



**If you build it,
will they come?
And if they come,
will they stay?**



Lessons learned in engaging and retaining people living with HIV/AIDS in oral health care

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Lessons learned in engaging and retaining people living with HIV/AIDS (PLWHA) in oral health care

Introduction

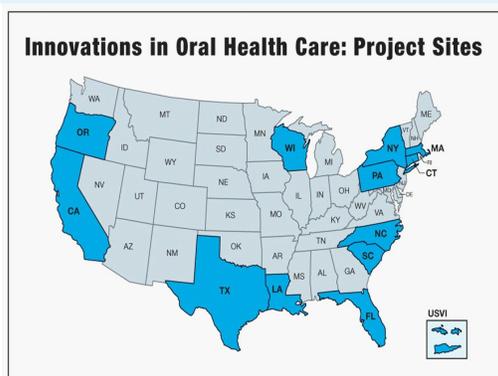
Assessments of the needs of people living with HIV/AIDS at the state or city level find that dental care still tops the list as the greatest unmet need.

The Surgeon General's 2000 Report: Oral Health in America makes a compelling case for the integration of oral health into overall health.¹ This landmark report notes the many disparities in access to oral health care across the country, including socioeconomic factors, lack of transportation, presence of disability or chronic illness, lack of dental insurance and personal factors such as lack of awareness about the importance of oral health. These access barriers are particularly important for people with chronic illnesses or compromised immune systems, including people living with HIV because of the inter-connection between physical health and oral health.

Proper dental hygiene and preventive care are essential to prevent or arrest the development of dental caries, periodontal disease and other oral health complications that can impact nutrition, affect glycemic control and are associated with systemic diseases such as pulmonary and cardiac disease. Digestion, nutritional uptake and comorbid conditions in turn impact the trajectory of HIV disease. Furthermore, the presence of oral disease or symptoms can signal HIV treatment failure or a decline in immune system function that require

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¹Oral Health in America: A Report of the Surgeon General, 2000. <http://www.surgeongeneral.gov/library/oralhealth>.



15 SPNS Demonstration Sites

- AIDS Care Group, Chester PA
- AIDS Resource Center of Wisconsin (ARCW), Green Bay WI
- Community Health Center, Inc. (CHC), Middletown CT
- Harbor Health Services, Inc. Dorchester, MA
- HIV Alliance of Lane County, Eugene OR
- Louisiana State University Health Sciences Center, Baton Rouge LA
- Lutheran Medical Center, Brooklyn NY
- University of Miami School of Medicine, Miami FL
- Montefiori Medical Center, Bronx NY
- Native American Health Center, Oakland CA
- Sandhills Medical Foundation, Inc., Jefferson SC
- Special Health Resources for Texas, Longview TX
- St. Lukes-Roosevelt Hospital Center, CCC, New York NY
- Tenderloin Health, San Francisco CA
- University of North Carolina School of Dentistry (UNC), Chapel Hill NC

prompt medical attention. Yet today, nine years after the Surgeon General's report was issued, many assessments of the needs of people living with HIV/AIDS at the state or city level find that dental care still tops the list as the greatest unmet need.² This lack of access to oral health care perpetuates the disconnect between physical and oral health that is so problematic for people with compromised immune systems.

In September 2006, the Health Resources and Services Administration responded to this gap in the continuum of HIV care and launched a national demonstration project through the HIV/AIDS Bureau's Special Projects of National Significance (SPNS) program entitled Innovations in Oral Health Care Initiative. The purpose of the demonstration project was to increase access to oral health services that are out of reach, both financially and geographically, for many people living with HIV in order to strengthen the continuum of HIV care. Fifteen SPNS demonstration sites were funded in both urban (7) and rural (8) parts of the country, and include a wide variety of program models, including mobile vans, satellite clinics, and clinics developed in collaboration with dental and hygiene schools.

It is well established that financial barriers – either the lack of dental insurance or the inability to pay out of pocket for services – are common barriers to oral health care.^{3,4} A report recently released by the National Association of Dental Plans (NADP), “The Haves and the Have-Nots: Consumers with and without Dental Benefits,” notes that people without dental coverage visit

²Dental Partnerships: Ryan White HIV/AIDS Program Community Based Dental Partnership Program. 2008. <http://hab.hrsa.gov/publications/cbdpp08/>

³Heslin K et al., 2001. A comparison of unmet needs for dental and medical care among persons with HIV infection receiving care in the United States. *J Public Health Dent.* 61(1): 14-21.

