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The positive outcomes of HIV palliative care consultations: five meaningful cases

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The primary goal of palliative care is to maximize the patient's sense of control, strengthen relationships with loved ones and limit care burdens.¹ The importance of access to appropriate palliative care services and consultation for the chronically or terminally ill person with HIV cannot be overestimated. Since the inception of PalCare, a palliative care program for persons with advanced HIV/AIDS, palliative care consultations at the clinic where I work have been instituted on an inpatient and outpatient basis. (PalCare is a demonstration project of the Robert Wood Johnson Foundation's "Promoting Excellence in End-of-Life" national program.)

As an interdisciplinary team, PalCare provides case management, as well as palliative care consultations, focused on pain and symptom management, end of life decision making, advanced care advocacy and planning. Team membership includes physician, nurse practitioner, palliative care nurse specialist, social worker, and nutritionist. Each member of the PalCare team brings a unique and important dimension to such care planning and support.

This article presents several actual patient/family cases where a single palliative care

consultation greatly influenced care intervention and outcome. Referrals for the consultation were requested by inpatient social workers, nurses, and medical providers because of perceived concerns of uncontrolled pain, family conflict, end-of-life decision making, ethical dilemmas and advanced care planning frustrations. As the HIV palliative care nurse specialist who provided these consultations, I believe it is important for the advanced care issues of HIV-infected women to be acknowledged, documented, and discussed. Names have been changed to protect the identification of patients and family members. May their lived experiences provide lessons for those we care for now and in the future.

"Barbara"

Barbara was a 31-year-old African American heterosexual woman with a history of IV- and non-IV substance use. She had not taken illicit street drugs for two years. She was a single parent of four children, ages 4, 5, 7, and 9 years. Barbara's condition was considered grave. She had been hospitalized for 43 days which included 40 days in the intensive care unit, and three days on the HIV/TB inpatient unit. She had not come to any scheduled HIV outpatient visits in

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New website specializes in HIV information

AIDSinfo is a new federal website which merges two earlier sites: HIV/AIDS Treatment Information Service (ATIS) and HIV/AIDS Clinical Trials Information Service (ACTIS).

The new AIDSinfo site includes all of the services that were available from ATIS and ACTIS, plus quick and easy access to wide-ranging federal resources on HIV/AIDS clinical research, treatment and prevention, and medical practice guidelines for clinicians and consumers.

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The site is a service of the U.S. Department of Health and Human Services. It is sponsored by a coalition of eight federal agencies. ♦



Nursing

Palliative care consultations greatly influence care and outcome

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more than six months due to hospitalizations or poor health at home. She had a history of poor adherence to HAART medication regimen and was hospitalized four times in the last 12 months. While she was in the hospital, Barbara's sister cared for Barbara's four children, plus two of her own children, in a very small 3-room shotgun home.

During this hospital admission, Barbara was brought to the hospital via EMS, and was unconscious with difficulty breathing. She was immediately put on a ventilator and remained intubated with ventilator-assisted breathing for 40 days with heavy sedation. A palliative care consult was requested to evaluate her pain and assess status of end-of-life planning three days after she was moved to the HIV/TB inpatient unit.

The initial palliative care consult began with an assessment of Barbara's physical surround. Although there was a large glass panel in the door to Barbara's room, just outside of the nurses' station, staff could not view Barbara and she could not see anyone or anything from her bed due to the cloth curtain pulled around the bed. The television was buzzing loudly but she was unable to reduce the volume. Her call light button had fallen off the bed. The bedside tables were pushed away from the bed, making it impossible to reach the emesis basin for her frequent spitting. Her bed was littered with cups and the floor was scattered with soiled paper products from an overflowing waste basket. Barbara's personal (and only) environment was dirty, cluttered and visually closed off from others. The patient's direct personal space suggested a lack of respect for cleanliness, dignity, and understanding. There were no personal items visible in the room. For a young mother who had been away from her children for more than a month, the surroundings were devoid of drawings, cards and pictures of or from her children.

I found Barbara to be alert, agitated, profoundly short of breath, with rapid shallow respirations and oxygen at 4 l/min per nasal cannula. Barbara had two separate IV lines with

numerous bags of fluids and antibiotics running simultaneously on either side of her body. She had an adult nasal gastritis tube secured with a sub-clavian dressing taped to her nose and cheek. This tube was attached to a food bag and pump. She was incontinent of loose foul-smelling stool which had been seeping into her sacral decubitus prior to attachment of a fecal collection bag. Barbara had a Foley catheter, and a dressing over her draining sacral decubitus. She was also living in contact and respiratory isolation due to identification of at least three drug resistant infections (VRE, MRSA, MRSE). Barbara recently failed a swallowing study and was NPO. The

Each member of the PalCare team brings a unique and important dimension to care planning and support.

medical team requested a palliative care consult because they were upset that Barbara still wanted to be a full code.

Barbara was on the phone with her mother from whom she was refusing the offer of a strawberry snowball even though she really wanted it. She reported that the nurses would not let her have it because she might choke. After she completed her phone call, I introduced myself as the palliative care nurse, the person who visits people who have been sick to see if we can make them feel better. I asked her how she was feeling and if there was anything we could do for her. Barbara immediately stated "I want to get better so I can see my children."

We engaged in a conversation about her children, affirming her as a parent, an adult, a mother with closure issues for her children. At length, Barbara spoke of her lack of contact with her children. When I asked her what her

children were being told about her condition, she reported, "My sister tells them 'Mommy is getting better and will be home soon.'" When I asked her if this was true, Barbara looked me in the eyes and stated that she believed she would die before discharge out of the hospital.

There were many clinical, social, emotional and spiritual issues. The medical staff was strongly and urgently committed to feeding tube placement. The patient did not want the procedure because she was still seeping blood from the triple lumen catheter insertion site two days earlier. Doctors had told her she could go home, but her family had not been part of the discussion. When the social worker queried the patient's sister and mother regarding caregiving interest and availability, they related that they were too busy with family care to meet her physical care needs properly. They were also afraid of all the infections and felt they could not keep children and animals from jumping in bed and possibly spreading these conditions within the household. Bottom line, they could not take her home. Because of the drug resistant infections, the patient was not eligible for nursing home placement, and home care could not support the frequent antibiotic drug dosing.

After short conferencing, we decided to have a special patient care planning conference facilitated by myself and the hospital social worker. Advocating for the patient's desires and priorities, the team was able to refine patient goals from cure-focused to care-focused. Barbara did not desire the feeding tube and felt the doctors were pushing her to get it. She was most afraid she would never see her children again and that was *her* most important goal. Communication of Barbara's concerns and desires were conveyed to the inpatient staff and actions taken accordingly.

