SYNOPSIS

Objectives - In response to a lack of standardization in oral health care for PLWHA, the New York State Department of Health, AIDS Institute, Office of the Medical Director hosted a forum to bring oral health experts from across the nation together with three goals in mind: (1) initiate a standardized approach to oral health care for people living with HIV/AIDS; (2) identify priority areas in policy, guidelines, and education that will lead to standardization and promote quality care; and (3) support oral health as part of overall health care for those with HIV/AIDS.

Methods – The invitation-only forum was held on January 25 – 26, 2010 in New York City. Participant comments regarding specific priorities and tasks needed to advance the quality of oral health for PLWHA were recorded. Following the forum the participants were surveyed to rank the importance of these priorities and tasks.

Results – The final product of the forum was a set of 10 priorities and 9 tasks. The priorities and tasks were further subdivided; priorities were separated into national or New York State priorities, and tasks were grouped by policy, education, or guidelines.

Conclusions – The forum-derived priorities and tasks can serve as a useful framework to guide future New York State policy, guideline, and education development.

BACKGROUND

Why oral health is important to PLWHA
Most oral health problems can be found in people who are either HIV positive or negative. Yet there are some important differences. A few conditions are seen almost exclusively in people with HIV/AIDS (PLWHA), while some that are found in both populations are more problematic for people with HIV, especially those with advanced disease. A diminished immune system can alter the course of oral disease and require more aggressive treatment to prevent minor troubles from escalating into major health problems (1).

Certain kinds of oral conditions that are more likely to affect people living with HIV/AIDS include (1, 2):

Dental caries - Some medications used by people with HIV may cause dry mouth, which can lead to rampant caries
Periodontal disease - A particularly severe form appears to be unique to those with compromised immune systems

Oral Hairy Leukoplakia - Lesions usually have an irregular surface and may have hair-like projections

Mouth Ulcers - Larger, more painful sores that take longer to heal than those found in people who do not have HIV/AIDS

**Evidence that there is a lack of a standardized approach to oral care for PLWHA**

A consumer survey conducted in the fall of 2009 by the NYSDOH AIDS Institute revealed that almost half (49.6%) of respondents disagreed or were not sure if dentists are knowledgeable about how to treat oral conditions related to HIV infection. 43.7% of respondents disagreed or were not sure if most people living with HIV have access to a dentist when they need one. These results show that there is a lack of confidence in the ability to obtain high quality oral care among the HIV/AIDS population in New York State.

In addition to these findings, the national and NYS scores for the Federal Ryan White HIV/AIDS program quality indicator show room for improvement. The indicator states that “all HIV+ patients should receive a dental exam during the past 12 months (3)”

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<th>2007 Median Facility Score</th>
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<td>NYS: 35.7%</td>
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<td>United States: 40.8%</td>
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While NYS is not far from the U.S. average, both need improvement.

**Why lack of standardization is a problem**

The lack of standardization in oral health care for PWLHA results in the absence of reliable, evidence-based information for dental providers treating patients with HIV/AIDS. Without established guidelines and standards, patients may not receive the highest quality care possible. In addition, lack of standardization in care contributes to missed opportunities for screening for other health conditions such as diabetes and Hepatitis or for identifying links between oral conditions and other health conditions.

In response to the lack of standardization in oral health care for PLWHA, the New York State Department of Health AIDS Institute Office of the Medical Director hosted a forum to bring oral health experts from across the nation together with three goals in mind: (1) initiate a standardized approach to quality oral health care for people living with HIV/AIDS; (2) identify priority areas in policy, guidelines, and education; and (3) support oral health as part of overall health care for those with HIV/AIDS.
METHODS

Forum planning and recruitment
A planning committee was established for the forum. Members included Bruce Agins, MD, Medical Director for the NYSDOH AIDS Institute, Lyn Stevens, NP, Deputy Director of the Office of the Medical Director, NYSDOH/AI, Howard Lavigne. David Nassry, DMD, Cheryl Stolarski, DMD (all of OMD staff) and Stephen Able, DDS, Co-Director of the New York/New Jersey AETC Oral Health Center.

The forum was designed as an invitation-only event. The planning committee identified thought leaders and decision makers on a state and national level as potential participants. These included the faculty of the New York/New Jersey AETC, Dental Directors of all national AETCs, faculty from NYS dental schools, dentists from national SPNS projects and Community Based Dental Partnerships.

Potential participants were surveyed regarding their willingness to participate in the forum and their thoughts regarding location, agenda items and duration of the meeting. Thirty-two individuals attended the forum, fairly evenly distributed among the following classifications:

- Academic 37%
- Non-academic leadership 30%
- Health care providers 33%

Forum structure
The Forum took place on January 25 & 26, 2010. A total of six presentations were given throughout the two days and covered the following topics:

- The Role of the Dentist in Primary Care - outlined how dentists can assume an expanded role in the health care of HIV-positive persons by using simple tests to diagnose chronic diseases and refer patients to appropriate healthcare providers.

- HIV Medical Management Update – stressed that dentists can play an integral role in multidisciplinary HIV care by educating and encouraging their patients to: see their primary care providers regularly; know their CD4 and viral load counts and what they mean; adhere to antiretroviral regimens; and understand the potential danger of oral and lung infections.