⁴Marcus M, 2005. A longitudinal analysis of unmet need for oral treatment in a national sample of medical HIV patients. *Am J Public Health.* 95(1): 73-75.

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the dentist less frequently and are more likely to have extractions and dentures than restorative work.⁵ As the SPNS initiative was implemented and dental services were provided at no cost to people living with HIV, we expected that the removal of financial barriers would increase access to oral health services.

However, we know from practice and the literature that other important factors prevent people from obtaining dental care, including dental fear, lack of transportation and low dental health literacy.⁶⁻⁸ The NADP report cited above noted that among individuals who had dental benefits, “fear of dentists” was the main reason given for not visiting a dentist.⁹ One focus of the SPNS demonstration project was to understand and address these other barriers to care and identify what other interventions might be necessary to bring people into dental care and keep them in care. Below we describe the lessons learned about outreach and retention in oral health services over the first two years of this initiative.



“Fear of dentists” is an important reason given for not visiting a dentist.

Methods

Information for this report was obtained from dentists, program directors and dental case managers over a period of two years from 2007-2009. This period coincided with the start-up of the demonstration projects. An evaluator and dentist or hygienist from the multi-site evaluation center conducted site visits with all sites and collected data on referral

sources, community partnerships, relationships with medical providers, outreach and marketing. In addition, a subset of the sites participated in periodic conference calls and workshops at semiannual grantee meetings to discuss outreach and retention strategies. At one meeting, a list of outreach and retention strategies was generated by the group, and seven of the demonstration sites subsequently provided written testimony documenting these strategies as well as their lessons learned during program implementation. These materials form the basis of this report.

⁵National Association of Dental Plans (2009). “The Haves and the Have-Nots: Consumers with and without Dental Benefits,” Retrieved from <http://www.nadp.org>.

⁶Vargas, 2003

⁷Heaton, 2004

⁸Riley, 2006

⁹National Association of Dental Plans (2009). Op.cit.

Results

ENGAGEMENT IN CARE

All fifteen dental programs offered preventive and restorative dental care, free of charge, to their SPNS patients. Third party payers were billed for any covered services, particularly for those patients receiving Medicaid benefits in states that covered some adult dental services. In addition, many of the programs offered specialty services such as root canal therapy, removable and fixed prosthetics and oral surgery. While the capacity to provide “free care” removed a major barrier to the receipt of dental care, most programs found that additional outreach or marketing was necessary to bring patients into care. One of the demonstration sites summarized this experience as follows:

Nearly all of the demonstration sites conducted some marketing activities at the beginning to spread the word about the availability of dental care.

Outreach and retention were two things we did not anticipate to be problematic when planning for this grant. As we began to open our clinic and serve patients, we realized that this is one of the most important aspects of operating a dental clinic for this population.¹⁰

Across the demonstration sites, several strategies were employed to attempt to address these other barriers to care, including marketing, outreach to other HIV service providers, transportation assistance, mobile vans, special events, and word of mouth.

Marketing

Although widespread advertising was not the primary method of outreach, nearly all of the demonstration sites conducted some marketing activities at the beginning to spread the word about the availability of dental care. This included advertising in both paid media and unpaid media. Advertising posed some special challenges however, because under the terms of the grant funding, dental services were provided free of charge for people living with HIV, but not necessarily free or even available for people who were HIV-negative. Thus it was challenging for some sites to advertise broadly without stigmatizing the target population, or conversely to explain to HIV-negative individuals why the services were not available or only available at cost.