Special plans were quickly made to move Barbara to a more spacious empty semi-private room. As per her request, the nasal gastric tube was removed, and antibiotics discontinued. Nurse assistants assisted Barbara's bath and hair styling to promote the most normalized and well-kept appearance for the children she had not seen for so long. Arrangements were completed for



all four children to visit with the help of infection control and pediatric nurses. The extra staff helped gown, mask and glove the children and facilitated a loving and meaningful visit. After the visit the patient glowed. She was calm, relaxed, and thankful for the private time with her children. She requested all medications to be stopped and found that her ability to swallow soft foods and supplements returned.

When advanced care options were explained, Barbara requested hospice care and was transferred to an HIV group home residence where she continued to reside, off all treatment-based medications for over three months. Barbara died peacefully at the home in the group residence surrounded by drawings and pictures of her children and with those she loved around her.

There can be differing expectations between the patient and the health care providers. Care conflicts can arise around the uncertainty of treatment outcomes, the perception of risk with new medication strategies or diagnostic procedures, continued intervention, lack of intervention and concerns of legal recourse. Most of the time in these situations, it is simply a matter of acquiring more information from all sides.

“Lily”

An unforgettable example of this type of conflict was with the “Bird Woman.” This patient’s name was Lily, but she was given the title of “Bird Woman” because she spent her entire day perched (like a bird) up on the windowsill ledge. Lily would sit with her legs folded close against her chest and her arms resting like wings over her legs and sides. She was staring out of the window into the west side of the city. The inpatient unit staff reported she wanted to be discharged so she could go to Children’s Hospital and visit her critically ill young daughter. Lily’s family had brought Lily to the hospital by ambulance four days earlier because she was running a high fever at home, appeared dehydrated, and was “talking out of her head.”

Lily adamantly refused all medications throughout this hospital stay. The members of the psychiatric team who assessed Lily two days earlier were not in agreement about her current condition when I was asked to meet with her. A palliative care consult was requested because the staff thought we could convince her to take her medications and complete diagnostic

tests, yet there was a question as to ethical consideration of forced care versus protective care with advanced HIV disease.

It was not a surprise to find the situation was much more complicated when I arrived at the inpatient unit. The nursing staff was angry at the patient for not taking her medications, or doing anything that they asked her to do. Several nurses severely misinterpreted some already inaccurate information regarding Lily’s child. One staff nurse pulled me aside to inform me of Lily’s daughter being in the hospital because of neglect and abuse. One of the new nurses on the unit told the palliative care team that the patient’s daughter was having surgery on her legs to repair the “abuse injuries” from Lily. Consequently, the unit staff (consisting of predominantly young mothers) felt and exhibited a diminished sense of respect for this patient.

Review of the nursing and medical progress notes revealed additional case concerns. Nursing notations described threatening 4-point physical restraints if the patient did not consent to the ordered blood transfusion. Notations included descriptions of administration of the blood transfusion with the assistance of the patient’s sister. When the infectious disease fellow was questioned about the severity of the nurses’ interpretation and implementation of the orders, they responded with alarm and surprise. Emotions were charged, rumors were out of control, care priorities were

mixed, and the patient’s voice was missing from the care plan.

Lily was cachectic, dressed only in a patient gown, with her lunch untouched on the bedside table. I was prepared by inpatient nursing and social work staff to expect Lily to be hostile and not interested in communicating with me. As I entered her room, I stood by the door and asked if I could visit her for a few minutes. It was minutes before she would glance at me, and when she did, she did not say a word. I sat on a chair about four feet away from Lily and the window and stared in the direction of her gaze. I explained that I was visiting “because I help people go home.” She slowly turned away from her window and looked at me, straight in the eyes, and said, “Oh yeah, Girl. Talk to me. That’s what I want. I want to go home.... I want to get to Children’s Hospital and hold my baby.” Our rapport developed immediately.

When I inquired about her daughter, Lily told me her daughter, Mimi, was four years old. She also looked away and told me Mimi was in the hospital “because” of her. When I asked her what happened, she said, “I gave her the HIV medicine, just like they told me. I didn’t want to because I was afraid of making her sick, but they told me I had to or they would take her away from me. So I gave it to her and now she is sick in the hospital. She needs me more than I need to be here.” It turned out that Lily’s daughter was ill not only from severe side effects of her HIV medications, but she was having surgery to release the tension in the lower leg tendons due to the contractures associated with a genetic spastic condition.

When questioned about why she was sitting on the window sill, Lily explained that she chilled easily and there was a big vent blowing cold air directly on her bed. Physical examination of her bed proved this to be accurate. When questioned about why she would not take her medications, she reported, “I’m afraid to get sick like my daughter...and if I was to get sick, who would take care of her?”

At the time of the palliative consultation, many of the reasons for Lily’s admission to the hospital were no longer current. She had no fever, dehydration or confusion. She was able to respond to all questions thoughtfully and accurately. Clearly, Lily was entitled to refuse antiretroviral medication as long as she had been fully informed of

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Nursing

Patient and clinician sometimes have differing expectations

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her options. The staff was very concerned about Lily's lack of medication for her HIV status. The perception of staff was that if she would take the medicine, she would get better and live longer. The patient believed she had witnessed other people take the new medications and "get sick and die." She was not ready for the end of her life at this time.

The most complex component of this case was the poor communication between the patient, family, nursing, social work, and medical staff. Inaccurate judgments and assumptions of this person stigmatized and negatively influenced her care. She was labeled as a crazy child abuser who was refusing what was best for her. Instead of acting as agents of advocacy for this patient, some of the team members badgered her into aggressive care options (such as blood transfusions) that were not of her desire.

Closure of this case included the next months' new set of physicians kindly explaining the risk of dying too soon due to uncontrolled HIV infection. They gave her the option of stopping the medications whenever she wanted. She agreed to all of these measures telling me later, "I would have said anything, just to get the hell out of there."

Lily was discharged to home to be cared for by her mother and sister. Upon arrival home, she felt poorly and did not attempt to visit her daughter for almost two weeks. She eventually visited Mimi prior to her discharge home. Lily died "unexpectedly" at home about two months after her inpatient stay.

"Rose"

Rose was a 29-year-old single mother of three young children, ages 4, 6 and 7 years. She was extremely debilitated, dependent on care assistance for all activities of daily living and had been admitted to the inpatient HIV unit 12 times in the last 18 months. Rose had a history of prolonged ventilator-assisted breathing on three separate episodes. Rose had survived cardio resuscitation twice. The palliative care team was called to see Rose because the nurses were afraid of her going into respiratory failure again, and they did not want to "Code"

her again. They were also upset that the patient was refusing all offered food. The nurses and medical team shared the collective concern that they would cause more harm than good with CPR and ventilator assistance. The interdisciplinary team was ready for her to die peacefully. With reservations, the medical team maintained her "Full Code" status secondary to the patient's request for them to do everything possible, yet neither the medical nor nursing staff wanted this to occur on their shift. No one wanted to be a part of pounding on Rose's fragile little frame, fearing they would break her bones, and that she may never have a conscious moment again once on a ventilator.

