



Increasing Access to Oral Health Care for People Living with HIV/AIDS: The role of dental case managers, patient navigators and outreach workers

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Introduction

In 2006 the HIV/AIDS Bureau of the Health Resources and Services Administration (HRSA) funded the Innovations in Oral Health Care Initiative as a Special Project of National Significance (SPNS). The goal of this five-year initiative is to expand access to oral health care for HIV-positive underserved populations in both urban and rural areas across the country. Nine of the fifteen demonstration sites included in this initiative employ a dental case manager, patient navigator or outreach worker as part of their program model.

Case management has been part of the continuum of HIV care in the US since the early days of the epidemic and was mandated as a service by the Ryan White CARE Act of 1990 to ensure service coordination and continuity (Fleishman, 1998). Although there is some variation in the key functions of case managers across case management programs, the Centers for Disease Control and Prevention (1997) have identified six core tasks that form the basis of most of HIV case management programs. These core tasks include:

1. Client identification, outreach, and engagement;
2. Medical and psychosocial assessment of need;
3. Development of a service plan or care plan;
4. Implementation of the care plan by linking with service delivery systems;
5. Monitoring of service delivery and reassessment of needs; and
6. Advocacy on behalf of the client (including creating, obtaining, or brokering needed client resources).

While it is common to find HIV case managers working in medical settings (medical case management) or social service organizations (psychosocial case management), the concept of dental case management is relatively new. Most of the programs that use dental case managers or related personnel such as patient navigators or outreach workers [hereafter all referred to as dental case managers unless otherwise noted] as part of the SPNS initiative do so, in large part, to increase access to and retention in oral health care. This report describes the emerging concept of dental case management and how it is implemented in community settings to expand access to oral health care. Sections include:

- Methods
- The importance of oral health care for people living with HIV
- Barriers to care for people living with HIV
- The role of dental case managers
- How dental case managers improve access to care
- How dental case managers are different from HIV case managers
- How the dental case manager role can be incorporated into other practices

Methods

In June 2008 the Evaluation Center for HIV Oral Health (ECHO), the multi-site evaluation and technical support center for the SPNS Oral Health Initiative, convened a focus group with demonstration site staff who function as dental case managers to learn more about their roles. Nine individuals participated in the focus group, six of whom had a formal title or role as a dental case manager, patient navigator or outreach worker. The other three individuals, two of whom were research assistants and one of whom was a research hygienist, participated in the focus group because some of their functions overlapped with the case managers or outreach workers.

The six core participants worked at three large urban sites (two in San Francisco and one in New York) and three rural sites (Eugene, OR; East Texas; and Green Bay, WI). We also received written materials from three additional case managers who work in rural locations (Chester, PA; Cape Cod, MA; and Middletown, CT).

Dental case managers are critical in helping patients overcome the fear, stigma and other barriers that inhibit patient access to oral health care.

The importance of oral health care for people living with HIV

While good oral health habits are important for all people, they have particular significance for people living with HIV. Many of the first signs of HIV infection may occur as oral manifestations that can be identified during a routine oral examination by a dentist or hygienist. A review of the patient's medical history and risk assessment in conjunction with an oral lesion may prompt the dental team to refer the patient to an HIV testing site or a medical provider for a comprehensive work-up. This referral is especially important for patients who do not know their HIV status.

On the other hand, if a person is aware of their HIV status and oral manifestations are present, this could indicate a change in the immune system or a failure of the current drug regimen. People may find that treatable conditions such as gingivitis or early periodontitis can become serious quickly if the immune system is weak. In addition, medications prescribed to treat HIV can cause a reduced salivary flow and lead to dry mouth or xerostomia. Without adequate saliva, which contains protective enzymes, cavities or other infections may occur. If not treated, oral health complications can make it difficult to chew or swallow, which in turn can impact nutritional status or the ability to take HIV medications (Cherry-Peppers, 2003). This close and interdependent relationship between physical health and oral health is reflected in the Presidential Advisory Council on HIV/AIDS report on Achieving an HIV-Free Generation: Recommendations for a New American HIV Strategy, which recommends that "Oral health be part of core services available under the Ryan White CARE Act" (DHHS, 2005).