Other program marketing included public service announcements, radio talk shows and ads placed in newspapers. Some sites printed their own brochures and distributed them at health fairs and other community events, while still others developed ads or wrote short announcements for HIV newsletters. Across all of the sites, valuable lessons were learned about the importance

¹⁰Communication with Amanda McClusky, HIV Alliance, Eugene OR

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of understanding the culture of the target audience and crafting targeted messages to these communities. For example:

- Targeted advertising in HIV newsletters that are sent to potential patients was generally more successful than broad advertising in paid media.
- At one site the Spanish-speaking dental case manager participated as a guest speaker on a Spanish language radio call-in show. This show generated many appointment requests.
- The literacy level of printed materials needs to be appropriate for the targeted community. One site developed and distributed beautiful brochures advertising free dental care, but no patients responded. When the brochures were rewritten and the literacy level revised to a sixth-grade level, patients began to come in for care.

Outreach to other HIV service providers



After initial advertising, the primary outreach strategy for demonstration sites was outreach to other HIV service providers.

After initial advertising, the primary outreach strategy for demonstration sites was outreach to other HIV service providers, mainly Ryan White case managers and clinics. As one site put it, Ryan White case managers

... not only provide referrals and word of mouth about our services, they are extremely helpful in helping us reconnect with patients that have missed appointments. If contact information doesn't work, the medical case manager often is able to provide assistance in connecting with the patient.¹¹

This organizational outreach was multi-faceted, and included education about the availability of dental services, the importance of oral health care for PLWHA, how to make referrals, and how to follow up with specific staff at the dental program. Much of this

outreach work was done by dental case managers/coordinators/navigators who connected directly with frontline staff in other AIDS Service Organizations, clinics and social service agencies, particularly HIV case managers. In Miami, the Spanish-speaking study coordinator conducted outreach in Spanish at community health centers to help people access oral health and HIV care. Clinical staff also engaged in organizational outreach, often combining the outreach with in-service trainings for case managers, nurses, doctors and other providers about the importance of oral health to the overall health of PLWHA.

¹¹Communication with Celeste LeMay, Harbor Health, Cape Cod MA

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One project, Project KYSS (Keep Your Smile Sharp) at St. Luke's Roosevelt Hospital in New York City, adopted an aggressive outreach effort to educate program directors, social workers, and case managers at community agencies providing social and/or medical services to HIV-infected New Yorkers. Project KYSS staff hosted an oral health seminar to provide up-to-date clinical information regarding HIV and oral health, and to promote Project KYSS services to frontline staff who would be the most influential in identifying oral health needs among their clients and referring them for dental care. Some agencies went on to appoint a specific worker as their onsite oral health coordinator and liaison to Project KYSS to better manage their clients' care and maintain contact with Project KYSS providers. Agency clients were invited to some of these sessions, and KYSS staff then provided oral screenings to assess the dental needs of each client. The Project Coordinator made appointments for routine oral health care to HIV-positive individuals attending these education programs.¹²

Another demonstration site, AIDS Care Group (ACG) in Lancaster, Pennsylvania, adopted a slightly different but equally ambitious organizational outreach effort throughout a large rural geographic area of Pennsylvania. ACG staff worked with the AIDS Planning Coalition in South-Central Pennsylvania to identify potential referral partners. The referral partners, mostly case management providers, scheduled client support group meetings and ACG sent out a dentist and nurse to publicize the service, screen patients and set up appointments for care. The dentist and nurse discussed transportation strategies with their future patients and exchanged contact information. After these initial encounters, word of mouth became a major vehicle for recruiting new patients into care. At other organizations that were not able to convene support groups, ACG staff brought incentives kits (containing toothbrushes, toothpaste, dental floss, etc.) to the case managers.¹³

A few words of caution or advice in outreaching to Ryan White case managers and other providers:

- a) It is important to take the time to educate case managers and other providers about the broad importance of oral health and HIV disease. They may be aware of the general importance of dental care, but not about the critical connections between medical and dental care and the impact of one on the other for people living with HIV disease.
- b) In working with Ryan White case managers, it is helpful to have very clear processes and expectations so that they know exactly how to make referrals and follow up on appointments. Clarity of process and expectations helps ease any burden associated with new referral relationships.¹⁴

¹²Communication with Michael DeMayo, St. Lukes-Roosevelt Hospital, New York NY

¹³Communication with Ann Ferguson, AIDS Care Group, Lancaster PA

¹⁴Communication with Amanda McClusky, HIV Alliance, Eugene OR

- c) It is essential to follow through on any promises made. Communications that are poorly understood can filter through an agency and destroy any collaboration that has been established.