Upon initial assessment, the palliative care nurse and social worker found the patient awake, alert and oriented to person, place and time. She was dyspneic and breathing 40 l/min on a 100% re-breather mask. Her chest was barely moving with each breath in between bites of her Burger King Whopper hamburger. Her hospital room was packed with personal toiletries, snack food, Ensure, and photos of her family. Numerous intravenous bags were attached to her supra-clavicular triple lumen catheter.

We had an extensive conversation with Rose during our first meeting. Rose described her general level of "comfort" as good, as well as her overall condition as "fine." She stated that she wanted to be put on machines if her breathing stopped, because it had helped her before. She reported she did not remember the other ventilator episodes because they told her she was put to sleep so she would not fight the machine. She said the ICU story was like a dream to her, or rather the memories of others.

When I asked, "What is the most important goal in your life at this time?" she said "I need to pray every night with my children." Rose mourned the fact that she had not been able to see her children at length as well as lead them in daily prayers. Because her children were so young, they could not visit her in the hospital. Rose whispered that a couple of the "nice" nurses would allow her children to visit but it was against the hospital rules.

Rose stated she was not interested in hospice care because she was not ready to die. She knew the machines had helped before and still wanted to be put on machines again. I suggested the possibility that not only would Rose not be able to be with her children, but she would not be able to communicate with them while she was on machines. We discussed the realities of mechanical support and that she may not be able to speak or possibly respond. This was new information to her. This was not a part of what she imagined. Upon learning this information, she stated that because she had gotten good results from the previous intubations, she wanted them again. Rose further clarified, "This time, only leave me on for 14 days, and if I still need to be on it, please turn 'em off and don't let my children see me like that, please."

It was with great relief that Rose was able to design her own advanced care plan. This empowered her, as well as relieved potential staff participants in a future Code. I documented Rose's desires in the medical progress notes and communicated to all members of the inpatient interdisciplinary team. Although the staff wished the patient had relinquished hopes for resuscitation, they were relieved to have documentation of the patient's realistic limit setting.

After this conversation, a case conference was held in the patient's room to coordinate goals and plans. Visitation regulations were eased to enable nightly prayers with her children. Within several days, Rose was discharged to a residential care facility which allowed her children to spend the night. Rose talked lovingly about her new friendships with other women with children living in the group home and about the pleasure of seeing their children play together. Through the course of her care, she was readmitted to the hospital one more time for evaluation and control of chronic nausea and diarrhea. At her last hospital discharge, she was referred to hospice at the residential facility and she died peacefully at this home five months later.



In the home setting, decision making power struggles ultimately reside within the patient and the family.

“Pearl”

Pearl was a 28-year-old woman with very advanced HIV disease. She had a history of repeated esophageal candidiasis, recurrent herpes zoster of multi-dermatomes, PCP, MAC, Cryptosporidium, CMV Retinitis, wasting and profound fatigue. Pearl was also the mother of three children. Her youngest son died of HIV complications at less than two years of age. Her oldest daughter was a healthy, HIV-negative 10-year-old. Unfortunately, Pearl’s 6-year-old daughter, Angel, was as sick as her mother. Angel was a serious child. She knew she was infected. She knew she did not have long to live. The greatest struggle within this family was the overwhelming decision of “who should die first.”

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At a unique point in Pearl and Angel’s life, they were both hospitalized at the same time. Pearl’s oldest daughter was living with her grandmother and planned to remain in her custody after Pearl died. During this combined hospitalization, both mother and child became close to the end of their lives. Both had ‘Do Not Resuscitate’ orders in place. Yet, due to insurance limitations, both were hospitalized in different hospitals. The community case manager of this family called for a palliative care consult because the family, nursing, social work, medical staff and pastoral services of both hospital units felt Pearl and Angel were “lingering” and would not let themselves die. It was difficult to decide which patient to see first. We decided to visit Angel first, knowing Pearl would want an update on her daughter.

Upon arrival at her hospital room, we found Angel was weak, needing assistance with all care and cradled in her grandmother’s arms. As she was sucking on iced juice chips, we asked Angel about how she was feeling. She replied, “I’m tired, very tired.” I asked, “Are you tired of being in the hospital?” Angel replied, “No, I’m tired of everything. I just want to go.” “What is keeping you here?” I asked. After a long silence, Angel replied, “I’m staying for my mom, she’s dying you know. If I go first, she will be very sad.” “What if you followed her?” “Oh, she would never want that, she said she would never leave me.”

We chatted, only slightly assessing comfort, support of grandmother and inpatient staff. I explained that we were going to visit her mother now, and told her “I hope you will be together soon.” Angel smiled and closed her eyes.

Pearl was in a similar state. Her sister sat by her side holding her hand. Pearl was agitated and anxious to hear about Angel. We reviewed the visit content and shared Angel’s concerns. Pearl cried and kept repeating a whispered “I don’t know what to do . . . I don’t know what to do.” When asked “What are you trying to decide?”, Pearl explained, “I’m tired, my baby’s tired, and what are we to do?” I asked, “What do you want to do?” Pearl replied with tears in her eyes, “I do not want to die first and leave my baby... but I don’t want to see her die before me.”

When asked how long it had been since they had seen each other, Pearl said it had been two weeks. We asked Pearl if we could call Angel’s room and she could talk to her. She said, “I need to see my baby.” Arrangements were made for Pearl’s day pass to visit Angel the next day.

After the visit, Pearl returned to her room and told the nursing staff, “I will die today. I’m going first. I’m going to welcome my baby into heaven.” And she did.❖

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- Mississippi 601-984-6105
- Arkansas 870-535-3062

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- National Warmline 800-933-3413
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Pharmacy

How common illicit substances interact with antiretroviral agents

*Tina Edmunds-Ogbuokiri,
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Recent reports in the literature have brought more attention to the life-threatening interactions, including deaths, that have occurred when protease inhibitors were combined with illicit drugs such as ecstasy (MDMA) and GHB (gamma-hydroxybutyrate) (Harrington 1999).

Although protease inhibitors have dramatically improved the prognosis for many HIV-infected patients, they are associated with numerous adverse effects including increases in serum glucose, triglycerides, lipodystrophy, hepatitis, nephrolithiasis and a large variety of GI side effects (Flexner, 1998).

In addition, protease inhibitors can cause serious adverse reactions and interactions when administered in combination with other substances, including illicit drugs, whose metabolism may be altered as a result of the inhibitory effects of the PIs on the cytochrome P450 enzyme system.