- Outreach, Barriers, Advocacy, and Retention in Care – cited specific strategies utilized by two different HIV/AIDS health programs that were successful in attracting and retaining patients; including gift cards/incentives, providing transportation, and establishing linkages with other community service providers to provide a continuum of health care. Also discussed were findings from patient and provider surveys conducted by NYSDOH AIDS Institute which identified several barriers to oral health care for people living with HIV/AIDS, including a lack of trained dental providers and reimbursement policies that discourage conducting multiple services in one visit.

* Please see appendix B for a detailed list of presentation titles and presenters.
Use of Technology in Teaching and Learning – discussed how healthcare organizations have been using social marketing tools such as blogs (web logs), wikis, podcasts, and social networking sites such as Facebook or Twitter to reach broader patient populations or to educate healthcare providers. These techniques and sites are popular because they are free or low-cost and are user-friendly. Although a certain segment of the HIV-positive population is hard to reach through this method because that are not computer literate, social marketing can still be a useful tool in reaching the rest of the HIV-positive population.

Having A Better Understanding of Addiction – explained that addiction is a brain disease that is chronic and relapsing in nature, which can complicate pain management techniques employed by providers. Dentists can contribute to the overall health and progress of substance users through strategies such as increasing patient follow-up to better assess pain levels and possible need for more medication.

Salivary Diagnostics: Role of the Dental Professional – discussed how oral/salivary diagnostic tests provide a safe, non-invasive means to diagnose HIV and other diseases. Research shows that patients are more willing to provide oral fluid samples than blood samples for diagnostic testing. This puts dentists in a unique position to perform a “triage” role in screening and referring patients for treatment.

Following each presentation was a discussion period in which all of the 32 attendees were encouraged to participate. A different moderator was assigned to each discussion period to facilitate the discussion and ensure that any participant who wished to speak was heard by the entire group. The discussion sessions were structured in this way versus individual breakout groups so that all could benefit from the comments offered by the entire group of experts, focusing on one issue at a time.

Data collection
During each discussion session, AIDS Institute Staff recorded ideas and suggestions that were generated by the participants. This was done on large, poster-sized paper so that it was visible to all participants.

Data analysis
The first analytic task involved reviewing the list of 35 topics that was generated through the discussion groups, removing any duplicative statements, and categorizing them as policy, education, or guidelines. At the end of this process, we had 11 policy tasks, 11 education tasks, and 7 guideline tasks; 1 task fell into both policy and education, 2 tasks fell into both policy and guidelines, 2 tasks fell into both guidelines and education, and 1 task was considered to be policy, guidelines, and education.

The next step in the process was to cluster the topics according to their level of specificity. If they were broad and far-reaching in nature, they were categorized as a priority. If they were specific with a reasonable expectation to be addressed with 18-24 months, they were categorized as a task. The priorities and tasks were further
subdivided; priorities were separated into national or New York State priorities, and tasks were grouped by policy, education, or guidelines.

A survey was created and disseminated electronically through Survey Monkey. Questions for the survey were developed with a goal of identifying which priorities and tasks were viewed by the participants as being the most critical to the advancement of oral health for people living with HIV/AIDS. To accomplish this, questions were structured by listing the topics and asking the participant to rate each topic on a scale of 1-5, with 1 being the most important. The survey consisted of five questions in total, two questions that focused on state and national priorities, and three questions focusing on the specific tasks that were grouped by policy, education, or guidelines.

Participants were given one week to complete the survey. After closing the survey, the results were compiled and overall group ratings were determined by calculating the average numeric value that the participants had assigned for each of the options. For the two questions regarding state and national priorities, the options with the five lowest average numeric values were identified as the five topics most valued by the participants (a value of 1 out of 5 represented the most important.) Similarly, the three topics regarding tasks with the lowest average numeric value were identified as the tasks that the group viewed as most important.

RESULTS

The participants identified the following priorities and tasks as being the most critical in advancing oral health care for people living with HIV/AIDS:

- **Priorities: national and state**
  
  *Top 5 National Priorities*
  1. Emphasize oral health care as health care
  2. Develop standards of care
  3. Update American Dental Association guidelines
  4. Promote dentists’ preventive role
  5. Develop "calibration" system for dental faculty

  *Top 5 Statewide Priorities*
  1. Increase communication between MDs and DDSs/DMDs
  2. Work with Medicaid to address reimbursement
  3. Provide oral health guidelines
  4. Promote dentists’ role in preventive care
  5. Foster infrastructure for interdisciplinary referrals

- **New York State Tasks: policy, guideline, and education**
  
  *Top 3 Policy Tasks*
  1. Emphasize oral health care as health care
  2. Include language in grants promoting dental referrals
  3. Work with Medicaid and others to address compensation
**Top 3 Guideline Tasks**
1. Develop best practices in oral health & HIV
2. Update NYS oral health guidelines
3. Develop guidelines on the role of dentists in prevention

**Top 3 Education Tasks**
1. Provide conference for DDSs/DMDs and MDs to discuss oral health
2. Train physicians to conduct thorough oral health exam
3. HIV training for dental faculty

**DISCUSSION**

**Next Steps**
The survey results were analyzed to determine which specific actions could be taken to address the identified tasks and priorities. Based on those findings, the following steps were identified:

1. Present findings via a poster that has been accepted at the national Ryan White grantee meeting and clinical conference in Washington, DC, August 2010.

