HIV

- Patients are reminded of expectation to be perfect or near-perfect adherers
- Multidisciplinary resources are coordinated for/with patients...
- Non-adherence or occasional difficulties with adherence is explicitly...

Group education about ART and HIV

- One-on-one counselling focused on adherence and living with HIV
- Group counselling focused on adherence and living with HIV
- Peer support programs for adherence

- None/Not Used or Not Avail
- Some/As Needed
- All/Most patients

- Africa 94% vs Not 83%
- Small 25% vs Larger 43%
- US 24% vs Not 52%
- Africa 86% vs Not 26%
- US 20% vs Not 51%
- Africa 67% vs Not 23%
- US 22% vs Not 41%
- Africa 80% vs Not 24%

- 85.4%
- 84.9%
- 70.0%
- 63.6%
- 42.9%
- 37.5%
- 35.3%
- 31.4%
### RESULTS - GEN ADH STRATS IN RLS (N 291-293)

<table>
<thead>
<tr>
<th>Intervention</th>
<th>None/Not Used or Not Avail</th>
<th>Some/As Needed</th>
<th>All/Most patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-physician clinicians managing patients on ART</td>
<td>31.2%</td>
<td>30.7%</td>
<td>Africa 49% vs Not 26%</td>
</tr>
<tr>
<td>Structured teaching modules as a form of pre-treatment education</td>
<td>26.6%</td>
<td>12.4%</td>
<td>US 22% vs Not 34%</td>
</tr>
<tr>
<td>Peer-driven, pre-treatment educational counseling</td>
<td>23.9%</td>
<td>11.0%</td>
<td>Africa 38% vs Not 20%</td>
</tr>
<tr>
<td>One-on-one peer support</td>
<td>8.9%</td>
<td>8.2%</td>
<td>US 4% vs Not 21%</td>
</tr>
<tr>
<td>Use of a trained, patient-nominated treatment supporter to provide partial DAART</td>
<td></td>
<td>6.2%</td>
<td>Africa 32% vs Not 7%</td>
</tr>
<tr>
<td>Clinic- or home-based DAART</td>
<td></td>
<td>5.1%</td>
<td>US 4% vs Not 18%</td>
</tr>
<tr>
<td>Monthly food supplementation packages</td>
<td></td>
<td></td>
<td>Africa 21% vs Not 8%</td>
</tr>
<tr>
<td>Technological interventions (interactive text messages) integrated with clinic contact</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Electronic drug monitoring (EDM) linked to clinic contact</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weekly text message reminders without clinic contact</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
RESULTS - STRUCTURAL STRATEGIES (N 361)

- Onsite treatment for various comorbidities: 11.4% None/Not Used or Not Avail, 25.2% Some/As Needed, 63.4% All/Most patients
- Patients are screened systematically for depression: 16.1% None/Not Used or Not Avail, 33.0% Some/As Needed, 51.0% All/Most patients
- Patients are screened systematically for adjustment or for mental health issues: 17.2% None/Not Used or Not Avail, 33.0% Some/As Needed, 49.9% All/Most patients
- Case management to coordinate care services secure food or basic resources: 32.7% None/Not Used or Not Avail, 36.0% Some/As Needed, 31.3% All/Most patients
- Transportation to clinical care: 15.0% None/Not Used or Not Avail, 50.0% Some/As Needed, 35.0% All/Most patients
- Vouchers to cover costs associated with coming to care: 14.4% None/Not Used or Not Avail, 33.2% Some/As Needed, 52.4% All/Most patients
- Food packets: 7.5% None/Not Used or Not Avail, 33.8% Some/As Needed, 58.7% All/Most patients

- Small vs Larger: 53% vs 68%
- US vs Not: 73% vs 26%
- Africa vs Not: 7% vs 24%
- US vs Not: 50% vs 12%
- Africa vs Not: 6% vs 38%
- Africa vs Not: 25% vs 56%
- Africa vs Not: 4% vs 58%
- Africa vs Not: 25% vs 56%
- Africa vs Not: 4% vs 58%
How many patients in your clinic/center make use of available support services for adherence?  

- Most (over 50%) 37%  
- About half (~50%) 34%  
- Some (1 to 25%) 22%  
- Not applicable (services not offered) 6%

How many patients in your clinic/center make use of available support services for retention?  

- Most (over 50%) 33%  
- About half (~50%) 38%  
- Some (1 to 25%) 18%  
- Not applicable (services not offered) 10%

- Sig higher estimated use of available adherence support strategies from respondents in Africa (52% vs 37% estimating use by over half of population)
RESULTS- ADEQUACY OF SERVICES?