Illicit substances most commonly abused include cocaine, marijuana, methamphetamine, ecstasy, heroin, methadone, ketamine, crystal and GHB.

As a result of the myriads of side effects that could follow use of these substances (see listing of side effects for ecstasy on following page), combination of

these substances with protease inhibitors especially increases the likelihood of an overdose due to these agents, for example, ecstasy.

Cocaine has been reported to increase the speed at which HIV replicates while combination of the protease inhibitors with marijuana increases levels of tetrahydrocannabinoids in the blood.

Because combination of methamphetamine with ritonavir (Norvir) causes an increase in the potency of ritonavir, two to three fold, the likelihood of overdose with methamphetamine is increased.

Concomitant use of ketamine in the presence of the protease inhibitors causes hepatitis, while ritonavir decreases plasma levels of heroin by 50%.

Potency of methadone is decreased in the presence of ritonavir, indinavir (Crixivan) and nevirapine (Viramune), while methadone increases the potency of ritonavir by 50%.

Nevirapine was demonstrated to reduce plasma methadone levels and to precipitate opiate withdrawal in patients who were maintained on methadone for narcotics addiction (Altice, 1999).

More recent studies have reported decreases in the amount of stavudine (Zerit) and didanosine (Videx) absorbed from the digestive tract into the bloodstream in the presence of methadone.

Table 1 gives the highlights of most of the side effects that

may be exacerbated by the use of ecstasy or MDMA, a powerful street drug recently associated with fatal drug interactions when co-administered with ritonavir.

Drug interactions between opioid analgesics and protease-inhibitor antiretroviral agents

Since most opiates are substrates of the CYP450 enzyme system, when they are coadministered with cytochrome P450 enzyme inhibitors such as the protease inhibitors, erythromycin and clarithromycin, marked increases in serum levels can occur, patients should be monitored for oversedation and initial dosages should be decreased by 50%.

Patients abusing opiate drugs are at risk of toxicity when co-administered with these agents and should be counseled appropriately (Maurer et al. 1993).

Table II lists metabolic pathways of frequently abused drugs potentially affected by co-administration with the protease inhibitors. ❖

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Table 1: Side effects of Ecstasy (MDMA) that may be exacerbated when used along with conventional drugs with similar side effects

Bradycardia	Pruritus
Faintness	Rash
Euphoria	Decreased libido
Dysphoria	Nausea and vomiting
Headache	Urinary retention
Insomnia	Visual disturbances
Drowsiness	Respiratory depression
Physical and psychological dependence	

Source: Centers for Disease Control and Prevention. Multistate outbreak of poisonings associated with illicit use of gamma hydroxybutyrate use-New York and Texas, 1995-1996. MMWR Morb Mort Wkly Rep. 1997; 46:28283.

Table 2: Metabolic pathways of frequently abused drugs potentially affected by human immunodeficiency virus-1 protease inhibitors (adapted from Harrington, 1999)

FREQUENTLY ABUSED DRUG	Metabolic Pathway Used (P450 Isoenzyme)
Opiates	
Methadone, Alfentanil, Fentanyl Meperidine Codeine, hydrocodone, oxycodone Heroin, Morphine, hydromorphone Propoxyphene (Darvon)	Cytochrome P450 (CYP3A4) Cytochrome P450 (CYP3A4?) Cytochrome P450 (CYP2D6) Glucoronidation? Cytochrome P450 (CYP2D6)
Benzodiazepines	
Diazepam (Valium) Alprazolam, clorazepate, estazolam, flurazepam, midazolam, triazolam	Cytochrome P450 (CYP3A4, CYP2C19) Cytochrome P450 (CYP3A4)
Other drugs prone to abuse	
Marijuana, dronabinol, zolpidem Sildenafil (Viagra)* Cocaine**	Cytochrome P450 (CYP3A4) Cytochrome P450 (CYP3A4) Hydrolysis by plasma cholinesterase.

*AUC of sildenafil (Viagra) is increased 2-11 fold in the presence of all protease inhibitors; patients should not exceed 25mg in any given 48 hour period.

**Cocaine increases the speed at which HIV-1 virus replicates and so worsens overall prognosis by abolishing gains made by antiretroviral therapy. Metabolism of cocaine should not be affected by protease inhibitors.

Plan ahead to attend HIV conferences...

▲ February 10-14, 2003
10th Conference on Retroviruses and Opportunistic Infections
Boston, Massachusetts
Email: info@retroconference.org

▲ March 27-30, 2003
2003 National HIV Prevention Conference
Atlanta, Georgia
Sponsor: Centers for Disease Control and Prevention (CDC)

▲ April 2003
5th International Conference on Nutrition and HIV Infection
Cannes, France
Email: hivcannes@wanadoo.fr

▲ April 27-May 1, 2003
16th International Conference on Antiviral Research
Savannah, Georgia
Email: korbabe@gusun.georgetown.edu

▲ April 28-30, 2003
7th International Conference on Malignancies in AIDS and Other Immunodeficiencies: Basic, Epidemiologic and Clinical Research
Bethesda, MD
Email: jquinn@mail.nih.gov

▲ May 15-18, 2003
13th Annual Clinical Care Options for HIV Symposium
Scottsdale, Arizona
Email: DPeralta@contacthmc.com

▲ June 10-14, 2003
XII International HIV Drug Resistance Workshop: Basic Principles and Clinical Implications
Cabo Del Sol, Los Cabos, Mexico
Phone: (770) 946 3480

▲ July 8-11, 2003
5th International Workshop on Adverse Drug Reactions and Lipodystrophy in HIV
Paris, France
Email: lipodystrophy@us.intmedpress.com

▲ July 13-17, 2003
The 2nd IAS Conference on HIV Pathogenesis and Treatment
Paris, France
Email: ias2003@jcdconseil.com



Medicine

HIV in pregnancy: an update of current recommendations

Ronald D. Wilcox, MD

On November 22, 2002, the CDC came out with the latest version of its recommendations for the use of antiretrovirals in pregnancy. The following is a summation of parts of the report.

When deciding on a treatment regimen for a pregnant women, one must take into account the benefits of therapy versus the risks of adverse events to the fetus, newborn, and woman.

In February 1994, the Pediatric AIDS Clinical Trials Unit (PACTU) introduced the results of Protocol O76, a regimen consisting of the use of AZT alone, starting with oral AZT beginning after the first trimester, then IV AZT during labor, followed by oral AZT for the infant for the first six weeks of life. This protocol showed a 70% decrease from 22.6% transmission to 7.6%. The incidence of AIDS in children has dramatically decreased since the introduction of the results from this study. Monotherapy during pregnancy was the standard of care for many years but, with current data, the standard of care is now the use of combination therapy. The current recommendations are primarily designed for use in the United States at this time.