2. Collaborate with existing AIDS Institute oral health initiatives. The AIDS Institute has a number of initiatives in place to promote quality oral health care for PLWHA. Dr. David Nassry, in his role as the Oral Health Policy Liaison, has conducted provider and patient surveys, mapped available dental services throughout New York State by HIV prevalence and compiled a directory of those services. This groundwork positions the AI to develop more focused policy that promotes oral health care as an integral part of overall health care.

Through its participation in the AETC, the AI is also positioned to influence educational efforts that will bring together the dental and medical providers through cross training and strengthen HIV education and training opportunities. Integrative curricula, multi-disciplinary meetings and updated provider information will be promoted.

AI-wide decision making and policy development will be influenced by informing the Executive Committee of developments regarding oral health and HIV, and promoting participation in cross-organizational Request for Applications (RFA) development and application review to ensure that oral care is being viewed as an integral part of overall care.

3. Review/update guidelines. Based on a preliminary meeting of the Dental Subcommittee of the HIV Guidelines Committee and the input gathered at this forum, a plan to update the oral health guidelines is recommended. Suggestions for
updates include such topics as smoking cessation, HIV testing in the dental chair and the role of the dentist in HIV prevention.

4. Describe efforts to integrate oral health care and primary health care in a manuscript to Public Health Reports for 2012 publication.

5. Convene sub-committees comprised of forum participants to concentrate on the top five national priorities that were identified at the forum.

**Anticipated Outcomes**

As a result of completing the specific steps outlined above, we anticipate that we will help increase recognition and the priority level of HIV oral health care. In addition, communication between NYS dentists and physicians will be improved through activities such as multi-disciplinary meetings; and patient awareness of the importance of oral health will increase as it is emphasized as an integral part of overall health.

With the experience that will be gained from working to address the identified tasks and priorities, we also anticipate that we will be able to influence a broader audience outside of New York State, including national and professional associations that are concerned with oral health as well as HIV.
Resources


Appendices

A. List of Attendees

B. List of presentations and presenters

C. Participant Survey
APPENDIX A: List of Attendees

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<thead>
<tr>
<th>Name</th>
<th>Organization</th>
<th>Email Address</th>
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APPENDIX C: Participant Survey

National Oral Health Forum: Survey of Top Priorities and Tasks

1. Top Priorities

1. The following topics were cited as areas of national importance at the Oral Health Forum. Please select five topics that you feel are the most important at the federal level, and rate them on a scale of 1-5 with 1 being the most important.

- Develop "calibration" system for dental faculty
- Update American Dental Association guidelines
- Develop standards of care
- Develop fee schedule reflective of all care provided
- Clarify use and regulation of new oral diagnostics
- Emphasize oral health care as health care
- Secure funding for innovative models of continuum of care
- Promote dentists' preventive role
- Provide professional incentive (credentialing/reimbursement)

2. The following topics were cited as areas of statewide importance at the Oral Health Forum. Please select five topics that you feel are the most important at the state level, and rate them on a scale of 1-5 with 1 being the most important.

- Merge interdisciplinary education
- Update guidelines
- Share best practices
- Work with Medicaid to address reimbursement
- Promote dentists' role in preventive care
- Direct oral health providers to drug interaction resources
- Promote training in pain management (include substance use)
- Foster infrastructure for interdisciplinary referrals
- Educate patients about importance of oral care with HIV/AIDS
- Increase communication between MDs and DDSs
2. Specific Tasks

Listed below are specific tasks and accomplishments discussed at the Oral Health Forum. For each category listed below, please select two items that you would like to see addressed within the next 18 - 24 months.

### 1. Policy Tasks (Pick 2)

- Emphasize oral health care as health care
- Support development of interdisciplinary referrals
- Include language in RFAs promoting dental referrals
- Promote website to identify drug-drug interactions
- Convene meetings of pain experts to develop dental policies
- Work with Medicaid and others to address compensation
- Urge Medicaid to reimburse dentists for oral screenings

### 2. Guideline Tasks (Pick 2)

- Update current guidelines
- Add chapter regarding rapid testing
- Add chapter regarding pain management
- Develop best practices in oral health & HIV
- Share guidelines with dental faculty & AETC websites
- Provide education credit for DDSs and hygienists
- Establish relationship with ADA to work on standards
- Develop guidelines on the role of dentists in prevention

### 3. Education Tasks (Pick 2)

- Provide conference for DDSs and MDs to discuss oral health
- Train physicians to conduct thorough oral health exam
- Pain management/substance use training for DDSs and faculty
- HIV training for dental faculty
- Rapid testing/oral diagnostic training for dental faculty
- Patient brochure: importance of oral health with HIV/AIDS

### 4. Please include any comments or additional information that you would like to share. Thank you for your participation!

[Box for comments]