How adequate are your current services to link people into care?
- Adequate: 30%
- Generally adequate but needs improvement: 56%
- Inadequate: 13%
- Not applicable (services not offered): 1%

How adequate are your current adherence support services?
- Adequate: 55%
- Generally adequate but needs improvement: 19%
- Inadequate: 1%
- Not applicable (services not offered): 1%

How adequate are your current services for retaining people in care?
- Adequate: 57%
- Generally adequate but needs improvement: 24%
- Inadequate: 16%
- Not applicable (services not offered): 3%

US vs Not: Sig higher reported adequacy of
- linkage strategies in use (41% vs 19%)
- adherence strategies in use (33% vs 15%)
- retention strategies in use (30% vs 18%)

Africa vs Not: Sig lower reported adequacy of
- linkage strategies in use (12% vs 34%)
- adherence strategies in use (9% vs 29%)
- retention strategies in use (12% vs 28%)
RESULTS - MOST NEEDED/IMPORTANT?

<table>
<thead>
<tr>
<th>Service</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding</td>
<td>24.2%</td>
</tr>
<tr>
<td>Peer information exchange/referral network</td>
<td>18.7%</td>
</tr>
<tr>
<td>Performance measures</td>
<td>15.4%</td>
</tr>
<tr>
<td>Additional staff</td>
<td>13.3%</td>
</tr>
<tr>
<td>Practice guidelines</td>
<td>10.6%</td>
</tr>
<tr>
<td>Best practices clearinghouse/portal</td>
<td>7.6%</td>
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<tr>
<td>Workshops/training opportunities</td>
<td>5.1%</td>
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<td>Management support (e.g., decision support tools)</td>
<td>5.1%</td>
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<td>(technical assistance)</td>
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</table>
SUMMARY

Majority of individuals completing the survey felt that the strategies used for monitoring and supporting linkage, adherence and retention could use improvement.

• Aside from funds to resource clinics, technology transfer, information and skills sharing and implementation support is needed.
# RECOMMENDATIONS I/II AND A/B

<table>
<thead>
<tr>
<th>Quality/Strength</th>
<th>Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>II A ✅</td>
<td>Systematic monitoring of successful entry into HIV care is recommended for all individuals diagnosed with HIV (74%)</td>
</tr>
<tr>
<td>II A ✅</td>
<td>Systematic monitoring of retention in HIV care is recommended for all pts (64%)</td>
</tr>
<tr>
<td>II B ✅</td>
<td>Brief, strengths-based case management for individuals with a new HIV diagnosis is recommended (79%)</td>
</tr>
<tr>
<td>II A ✅</td>
<td>Self-reported adherence should be obtained routinely in all patients (62%, 94%)</td>
</tr>
<tr>
<td>II B ✅</td>
<td>Pharmacy refill data are recommended for adherence monitoring when medication refills are not automatically sent to patients (46%)</td>
</tr>
<tr>
<td>II B ✅</td>
<td>Among regimens of similar efficacy and tolerability, once-daily (QD) regimens are recommended for treatment-naive patients beginning ART (65%)</td>
</tr>
<tr>
<td>I B ✅</td>
<td>Reminder devices and use of communication technologies with an interactive component are recommended (14%)</td>
</tr>
<tr>
<td>I A</td>
<td>Education and counselling using specific adherence-related tools is recommended</td>
</tr>
<tr>
<td>II A ✅</td>
<td>Individual one-on-one ART education is recommended (85%, 70%)</td>
</tr>
<tr>
<td>II A ✅</td>
<td>Providing one-on-one adherence support to patients through 1 or more adherence counselling approaches is recommended</td>
</tr>
</tbody>
</table>
## RECOMMENDATIONS I/II AND A/B

<table>
<thead>
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</tr>
</thead>
<tbody>
<tr>
<td>II B</td>
<td>Using nurse- or community counsellor-based care has adherence and biological outcomes similar to those of doctor- or clinic counsellor-based care and is recommended in under-resourced settings (31%)</td>
</tr>
<tr>
<td>I A</td>
<td>Directly administered ART is not recommended for routine clinical care settings (11-12%)</td>
</tr>
</tbody>
</table>

**SPECIAL POPULATIONS (only 1 reviewed here)**

| II A | Screening, management, and treatment for depression and other mental illnesses in combination with adherence counselling are recommended (51%) |
Limitations

Self-report and self-section for survey completion

The extent to which self-report of strategy use matches up with actual use or knowledge of availability from patient perspectives is not quantified here.

Greater emphasis on characterizing use of recommended [evidence based] strategies than characterizing other strategies used commonly in care.
FUTURE DIRECTIONS

Planning research, funding, and implementation agendas are needed to promote use of recommended strategies.

**HOW use or non-use** of specific strategies may associate with clinical outcomes is an important method for identifying practice-based-strategies and practice-based evidence.

Current practice and gaps between practice and evidence based recommendations should guide agendas for supporting dissemination and implementation of recommended approaches.
Thank you!

Thank you to all the providers who took the time to complete the survey and the IAPAC team that helped program and run the survey!
With deep appreciation for the efforts and contributions of

Steve Ketchum