Barriers to care for people living with HIV

Access to oral health care is problematic for many Americans, especially those living with HIV. With nearly half of all expenditures for dental care coming straight out of peoples' pockets (Badner, 2005), and most of the HIV-positive clients served by Ryan White programs living close to or below the poverty level, the presence or absence of dental insurance has a major impact on access to care. For most low-income individuals, the only source of dental insurance is the Medicaid program; yet only 60% of people who receive Medicaid benefits live in states that cover adult dental care (Freed, 2005). Even with Medicaid dental benefits, people often have difficulty finding dentists that will accept Medicaid payment, and Medicaid dental benefits vary from state to state.

In addition to the financial issues, people living with HIV face a host of other barriers to care, including provider shortages (particularly in rural areas), unwillingness to treat, other competing needs, stigma, discrimination, or fear of going to the dentist. Unmet needs for oral health care among people living with HIV are substantially higher than the unmet oral health needs

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in the general population (Marcus, 2000), and higher than unmet needs for medical care (Heslin, 2001). Racial and gender disparities also play a role in access to care, as African Americans, Hispanics, and women are less likely to receive dental care than other people living with HIV (Dobalian, 2003). This underscores the importance of developing interventions that address both the structural and the personal/cultural barriers to oral health care for people living with HIV.

Another significant barrier to care is the overall lack of awareness about the importance of regular dental care and the relationship between oral health and physical health for people living with HIV. This is not just a barrier for individual patients, who may have never received routine dental care, it is also a barrier for health care providers and HIV case managers who do not fully understand the role of oral health in the continuum of HIV care. Thus, HIV case managers may not include dental care on their screening instruments or make routine referrals to dental care, or doctors and nurses may not think to ask patients about their use of dental services.

In the context of the SPNS Oral Health Initiative, where financial barriers to care were addressed through grant funding, dental case managers play an important role in addressing many of the other barriers to oral health care.

The role of dental case managers

Nine of the fifteen oral health demonstration programs employ staff as dental case managers (6), patient navigators (2) or outreach workers (1). In practice, many of the functions of these staff overlap. For example, all staff, regardless of title, play an important role in client recruitment, appointment scheduling and making sure clients have a way to get to the appointment. In addition, all staff provide some level of patient education about the nature of the care they will receive, and are instrumental in following up any missed appointments. Another common function is coordination with (and referral to, if necessary) other services such as HIV case management, medical care, or support services. Finally, all of the dental case managers are part of a team that helps educate other providers in the continuum of HIV care on the importance of oral health care and how to refer their patients to dental services. While the above-mentioned functions are common across programs, both their methods of implementation and other functions may be unique to a particular patient population or differ based on the location of the program. Each dental case manager activity is described below with the results from the focus group used to illuminate the range of activities.

Patient recruitment. A key case management activity is to encourage patients to come in to receive oral health care. Dental case managers are critical in helping patients overcome the fear, stigma and other barriers that inhibit patient access to oral health care. The work involved in patient

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recruitment and appointment scheduling varies greatly across sites. Most of the dental case managers receive new patients through referrals from other health or social service providers; the patient has already decided to seek dental care. Thus, the recruitment work is actually conducted by building and maintaining relationships with referral providers rather than with patients directly. However, in two urban sites that employ patient navigators or outreach workers, these staff are more directly involved with patient recruitment, actually doing the work of talking patients into coming to see the dentist, helping to allay their fears, and offering to accompany new patients on their first visit to the dentist. In both of these circumstances, the patient navigator and outreach worker are connected to large HIV service organizations with a reasonably accessible patient population that is not already receiving dental care.

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Transportation and scheduling. Dental case managers who work in rural communities that provide services over a broad geographic area spend much more time arranging or coordinating transportation for their patients than those who work in urban programs. Some programs offer gas cards as an incentive for patients to come in for care, while others use a van to pick patients up and bring them in to the clinic. Still other programs help arrange car-pools, or try to arrange Medicaid-financed transportation. With patients coming to the dental clinic from far distances, the dental case managers also face scheduling challenges. They may need to schedule a patient for a large number of procedures on a single day, or they may need to coordinate the dental visit with a same-day appointment for medical care and/or HIV case management services. There are some circumstances in which a patient may need to be scheduled for an appointment in the afternoon and a subsequent appointment the following morning. This type of situation requires additional effort by the case manager to locate and/or book lodging accommodations for the patient.

....we have a lot of people....with no driver's license.... in rural areas it is needed because we don't have a massive transportation system here.....One of the other things we are doing....is....setting up satellite clinics around the state because it's not practical for us to drive three hours to pick somebody up for a dental appointment.

I accompany patients to the dentist office if they want me to. That means going in with them and explaining exactly what is going down....and why the dentist is doing that....because at times the patient doesn't like to ask the dentist....[they feel] more comfortable with asking me questions which I love to answer.