Transportation assistance

Lack of transportation to services is a major barrier to both engagement and retention in care. It is a problem in urban areas if people cannot afford public transportation or it takes a long time to travel across town by bus. This is particularly problematic in rural areas where public transportation is scarce. Some of the rural SPNS sites had patients who travelled 150-200 miles to come to the dental clinic. The provision of transportation assistance – either directly via a van or indirectly by arranging rides, providing bus tokens or reimbursing for gas – was key to improving access to care.



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Several sites planned to use vans to transport patients from rural areas to their dental clinic. ACG put thousands of miles on their van over the first six months of the project and spent an excessive amount on gas at a time when gas prices were approaching \$5/ gallon. At that point, they needed to investigate other strategies because it was clear that their van would not survive the five-year grant period. ACG staff helped people arrange carpools, and then scheduled appointments for people from the same community on the same day so they could drive in together. It was much more feasible to reimburse clients for gas than to maintain a van and driver and still pay for gas.

HIV Alliance in Eugene, Oregon also covered a vast service area and planned to use a van to bring people to their clinic in Eugene. They ran into many of the same problems as ACG. In response, they developed partnerships with other dental hygiene and dental assisting schools throughout southern Oregon in order

to establish satellite clinics. Now they provide clients with gas cards, hotel rooms, and food when they drive in from long distances, and help them establish clinic dates in different locations closer to home. They also try to schedule dental appointments on dates when clients are traveling to see their HIV specialist in the same town as one of the dental clinics.

Two other rural programs had more success in using a van to transport patients. At Special Health Resources of Texas, staff already transported patients from surrounding communities to one of their three satellite clinics for medical care. Thus, when they added dental care capacity to these clinics,

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they tried to schedule patients for “one-stop-shopping” visits for both medical and dental care, and continued to use the van. In Norwalk, Connecticut, where patients lived closer to the program site than patients in rural Oregon or Texas, the absence of any public transportation remained a major barrier to care. Community Health Center (CHC) staff used a van to pick people up at agencies with whom they were already connected, which eliminated another barrier to keeping appointments. The van also served as a safety net for the dental care coordinator. She could recruit patients from more distant areas, secure in the knowledge that the van was available to transport patients into care.

Using a Mobile Van to Co-Locate Services

Four of the demonstration sites used a mobile van to provide oral health services. Three of the programs, two in urban areas and one in rural South Carolina, co-located their van at HIV primary care clinics or hospitals where patients received their medical care. Thus they were able to create “one-stop shopping” for medical and dental care and obtain referrals directly from primary care clinics. The fourth mobile van, located in New Orleans, travelled to AIDS Service Organizations, Social Service Organizations and clinics with the same goal in mind.



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Special Events

CHC adopted a novel approach to patient recruitment and retention, known as “SPNS Days.” On these widely publicized and designated days, CHC provides transportation to the dental clinic, lunch, and incentives to a small group of patients on a single day. It works not only because they are particularly well organized on those days and have resources ready at their fingertips, but also because the patients enjoy being together. They typically come from only one or two agencies and know one another. Having a happy and satisfied group of people sitting in a room talking about how much they liked and appreciated the care they received has been invaluable for peer-to-peer and word-of-mouth advertising of the program.

Native American Health Center in San Francisco, CA had success bringing new patients in with dedicated “SPNS” clinic hours by opening their clinic on Saturdays.

Word of Mouth

Finally, as programs got off the ground and patients began to have positive experiences, the most effective outreach strategy of all came into play: word of mouth. Several programs reported that their patients began referring their peers to dental services, and one site was considering adding an incentive for peer recruitment. Positive patient experiences also had an important impact on referring providers. After hearing their patients talk about their satisfaction with dental care, health care providers at Montefiore Medical Center began to refer more of their patients to dental care. And at CHC, where staff originally encountered resistance to the program on the part of caseworkers, patients' reports of positive experiences are turning this around. Now both the patients and the caseworkers have voluntarily assumed the role of ambassador, putting a friendly and familiar face on the program.

RETENTION IN CARE

Broken appointments and no-shows are fairly common in dental clinics, running as high as 15% - 25% in clinics without strict policies or retention systems.