Recommendations regarding antiretroviral choices for treatment must take into account the possible dosing changes resulting from physiologic changes associated with pregnancy, potential drug effects on the pregnant woman, and potential effects on the fetus. The decision should be made after discussion of the known and potential unknown risks with the pregnant patient. During pregnancy, a woman's

gastrointestinal time is slowed down; fat and body water are increased with subsequent increase in blood flow to the organs; plasma protein levels are decreased; and there are changes in the physiology of both the liver and the kidney. Potential harm to the fetus depends on the type of drug, the amount ingested, the amount that crosses the placenta, the gestational age at exposure, and the genetics of the mother and fetus. Data are limited as to the long-term effects of fetal exposure to most antiretrovirals, including possible carcinogenicity.

The current recommendations for initiation of antiretrovirals in pregnant patients are based on the same parameters as those for non-pregnant patients or for those with a viral load ≥ 1000 copies/ml regardless of their immunologic or clinical status. One study has shown a decrease in HIV transmission from 9.8% to 1.0% in women whose baseline viral load was less than 1000 copies/ml while on antiretroviral therapy, usually consisting of AZT monotherapy in this select group. The placental passage of AZT is excellent, whereas that of other antiretrovirals is variable, leading to the recommendation that all regimens used to treat during pregnancy should include AZT whenever possible. AZT is metabolized within the placenta into its active triphosphate form, which may explain the protective effects it has in ways other than just the lowering of maternal viral load. This may be unique to AZT; it was not seen in studies of ddI or ddC. Initiation may be postponed until after the first ten to twelve weeks of gestation. Dual nucleoside therapy with either a

protease inhibitor or a non-nucleoside reverse transcriptase inhibitor should be given as standard-of-care, with mono- or dual-therapy regimens reserved for those women with baseline viral loads < 1000 copies/ml. Treatment with efavirenz (Sustiva) should be avoided during the first 12 weeks due to findings of significant teratogenicity seen in rhesus macaques. Women who are on therapy with good viral load suppression (< 1000 copies/ml) at the time of conception should continue with their current regimen, avoiding efavirenz, with consideration of adding or substituting AZT into the regimen. Women who are not virally suppressed on a regimen should have resistance testing considered and change of their regimen to decrease their viral load to less than 1000.

Women with no or minimal prenatal care with no prior therapy at the time of labor have four treatment options recommended: a single dose of nevirapine at the onset of labor with a single dose given to the infant at age 48 hours; oral AZT with 3TC during labor with one week of the combination therapy for the infant; IV AZT intrapartum with six weeks of AZT for the infant; or combination of the first and third regimens mentioned. The first three regimens are based on previous studies showing a decrease in transmission while the fourth regimen is a theoretical regimen. Of concern with the use of two-dose nevirapine is the development of NNRTI resistance mutations in 19% of antiretroviral-naive women and 15% of those who were on antiretrovirals but received an additional dose of



nevirapine at the time of delivery; the development of this resistance was associated with "significantly higher viral loads and lower CD4 counts."

The greatest change in the current recommendations is in the section regarding resistance testing. The incidence of resistance mutations in the therapy-naive patients varies by the type of assay and the geographic area. RT gene resistance mutation rates frequently are > 10% in surveyed areas in the Western Hemisphere with primary resistance rates for protease inhibitors ranging from 1-16%. The International AIDS Society USA Panel and EuroGuidelines Group for HIV-1 Resistance currently recommend that *all* pregnant women with a detectable viral load (usually > 1000 copies/ml) have resistance testing performed to maximize efficacy of therapy.

There definitely are some concerns with the use of antiretrovirals in pregnancy. A retrospective Swiss study of 37 pregnant HIV-infected women revealed preterm delivery in 10 of 30 deliveries. This rate did not differ between women who received a protease inhibitor or not. The European Collaborative Study and the Swiss Mother + Child HIV-1 Cohort Study investigated 3,920 mother-child pairings; there was a 2.6-fold increase odds of preterm delivery in patients on HAART with those on antiretrovirals before pregnancy having twice the chance of preterm delivery compared to women who initiated HAART in the third trimester. A contrasting study in the USA by the PACTU of 1,472 women with 78% receiving HAART during pregnancy showed no association with preterm delivery; the highest rate was in women who received no antiretroviral therapy.

HAART therapy with a protease inhibitor (PI) has been associated with the development of hyperglycemia and new-onset or exacerbation of diabetes mellitus, as has pregnancy. It is not known at this time if there is an increased incidence of these complications in pregnant patients on a PI-containing regimen.

Of concern also is the development of mitochondrial toxicity from the nucleoside analogues, with the incidence in descending order occurring with ddC > ddI > d4T > 3TC, AZT, and abacavir. Some of the clinical disorders associated with the mitochondrial toxicity include cardiomyopathy, neuropathy, lactic acidosis, hepatic steatosis, pancreatitis, and myopathy. The lactic acidosis and hepatic stosis have been shown to have an increased incidence in women. In 1999, Italian researchers reported a fetal death at 38 weeks gestation in a mother taking d4T-3TC who had a severe lactic acidosis. There have also been reports of three maternal deaths due to lactic acidosis on combination therapy with d4T-ddI; all women were on this regimen at the time of conception and continued throughout pregnancy. Caution with close monitoring must be given in women who remain on this regimen during pregnancy.

The use of AZT has been shown as mentioned above to decrease the transmission rate. The data from the Antiretroviral Pregnancy Registry has not shown any increased risk for congenital abnormalities among women who received AZT nor have there been long-term neurologic, developmental, or growth differences in uninfected children.

The incidence of transmission based on the mode of delivery has also been studied extensively. Several studies done early before

the advent of viral load testing and HAART therapy showed a 55-80% reduction in transmission when an *elective* cesarean section is performed as compared to a vaginal delivery. The data for non-elective cesarean sections has not shown a significant decrease in transmission. The current recommendation is that an elective cesarean section should be offered to all HIV-infected pregnant women whose HIV viral load is > 1000 copies/ml at the time of delivery. Maternal morbidity and mortality are greater when a cesarean section is performed, so when a mother's viral load < 1000 copies/ml, the decision concerning a cesarean section rests on other criteria and not HIV.

In summation, the report recommends the use of antiretrovirals in all HIV-infected pregnant women. Resistance testing for any pregnant woman with HIV with a detectable viral load is encouraged. AZT monotherapy or dual therapy should be reserved for those women with a baseline viral load < 1000 copies/ml; all others should receive HAART with AZT as one of the components with a goal of a viral load < 1000 copies/ml at the time of delivery. Efavirenz and hydroxyurea should be avoided during the first trimester and ddI and d4T together should be used cautiously. Cesarean section should be offered to those women without ideal viral load suppression near the time of delivery. ❖

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Mental Health

HIV infected are more at risk for intimate partner violence

*Jill Hayes Hammer, PhD
Nancy Freeman, LCSW*

In the 1990s, I was the psychotherapist for a woman named “Betty.” Betty had HIV and an abusive husband. In addition to being physically abusive, her husband would tell her what a dirty person she was because she had HIV. He threatened that if she left him, he would tell everyone her HIV status. Betty never called the police about the abuse, though she was seen in the hospital emergency room on several occasions. It was not until he began abusing her children that she left him.