Visit accompaniment. Two of the urban programs are more likely to serve immigrant populations that have limited experience with dental care. These programs offer visit accompaniment services to help ensure that patients attend their appointments or follow through on a referral to dental specialty services. A third urban program serves a population that is largely homeless, many of whom have mental health or addiction co-morbidities; this program also offers visit accompaniment services to help get their new patients in the door for care.

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Visit explanations. Both urban and rural program staff spend a significant amount of time, particularly with new patients, explaining what they should expect when they come in for a visit. This explanation serves several purposes. First, it helps to ease people's minds if they are worried about the visit, and it may also reassure them that the providers they will see are comfortable treating people with HIV. Second, when the patient arrives for the appointment, the dental case manager can introduce her/himself as someone the patient has already spoken with on the phone.

When I used to work in the front office I dealt with a lot of patient finances and translating for patients. So when it came to translating for Spanish speaking patients I was already explaining the treatment plans because the dentist wasn't able to do that. So having the patient relationship beforehand...helped me a lot because I built trust with a lot of patients whether they were HIV positive or not.

Referrals and translation. Other functions of the dental case managers at the point of entry into care include enrollment in benefits, particularly dental benefits if these are available, referrals to other services, and, in some cases, translation.

Retention services. Retention in dental care begins at the first visit when the case manager works to build a relationship with the patient and explains what to expect during the visit. This relationship is key to patient retention, as the dental case managers

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check in with patients following their appointments: “How did it go?” “Do you have the supplies you need?” “Do you want me to go over what is happening next?” “How are you feeling now?” All of the case managers provide appointment reminders just prior to the next appointment, and all follow up with any individual who misses an appointment. In the typical dental setting, if a patient fails to show up for an appointment, nothing is done to follow up to find out why. Instead, the patient’s name is likely to go onto a no-show list, and if it appears more than two or three times, the patient may be told to go elsewhere for care. Several of the SPNS oral health programs with high patient caseloads also had no-show policies, but they also used missed appointment follow-up as an opportunity to educate patients about the wait for services and how advance notice of a missed appointment helps the dental office accommodate other patients. In addition, most programs are willing to accommodate patients as walk-ins if they are unable to keep appointments.

Patient education. All of the case managers provide some level of oral health education, but the level of education depends on the clinical background of the staff. Most can explain how HIV affects the mouth, and things to watch for, as well as basic oral hygiene techniques. Two of the case managers/navigators are dental assistants by training, and they are able to provide more comprehensive education about specific dental procedures and follow-up care. All of the non-clinical case managers expressed an interest in receiving more oral health education themselves in order to share information with their patients. In contrast, the case managers who are dental assistants by training expressed an interest in learning more about specific case-management skills.

“Many.....don’t know how to brush their teeth; don’t know that you need to floss. We have a patient [whose] front teeth were perfect but behind the teeth was terrible because they learned that you only brush from one side. So education, education ...it makes a difference cost-wise also.”

Collaboration with HIV case managers. Another way in which dental case managers improve access to care is through their collaboration with HIV case managers and medical- and support-service providers. Dental case managers can help keep oral health on the radar screens of other providers by providing resources and support materials, promoting oral health assessment as part of comprehensive case management, and training HIV case managers to advocate for oral health services for their clients.

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Background and Qualifications. The formal qualifications for dental case manager positions vary across programs. Two of the case managers are trained dental assistants and most have a bachelor's degree. However, several of the positions have no formal education requirements, but require state-specific HIV training and experience with case management or in human services. Most of the case managers have a minimum of five years experience working in HIV care settings or other human services such as drug treatment, homeless services or domestic violence shelters. Two of the positions require a valid driver's license.

How dental case managers improve access to care

Dental case managers are able to address barriers to oral health care in a way that other HIV-care providers cannot. Most HIV case managers have a large patient caseload and a series of service areas to address, many of which may be more pressing than oral health care. Oral health often gets pushed to the bottom of the list, if it is on the list to begin with. Dental case managers enable HIV case managers to focus on other issues within a client's service plan without sacrificing access to oral health care. They arrange transportation, coordinate appointments, provide patient education and assistance with follow-up care, and help make sure that people return for their appointments. These are activities that few HIV case managers can undertake. And in most busy dental clinics, dentists, hygienists and dental assistants do not have the time to do all of this either.