Once patients came in for care and received a treatment plan, demonstration sites tried to ensure that patients returned to complete their treatment plans and were placed on preventive maintenance. Broken appointments and no-shows are fairly common in dental clinics, running as high as 15% – 25% in clinics without strict policies or retention systems.^{15, 16} In many dental clinics or practices, last-minute cancellations are required to pay a fee and the slots are often taken by another patient who is waiting for an earlier appointment. However, in the SPNS demonstration project, retention in oral health care was a priority for two reasons: (1) patients were enrolled in a longitudinal study and thus needed to return for study visits as well as for care; and (2) an important outcome of the demonstration project was to ensure that patients complete their treatment plan and go on preventive maintenance, which requires retention in care.

Appointment Reminders and Availability

Appointment reminders are the most common care retention strategy for dental services and were used by most of the SPNS projects. Montefiore program staff noted that their patients were more likely to return for care if follow-up appointments were scheduled to occur more promptly, noting that:

At three sites, appointment slots are 4 to 6 weeks out and at times as far out as 8 weeks. Appointments that far out are typically forgotten by patients and rarely rescheduled when left to the patient to self-manage.¹⁷

¹⁵Almog, D. et al. 2003. The reduction of broken appointment rates through an automated appointment confirmation system. J. Dent. Ed. 9/2003: 1016-1023.

¹⁶Dental Partnerships: Ryan White HIV/AIDS Program Community Based Dental Partnership Program. 2008. <http://hab.hrsa.gov/publications/cbdpp08/>

¹⁷Communication with Niko Verdecias, Montefiore Medical Center, Bronx NY

CHC's open access scheduling turned out not to be ideal for SPNS patients. Open access means that at the conclusion of an appointment, patients were not scheduled for their next appointment. Instead, they received a postcard in the mail instructing them to call for an appointment. Open access was designed to reduce the no-show rate and offer a host of other patient-practice advantages, but it did not work well with CHC's HIV-positive patients. Therefore, CHC changed their scheduling and appointment practices to block time out for SPNS patients and allow them to schedule their next appointment within those block-outs. Patients did not need to wait for postcards, and the front desk informed the dental case manager when a

SPNS patient failed to show up for an appointment. The dental case manager also proactively looked for and followed up on no-shows. When a patient was scheduled for a new or follow-up appointment, the front desk staff placed that appointment in the dental case manager's Outlook Calendar.



The navigators and case managers worked to develop a good rapport with patients, taking the time to build trust and provide information, which in turn made the patient more likely to return for follow-up services.

Dedicated Staffing: Patient Navigators and Dental Case Managers/Coordinators

Several sites employed dental case managers/coordinators or patient navigators to play a core role in patient outreach and retention.¹⁸ For example, rather than using automated calls for appointment reminders, a patient navigator or case manager made appointment reminder calls in person and sent reminder letters. The navigators and case managers worked to develop a good rapport with patients, taking the time to build trust and provide information, which in turn made the patient more likely to return for follow-up services. This was particularly important for some of the more marginalized populations, including active drug users, homeless individuals and people with mental health issues.

In addition, some patient navigators informed providers and Ryan White case managers that their patient had an upcoming dental appointment, thus enlisting medical and social service staff in the effort to provide appointment reminders. In some clinics, receptionists were responsible for tracking no-shows and making reminder calls. When these staff could not reach a client, the dental case managers/patient navigators worked with Ryan White case managers to find

¹⁸Communications with Native American Health Center, HIV Alliance, CHC, Harbor Health, Montefiore Medical Center

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clients. In some programs, the dental case manager provided rides or other transportation assistance to clients, and helped to troubleshoot other barriers to dental care.¹⁹

As the Native American Health Center (NAHC) described, their patient navigator was responsible for the success of their program. When NAHC started enrollment, they had one patient navigator for about 60 HIV-positive clients.

The majority of the clients had dental phobia, substance abuse and mental health issues and needed major dental treatment. It was hard to keep up with so many treatment plans, and each client had specific needs of encouragement to come and see the dentist.

“

Make staff hiring very carefully...It is essential that the DCC [Dental Care Coordinator] be an articulate, knowledgeable communicator who maintains a clear and supportive vision of the full range of services and their benefit for individual patients.