Once upon a time, intimate partner violence (IPV; formerly called domestic violence) was considered a “family issue.” Back then, even if the police were called to the scene, they may not have arrested the perpetrator, telling both parties to leave each other alone for a while to “cool off.” After Nicole Brown Simpson was murdered on June 13, 1994, IPV came out of the closet and into the headlines. Police are now discouraging dual arrests (i.e., when both partners are arrested) because this action victimizes the victim twice—once by the batterer and again by the criminal justice system. Judges are sentencing batterers to the same amount of jail time as criminals who commit assault (i.e., a felony). Before the 1970s, family violence was considered a misdemeanor in some states.

Although the criminal justice system has been somewhat proactive, some clinicians are still reluctant to discuss the issue with their patients. Often medical personnel are the first non-family members to become aware of violence in the home and consequently are some of the first professionals in a position to assist the patient/victim.

In this, the first of a two-part article on domestic violence and HIV, the goal is to assist clinicians in identifying/defining domestic violence, understanding the magnitude of the problem, and recognizing the special circumstances of battered individuals who also have HIV/AIDS. The next article will cover screening for domestic violence in a primary care population.

**Approximately
two thirds of women
with HIV have
been battered
at some point in
their lifetime.**

Intimate partner violence includes not just physical abuse and injury, but also consists of psychological, emotional, verbal, and sexual abuse. Intimidation, such as threats of harm or restricting finances, social isolation, degradation, and deprivation are also considered IPV. While there is no clear-cut

profile of a woman who is likely to be battered, researchers have indicated that women between the ages of 17 and 28, women who abuse alcohol/drugs (or who have partners that do), women who are pregnant, and women who are with possessive partners are at increased risk.

Nevertheless, IPV occurs in all racial, gender, socioeconomic, educational, age, ethnic, and religious groups (American Medical Association, 1992). No group is immune. Many people, due to cultural or other reasons, do not realize they are the victims of IPV.

The extent of domestic violence is staggering. Researchers estimate that approximately 1.5 to 4 million women are raped and/or physically assaulted each year by an intimate partner (Tjaden & Thoennes, 2002) and 8-12 million women are at risk of being battered at some point during their lifetime (American Medical Association, 1992).

Other statistics include:

- Fifteen percent of men who live with men reported being raped, physically abused, or stalked by their partners, with 7.7 percent of men who live with women reporting the same.
- Approximately 11 percent of lesbians indicated being raped, physically assaulted or stalked by their companions, with 30.4 percent of women who live with men reporting the same.

The integrity of the victim, both psychologically and physically, is often compromised following a battering episode. In



the *Diagnostic and Treatment Guidelines on Domestic Violence* published by the American Medical Association (1992; <http://www.ama-assn.org/ama1/pub/upload/mm/386/domesticviolence.pdf>), researchers estimated battered women accounted for 19-30% of emergency department admissions, 14% of ambulatory-care internal medicine clinic visits, and 25% of psychiatric emergency services. These numbers are likely higher in the population of individuals with HIV because researchers recently estimated that approximately 2/3 of women with HIV have been battered at some point during their lifetime. This figure is a great deal higher than the overall national average.

Individuals with HIV are particularly vulnerable to IPV. They may or may not have publicly disclosed their HIV status, and they may still be reconciling themselves to having

the illness. Accordingly, they are frequently susceptible to coercion about their illness.

Taken together, IPV is a national problem, resulting in victim (and child) pain and suffering, as well as increased health care costs. Recognition and attention focused on the problem is the first step. The next is screening, and this will be addressed in the next article. ❖

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Most downloaded document on Delta site is Dr. Zachary's guidelines summary

If number of downloads is any indication, clinicians all over the globe are utilizing the document entitled "Practical Antiretroviral Guidelines for the Management of the Adult HIV-Infected Patient."

The document, created for Delta AETC by Dr. Jim Zachary, is notable for its comprehensive yet concise summary of the current treatment guidelines for HIV/AIDS. It is updated several times a year as regimens change.

Dr. Zachary is Assistant Professor of Clinical Medicine, Section of Infectious Disease, LSU Health Sciences Center, and Staff Physician, HIV Outpatient Program, Medical Center of Louisiana.

The popular document includes sections on the following topics:

- Available drugs:
 - NRTIs
 - NNRTIs
 - PIs
 - Combinations
- Criteria for:
 - initiation of therapy
 - changing a regimen
 - discontinuing therapy
- Resistance testing
- Antiretroviral agents:
 - dosing
 - side effects
 - interactions
 - laboratory monitoring
- Preventative therapies for persons with HIV infection

The document is available at www.deltaetc.org/arvguide.pdf

Ways in which abusers use their own or victim's HIV status as a weapon of coercion

- Threatening to reveal HIV+ status to children, family, friends, employer
- Threatening to use victim's HIV+ status as grounds for paternal custody
- Reinforcing a victim's guilt about the HIV+ status of children
- Sexually humiliating or degrading the victim for having HIV. Telling the victim s/he is "dirty" or undesirable.
- Isolating the victim on the basis that s/he poses a threat of infection to others
- Abusers may use victim's HIV+ status as an excuse for their violence
- Abusers who are HIV+ may fake illness in order to convince victims not to leave or to woo them back if they have left
- Abusers who are HIV+ and who require caregiving may be successful at manipulating victims into providing care
- Blaming the victim for infecting him/her as a means of manipulation

Adapted from New York State Office for the Prevention of Domestic Violence, 80 Wolf Road, Albany NY 12205, http://www.opdvstate.ny.us/health_humsvic/health/hhtml. Also includes information from interviews with individuals with HIV



Dentistry

Evidence-based dental practice and HIV: Is there relevance?

Nicholas Mosca, DDS

In March 2001, the American Dental Education Association (ADEA) Signature Workshop entitled *The Scientific Basis for Clinical Dental Education: A Dialogue* challenged clinical dental educators to consider if clinical dentistry should be *learned* as a science. If agreed, clinical dental educators would have to pursue the best available evidence for use in educating students about patient care.