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"The best experience is being able to treat those patients...that are coming from so far away and haven't gone to a dentist in so many years because of...access, insuranceit is really nice to have them come in and treat them and for them to feel good about themselves."

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How dental case managers are different from HIV case managers

Unlike HIV case managers, dental case managers do not conduct comprehensive psychosocial or health assessments, nor do they develop, implement and monitor treatment plans. This is typically the work of the clinical members of the oral health team, the dentist and the hygienist. Thus, the work of an HIV case manager is much more comprehensive than the work of a dental case manager. HIV case managers have to address a broad range of issues, many of which are immediate needs for their patients and are not typically related to dental care. Dental case managers perform fewer tasks per patient and as a result can serve a higher volume of patients than an HIV case manager can. In addition, their education role is different – they focus mainly on dental care rather than on the broader spectrum of HIV care.

In contrast, while an HIV case manager, under the best of circumstances, may make a referral to dental care, they are not able to follow up to make sure the patient gets the care he or she needs. This is something that the dental case manager can do – arrange the transportation, accompany patients to visits, and provide the one-to-one attention a patient needs. For dental case managers, dental care is at the top of the list rather than at the bottom; they make sure it is available and accessed.

"...the regular HIV case managers have so many things to do."

How the dental case manager role can be incorporated into other practices

Nearly all of the dental case managers involved in this demonstration wore multiple hats. For example, all played an important role in program evaluation, recruiting study participants, conducting patient surveys and entering data. Some of the staff also drove mobile vans, or functioned as receptionist/front desk staff. In addition, the outreach workers conducted outreach for other services and the dental assistants assisted with the dental care. Despite wearing these multiple hats, the case managers involved in the SPNS initiative served between 150 and 300 patients, depending on the severity of patient needs and the

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scope of their other duties. Thus, it is quite possible that some of the functions described above as dental case management could be incorporated into the roles of other dental clinic staff, especially receptionists, clinic coordinators, schedulers, translators or dental assistants.

Within larger organizations, such as AIDS Service Organizations or HIV clinics that provide both medical and dental care, some of the functions described above could be picked up by HIV case managers if they are given the time to do this. In organizations that have multiple case managers, one case manager could be dedicated to oral health. Ryan White nurse case managers could be trained to provide basic oral hygiene education and include oral health as part of their clinical assessments.

Ultimately, many of the tasks performed by dental case managers are non-reimbursable services and the position or functions must be funded from general revenue or grants. However, it can be argued that if the patient education, tracking and retention functions result in a reduced no-show rate, the position may pay for itself through additional visit revenue. In clinics where the dental case manager is a clinician, such as a dental hygienist, certain patient education services may be billable services. Clinic billing personnel can review all third party payer reimbursement codes to identify any codes that are associated with chair-side patient education as a possible source of revenue. Finally, a case can be made that the provision of oral hygiene education and early treatment for conditions such as periodontal disease reduces long-term costs for dental care. This is a strong argument for including access to and retention in care services in capitated oral health care programs where long-term cost savings can help finance the functions necessary to ensure the provision of early care and treatment.

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Sample dental case manager job description

POSITION TITLE: Dental Case Manager

REPORTS TO: Executive Director

POSITION AND BENEFITS

1. Current FTE: Up to .5 FTE (20 hours/week)
2. Paid holidays, vacation time, and discretionary leave prorated to FTE
3. Health insurance (medical, dental, vision) available to employees working .75 FTE and above.
4. This position is salaried & exempt, i.e. not subject to state and federal wage and overtime requirements.

THE POSITION

The dental case manager provides dental case management for people living with HIV including assisting them in receiving services from the Lane HIV Alliance's dental program. The dental case manager assists clients in filling out the necessary paper work, organization of paperwork, making appointments, getting to appointments and any follow up necessary in a timely manner.

RESPONSIBILITIES

1. Maintain an individual client load as Dental Case Manager
2. Familiarity with Ryan White Care Act (RWCA)
3. Experience coordinating medical and/or dental care
4. Experience with Word, Excel and Access
5. Detail-oriented
6. Self-motivated/self-manager
7. Ability to work with diverse populations
8. Experience working with clients with drug and alcohol, mental health issues
9. Record keeping and organizational skills
10. Team player who is self-motivated, high-energy, enthusiastic
11. Valid Oregon Driver's license, driving record sufficient to be covered by agency auto insurance policy, ability to transport self to job-related events, meetings and locations
12. TB test (provided at agency)
13. Flexible hours required, including some evenings and weekends
14. Ability to pass agency criminal background check