”

NAHC then hired a second patient navigator and was able to double its recruitment in three months. Having enough staff to sustain both recalls and retention was vital for engagement and retention in oral health care.²⁰

Staff qualifications

All of the projects that used patient navigators or dental case managers/coordinators stressed the importance of hiring the right person to do this work. As CHC reported:

Lesson Number One: Make staff hiring very carefully because it is integral to program success and was probably CHC's biggest obstacle to more effective recruitment and retention during the early stages of the program. Our experience has been that the Dental Care Coordinator (DCC) is the first and primary contact person involved with identifying and referring patients. It is essential that the DCC be an articulate, knowledgeable communicator who maintains a clear and supportive vision of the full range of services and their benefit for individual patients.²¹

Montefiore and Harbor Health program staff echoed this sentiment. Montefiore reported that patient navigator personality characteristics were critical to their success. The navigators had to be passionate about the work they were doing, have effective communication skills, and have a problem solving, collaborative attitude. Because the case managers also helped patients address many complex health and human services issues in addition to their

¹⁹Communication with Amanda McClusky, HIV Alliance, Eugene OR

²⁰Communication with Lucy Woods, Native American Health Center, Oakland CA

²¹Communication with Steven Gaarder, Community Health Center, Middletown CT

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dental needs, they also needed good training and support. Supervision is needed to include both a clinical approach and a social service approach to allow for discussion of difficult issues.

Many of the patients who participated in this demonstration project had serious competing needs or comorbidities such as poor health, active alcohol or drug use, homelessness, or mental illness. Persistence was often the key to retention. As HIV Alliance staff put it:

Being persistent has proven to help us keep clients in our clinic. It has been really important for us to have staff available to spend time tracking clients down. We... [use] volunteers and interns in our clinics to assist our dental case manager in contacting clients. This extra help has proven to be very beneficial to our program.



When both the dentist and the dental case manager reviewed treatment plans with the patients, the patients gained a better understanding of why the proposed treatment was needed and what it entailed.

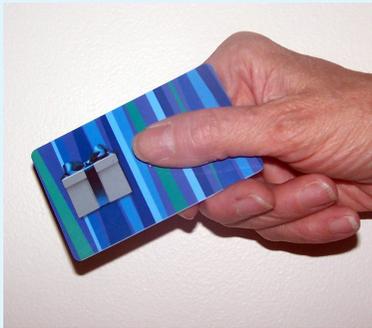
NAHC maintained contact with each client monthly whether or not they had an upcoming appointment. They had one patient who needed multiple extractions and dentures. In the beginning of his treatment, he was hesitant to have his teeth extracted because he felt that he was too young for dentures and was embarrassed. He also had to travel out of state for 6 months, but the case manager continued to contact him through phone calls and mailings. When the patient returned, it took another 3 months of case management calls in combination with support from the dentist and the patient's partner to complete the treatment plan. The patient finally had all extractions and denture work completed 2 years after his initial treatment plan was proposed.

Patient Education and Empowerment

Patient education and the engagement of patients in the discussion of treatment plan options was another important factor in care retention. The University of North Carolina site implemented a program to provide patient education at the time a patient first entered care in part to improve retention rates. Their hygienist provided comprehensive oral health education one-on-one with each patient as part of the first visit, including information on the oral manifestations of HIV disease and the importance of preventive care and maintenance. They felt that this information and knowledge would help motivate patients to return for follow-up care, a theory that will be tested in their local evaluation.

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Other sites noted that clients appreciated staff honesty about treatment plans and the cost of procedures.²² When both the dentist and the dental case manager reviewed treatment plans with the patients, the patients gained a better understanding of why the proposed treatment was needed and what it entailed. Patients had a second opportunity to ask questions, express concerns, and discuss any emotional impact the treatment plan might have. They were also more empowered to discuss treatment options and become involved in their own care. Several of the programs employed dental case managers who were also trained as dental assistants and played a vital role in educating patients about their own self-care.



CHC offered grocery store gift cards, and they reported that these contributed significantly to both patient recruitment and retention, particularly since they were handed out immediately after the visit so that patients did not have to wait to receive them.