Dr. Steven D. Shafersman, in his 1997 paper on scientific education, proposed that to succeed in presenting scientific thought to students, educators must agree that science is not merely a collection of facts and concepts, but is a *method* of investigating nature. Accepting science into clinical practice requires that dental providers also want to search for the best evidence that supports their care.¹

Dental practitioners today can have lightning fast access to a wealth of health information through computer technology, which is very important in the rapidly evolving field of HIV/AIDS care. However, our clinical decision-making skills have yet to fully realize the potential of this technology as evidenced by dentist's willingness to "try out" new dental materials without debate or research based on a dental representative's encouragement in an exhibit hall.

Quite commonly, when two dentists encounter an identical

clinical problem, differences of opinion occur, usually followed by an authoritarian opinion, stated, for example, as "Well, that's what I do in my practice." Such statements demonstrate the application of authoritarian evidence, or rather the beliefs that those in authority tell you are true through books, television commercials, etc. Many clinical practitioners will attest that the knowledge they acquire from reading someone's textbook is scientific evidence. However, the knowledge that is shared by the textbook's editor is still represented as authoritarian evidence, and may not necessarily reflect *reliable* evidence.

Shafersman (1997) implies that true scientific evidence is empirical, meaning that it is evidence that can be found in nature by our own sight, hearing, touch, taste, or smell; it is repeatable evidence that is susceptible to one's senses. True scientific thinking requires that we reject authority and use logical reasoning based on this empirical evidence. Applying scientific thinking to clinical practice empowers the clinician to be questioning and critical in forming conclusions. So how can we apply evidence-based practice to the oral health care of those with HIV disease? What is the reliable evidence upon which we should base our clinical decision making?

Randomized controlled research trials are considered one of the most effective ways to obtain empirical evidence about

disease intervention. However, most clinical practitioners do not have the time, resources or desire to practice and conduct clinical research simultaneously. Therefore, other methods to promote the application of empirical evidence in patient care are necessary to encourage their use. The Cochrane Collaboration is one such resource. The Cochrane Collaboration performs systematic reviews of clinical research to provide strong empirical evidence on the effectiveness of different clinical strategies, and to promote their use in clinical practice. The Cochrane Collaboration was established in 1992, and comprises 50 collaborative review groups known as CRGs, which performs systemic reviews and disseminates their findings.²

The Cochrane Collaboration's CRG on HIV/AIDS, established in 1998, announced in June 2002 that it has completed 12 systemic reviews, and has 40 more reviews in progress. Their findings are disseminated through an electronic journal known as the Cochrane Library, which can be accessed from the Internet at <http://www.update-software.com/cochrane/>. A fee is charged to access this library, however, most academic health centers provide free access for their faculty members, while some countries offer free access for their citizens.

There are several advantages to using systemic reviews in clinical practice, but the clinician must know how to do



so effectively. The clinician must first understand how a systemic review is performed to consider its usefulness in practice. First, a reviewer must formulate a clear clinical question. For example, what is the most effective drug to treat oral thrush? Next, the reviewer conducts a literature search for relevant articles and evaluates each one to determine the usefulness and validity of its evidence. Validity is based on a measure of the study design (case-controlled versus cohort study with control group for example), and whether randomization of data collection occurred. Reliable evidence is reported as useful in clinical care, while studies with weak or unreliable evidence are also acknowledged.³ Pharmacological studies appear to provide useful systemic reviews with reliable evidence, as such research includes true randomized trials to obtain Food and Drug Administration approval. Dental research is less likely to meet the criteria of a good systemic review because most dental materials are licensed as devices, not as drugs, and there is little incentive for dental manufacturers to conduct randomized controlled trials. However, there are some evidence-based reviews available about the dental care of the HIV+ positive patient.

In the Cochrane Database of Systemic Reviews, Issue 4, 2002, reviewers posed the clinical question of whether nystatin decreases morbidity and mortality when given prophylactically or therapeutically to immunosuppressed patients. Twelve randomized trials were

selected for review, consisting of data collected from 1,464 patients. Nystatin was given prophylactically in ten trials and as treatment in two. Only one trial involved AIDS patients. The reviewers found that Nystatin acted no differently than placebo on fungal colonization and was less effective than fluconazole in preventing fungal infection or colonization. Based on this evidence, they reasoned that Nystatin could not be recommended for the prophylaxis or treatment of Candida infections in immunosuppressed patients.

Of the Cochrane HIV/AIDS Group Reviews in progress, a few are relevant to dental practice. These include antimicrobials for preventing and treating oropharyngeal infections in persons with HIV, Cotrimazole for prophylaxis of opportunistic infections in adults or children with HIV, and chemotherapy for treatment of Kaposi Sarcoma in HIV-infected persons. Another evidence-based resource for dental providers can be found on the Agency for Health Care Research and Quality's website at <http://www.ahrq.gov/>, entitled Management of the Dental Patients with HIV (Evidence Report #37). This review concluded that there is little evidence of unusual rates or severity of complications for root canal therapy or extraction procedures performed on persons with HIV/AIDS, evidence for the utility of selected oral lesions as markers for seroconversion is limited to a single study of a single oral condition—candidiasis, and fluconazole is a useful medication to prevent oropharyngeal candidiasis, but

other antifungal agents did not have sufficient evidence available to review.

In conclusion, evidence-based practice is an emerging concept that will become more relevant to clinicians as systematic reviews are performed and disseminated using the Internet. However, accepting a reliable evidence-based approach towards patient care will ultimately depend on our demand and support for good clinical research to provide us with empirical evidence.❖

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Nutrition

Expertise is needed to provide medical nutrition therapy in HIV

Ginger Bouvier, Med, LDN, RD

Medical nutritional therapy involves both nutrition assessment and appropriate treatments, particularly specialized nutrition-based therapies, to optimize nutritional status. Nutrition evaluation and medical nutrition therapy (MNT) should be integral parts of the ongoing health care for patients with HIV.¹ (MNT in HIV disease is discussed in depth in *HIV Clinician*, Spring 2000.)

Evidence indicates that, in general, MNT reduces mortality and morbidity, improves health outcomes, reduces health care costs, and shortens hospital stays.^{2,3} Several studies regarding MNT in HIV disease indicate that patients who receive MNT show improvements in weight and nutritional status compared to those who receive no MNT.^{4,5}

As a registered dietitian at an HIV outpatient clinic, I am fortunate to be part of a dynamic interdisciplinary team, where I provide nutrition assessment and MNT for our patients, and serve as a resource for other health professionals.

I recently attended the Association of Nurses in AIDS Care (ANAC) annual conference. I was very interested in, and attended, presentations that dealt with nutrition-related problems in HIV disease. Several presenters discussed research they had conducted in conjunction with HIV-knowledgeable dietitians, and encouraged members of the audience (mostly nurses) to refer patients to registered dietitians (RDs) for nutrition evaluation and comprehensive nutrition therapy. The speakers seemed confident that dietitians play an important role in

the care of HIV-infected individuals. I was convinced that these health care providers recognized the expertise that dietitians bring to the HIV arena.

