Background

Studies examining engagement in HIV care often capture cross-sectional binary snapshots of individual patient status to estimate retention and identify predictors of attrition. This approach partially describes longitudinal engagement and retention in care in that it provides only a summary view, ignoring patterns of longitudinal patient care-seeking behaviors, including the cyclical nature of engagement, disengagement, and re-entry into care.

Objective: We propose a state space representation to characterize the longitudinal process of engagement and retention in HIV care using data from the CFAR Network of Integrated Clinical Systems (CNICS), one of the most comprehensive multisite HIV clinical databases in the US.

Methods

- Each phase in the HIV care cascade is viewed as a state.
- Multi-state models: parameterized by probability of transitioning from one state to another
  - $S_t$ = state at time $t$
  - $p_{S_t}$ = probability of transitioning from one state to another
- $P_{intra}:$ probability of transition from engaged to engaged (retention)
- $P_{intra}:$ probability of re-entry into care after disengagement
- Effect of covariates on $p_{intra}$ can be assessed by multinomial logistic regression:
  \[
  \log\left(\frac{p_{intra}(S_t | S_{t-1})}{p_{intra}(S_{t-1} | S_t)}\right) = \beta X_t \quad (1)
  \]
- We set engaged in care (state=1) as the reference state as transition to engagement in care is a desirable transition.

Data Preparation

- Set time grids at every 200 days: State membership was ascertained at equally spaced 6-month intervals to reflect the CNICS viral load monitoring guidelines, which recommend viral load monitoring twice a year at minimum, as viral load is often used as a proxy for care visit. We allowed extra two weeks to allow for scheduling variation.

Results

Participants: 31,099 patients in HIV care from eight contributing sites (CWRU, Fenway, JHU, UAB, UCSD, UCSF, UNC, UW) who are engaged in CNICS affiliated care in modern HAART era (from January, 1996 through July, 2015).

CNICS cohort were 81% male, 11% Caucasian, and 39% African American. Risk factors for HIV acquisition were mostly MSM (51%) or heterosexual (49%) behaviors (30%). Median age at the first primary visit to a CNICS care was 39 years (IQR = 32 – 46). Median CD4 counts and log$_{10}$ viral load were 348 (IQR: 155 – 556), and 4.46 (IQR: 3.66 - 5.06), respectively.

Effect of clinical characteristics: Lower CD4 counts (<250), higher viral load, and not initiating ART are consistently associated with disengagement, lost, and death. AIDS defining illness is a strong predictive factor for most unfavorable transitions.

Race/Ethnicity disparity: Reverse racial disparity than existing results in long-term retention behaviors were found - Among engaged, Caucasians are at the highest risk of transitioning to death. Among disengaged, Caucasians are at the highest risk of continued disengagement, being lost, and death. No difference in long-term retention between Hispanic and non-Hispanic was found.

Effect of behavioral and HIV risk factors: Age and gender-HIV risk factors were significantly associated

<table>
<thead>
<tr>
<th>Prior state</th>
<th>Current state</th>
<th>Engaged</th>
<th>Disengaged</th>
<th>Death</th>
<th>Lost</th>
<th>Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>CD4 counts</td>
<td>Overall STR</td>
<td>0.86</td>
<td>0.01</td>
<td>0.24</td>
<td>0.01</td>
<td>0.16</td>
</tr>
<tr>
<td>250-500</td>
<td>Engaged</td>
<td>0.86</td>
<td>0.01</td>
<td>0.24</td>
<td>0.01</td>
<td>0.16</td>
</tr>
<tr>
<td>&gt;500</td>
<td>Disengaged</td>
<td>0.86</td>
<td>0.01</td>
<td>0.24</td>
<td>0.01</td>
<td>0.16</td>
</tr>
<tr>
<td>Reverse</td>
<td>Death</td>
<td>0.86</td>
<td>0.01</td>
<td>0.24</td>
<td>0.01</td>
<td>0.16</td>
</tr>
</tbody>
</table>

Table 1. Effect of known determinants of retention in clinical care

Conclusions

The proposed approach is the first attempt to capture all possible transition dynamics in longitudinal engagement and retention in care and to find determinants of the transitions. Beyond binary retention status, more comprehensive longitudinal patient behaviors should be examined. Our findings can be used for policy, clinical, and programmatic purposes to enhance retention in care.

Acknowledgements: The authors were partially supported by the Division of Intramural Research Program of the National Institutes of Health (NHG grant 5RO1-MH092682 and by a grant to the USAID AFATH Program [U54-USAID contact number 623-A-00-069-00033-08]. Further support was provided by NHL grant R21 AI110841 and K12 MH090486. The content is solely the responsibility of the authors.