Gifts and incentives

Because the SPNS demonstration project was also a study, some sites offered incentives or thank-you gifts for study visits. Study visits were usually scheduled to coincide with dental clinic visits, and thus the incentives were likely to support retention in care as well as retention in the study. For example, CHC offered grocery store gift cards, and they reported that these contributed significantly to both patient recruitment and retention, particularly since they were handed out immediately after the visit so that patients did not have to wait to receive them. NAHC also offered a gift card to a grocery store as a surprise at the end of the intake interview. This was a wonderful tool for retention because each patient who came in for their follow-up interview receives another “Thank You” (gift card). They also welcomed patients with a drink or small snack when they came in for a case management session and provided bus tokens to patients who needed help getting to and from their appointments.

²²Although services were provided at no cost to patients, patients were often interested in knowing what the cost of the service would have been in the absence of the program.

Discussion

Many of the strategies described above are more common in HIV primary care settings, where there has been a growing focus on the importance of engagement and retention in HIV primary care and treatment in recent years. However, the concept of engagement and retention in oral health care, while evolving, is still in its infancy. Historically when a new dental clinic or practice opened its doors, all available appointment slots would be filled quickly and waiting lists would be established. Practices would concentrate on “managing” their no-show rate by filling available slots with patients from the waiting list. Engagement and retention in care was considered in the context of practice management.

This is beginning to change as dental educators and safety net providers in the dental profession are beginning to promote strategies that support retention in care and embrace the concept of a “dental home.”²³

As with dental case management, the dental home concept is perhaps even more important for individuals with compromised immune systems whose oral health needs may be very complex and whose oral health over the long run may have a significant impact on their physical well-being and quality of life.

The American Dental Association recently issued a white paper calling for case management services to help ensure access to care²⁴, and some practices, clinics and public health departments across the country are beginning to employ staff in the role of dental case managers, patient navigators, or intervention specialists. These staff are charged with following up with patients, providing reminders about upcoming visits, and helping patients overcome obstacles to retention such as providing transportation assistance. A few dental schools, such as University at Buffalo, the State University of New York, have hired social workers to help patients navigate barriers to dental care and improve retention rates.²⁵ Although few of these dental case management/navigation programs explicitly target patients with HIV or other chronic illnesses, they are often employed in programs that serve low-income communities where access to oral health care is problematic.

The concept of a dental home, where comprehensive oral health care is coordinated and delivered in a patient-centered manner, is also fairly new. The dental home concept emanates from the medical field, where pediatricians and the American Academy of Pediatrics have long advocated for a medical home for children.²⁶ An early conceptual description of a dental home for children emphasizes the importance of care that is accessible,

²³Glick, M. 2009. A home away from home: the patient-centered home. JADA 140: 140-142.

²⁴ADA, 2004. State and community models for improving access to dental care for the underserved.

²⁵Zittel-Palamara K, et. al. 2005. Improving patient retention and access to oral health care: The CARES program. Journal of Dental Education. 69 (8): 912-918.

²⁶The American Academy of Pediatrics Ad Hoc Task Force on Definition of the Medical Home. 1992. The medical home. Pediatrics 90:774.

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family-centered, continuous, comprehensive, coordinated, compassionate and culturally competent.²⁷ As with dental case management, the dental home concept is perhaps even more important for individuals with compromised immune systems whose oral health needs may be very complex and whose oral health over the long run may have a significant impact on their physical well being and quality of life.

In this SPNS initiative, engagement and retention in oral health care were explicitly stated programmatic goals from the outset. Because the patients who received care in the demonstration projects were also enrolled in a longitudinal study, there was added motivation to retain patients in the study as well as in care. The strategies described above –marketing and outreach, education of health care and other providers, transportation assistance, patient navigation and care coordination, patient education and empowerment – all contributed to patient engagement and retention in the demonstration project. We hope, at the conclusion of the study, to be able to demonstrate that this retention leads to improved oral health and health-related quality of life, and that these strategies, while employed to help reduce disparities in access to oral health services among people living with HIV, are applicable for many other underserved populations who face challenges in accessing oral health care.

²⁷Nowak AJ and Casamissimo PS. 2002. The dental home: A primary oral health concept. J Am Dent Assoc 133: 93-98.