Then, on the last night of the conference, my bubble of confidence burst at a symposium on highly active antiretroviral therapy (HAART). One of the speakers, a clinician who treats HIV-infected patients, discussed the management of the side effects of HAART. In his presentation, the clinician showed a slide with a list of interventions for diarrhea, including "dietary changes." When he got to this intervention, the speaker told the audience, "You don't need to bring in a registered dietitian or nutritionist, you can do this yourself." Then, to make matters worse, he gave us an example of how to do this ourselves: If a patient tells us he gets diarrhea when he eats refried beans, tell him not to eat refried beans. Is this dietary management of diarrhea? I liken this approach to the old joke, "Doc, it hurts when I touch my head," and the doc replies, "Then don't touch your head!"

After the initial shock, I became concerned that some clinicians still do not realize what medical nutrition therapy is or that RDs are uniquely qualified to provide MNT to persons with HIV disease, or that MNT works! Nutrition screening and referral information for HIV-infected adults can be found in *HIV Clinician*, Summer 2000.

Registered dietitians are experts who apply the science of food and nutrition to health. Many dietitians specialize in HIV/AIDS medical nutritional therapy, and some of these specialists have done extensive research, created guidelines, and written protocols for MNT in HIV disease.

Unfortunately, not all HIV clinics and medical practices employ or refer to HIV-knowledgeable dietitians, however there are many resources to assist them in providing optimal nutrition-related care.

The American Dietetic Association includes a group of HIV specialists in the HIV/AIDS Dietetic Practice Group. Information on this group and links to related sites can be found at www.hivaidspg.org.

*A Clinician's Guide to Nutrition in HIV and AIDS*⁶ is an incredibly comprehensive resource on all aspects of nutrition in HIV disease. This book is currently under revision.

The Health Resources and Services Administration (HRSA) has created a manual, *Health Care and HIV: Nutritional Guide for Providers and Clients*,⁷ which provides a much needed link for HIV clinics and health care settings where a dietitian is not available. ♦

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Psychosocial

HIV and substance use: Pain and the drug-seeking patient

Danny Sansovich, LCSW

John Doe 1 has a CD4 count <100, viral load >750,000 and multiple HIV symptoms including a history of PCP twice. He frequently complains of generalized pain and peripheral neuropathy and has been prescribed Vicodin, methadone, Xanax, Roxanol. He refuses ARV therapy.

John Doe 2 has a CD4 count >1000, VL <400 and chronic pain including back pain. He has been prescribed Percocet, then Vicodin.

Jane Doe 1 has a CD4 count near 300, VL <5,000, peripheral neuropathy, and has been on MS Contin and methadone.

John Doe 3 has a CD4 count near 200, VL >60,000, weight loss and severe generalized pain for which he was prescribed methadone. He also was on Xanax which was prescribed by Psychiatry.

The individuals described above are real patients at the HIV outpatient clinic where I work. In addition to having similar complaints of pain requiring narcotics, they share some other characteristics. All have undergone urine toxicology drug screens and have tested negative for prescribed narcotics and positive for other prescription narcotics and/or illegal drugs, usually cocaine.

Most have tested positive for cocaine more than once. Most have gone "doctor shopping" in search of narcotics without informing their primary care provider.

All have been suspected of diverting prescribed narcotics to obtain illegal drugs, with one patient attempting to sell his prescribed narcotics while in the clinic's patient waiting room.

In the last issue, I pointed out that a review of the clinic's team meeting notes for the past six

months indicated that about 60% of the patients presented at our team meetings had substance use/abuse issues that created obstacles to the provision of primary care. The case examples presented here represent the characteristics of most of the patients presented at team meetings for substance use/abuse problems.

The challenge to primary care providers is developing a plan that addresses the legitimate pain complaints of many patients while recognizing the potential for abuse. Developing such a plan is much easier said than done and this is reflected in research that suggests that pain in AIDS patients is frequently undertreated (Breitbart, et al., 1999).

The behaviors of the addicted or drug seeking patient understandably complicate the relationship between the patient and the primary care provider.

One study looked at mutual mistrust between providers and patients with drug use histories and identified four major themes that distinguished this relationship (Merrill, et al., 2002).

Those themes are:

1) *Fear of deception.* Stories abound at our clinic of patients losing meds, having them stolen, losing drugs down the sink, forgetting them on the bus.

2) *No standard approach to care.* It's difficult to develop a standard approach when dealing with less than standard behavior, including missed appointments, in adherence to care, and attempts to split staff.

3) *Avoidance,* ranging from not wanting to acknowledge the patient's drug problem to not wanting to see the drug-seeking patient.

4) *Patient fear of mistreatment,* or of being inadequately treated which can lead to frequent changes in providers or to vigorous

accusations of being ignored and mistreated.

Effectively treating the legitimate pain in HIV/AIDS patients perhaps has to start with identifying differences between the drug seeking patient and the pain patient.

Heit (2001) has suggested six characteristics of the pain patient versus the addicted patient.

The Pain Patient:

1. Not out of control with medications
2. Medications improve the quality of life
3. Aware of side effects
4. Concern about medical problems
5. Will follow the agreed upon treatment plan
6. Has medication left over from previous prescriptions

The Addicted Patient:

1. Out of control with meds
2. Medications increase the quality of life
3. Wants medications to continue or increase despite side effects
4. In denial about medical problems
5. Does not follow the treatment plan
6. Does not have medications left over, loses prescriptions, and always has a "story"

See HIV and substance use next page



Psychosocial

Pain in AIDS patients is often undertreated

HIV and substance use, from page 15

Additionally, some of the drug-seeking patients at our clinic will report intolerable side effects to all pain medications *except* Oxycontin, or will report intolerable side effects to Duragesic patches.

Once the potential for abuse is identified, the clinic has tools in place that attempt to provide the best level of care for the patient who may have a drug problem.

The first is the urine drug toxicology screen. As mentioned earlier, most of the patients identified in team meetings as potentially having drug abuse issues have positive drug screens for unprescribed narcotics or illegal drugs such as cocaine.

Second, the clinic has a pain specialist who is available to consult with providers and/or see the patients for a pain workup and plan of care.

Third, the clinic has a pain contract. The pain contract specifically lists patient expectations and behaviors that must be adhered to in order to continue receiving narcotics for pain. *Readers interested in*

obtaining a copy of the pain contract can e-mail me (dsanso@lsuhsc.edu) with a mailing address and a copy will be sent.

The next article in this series will examine harm reduction and the effects of substance use on the immune system. The last article will focus on some of the issues about which readers have e-mailed me regarding their own challenges when dealing with this population.

I look forward to additional feedback and any comments or questions raised by this article. ❖

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