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New information sheds light on the lactemia often associated with HAART therapy

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A number of metabolic complications have been recognized over the past several years associated with the widespread use of HAART therapies. These include insulin resistance and diabetes mellitus, hyperlipidemias, osteopenia and elevated lactic acid levels. Of these, increased lactate levels or lactemia is the one that is probably least understood. As a result, guidelines for diagnosis, monitoring and management of lactemia have been lacking. Some newer information is now available that begins to address this problem.

Lactemia is defined as an elevated lactic acid level above 2 mmol/L in the presence of a normal pH. In lactic acidosis, there is an elevated lactate level with a pH <7.35. Lactemia can be further classified into mild (lactate between 2-5 mmol/L), moderate (lactate 5-10mmol/L) and severe (lactate level >10 mmol/L). Mild lactemia is accompanied by a normal pH and is usually asymptomatic. Moderate lactemia is rarely associated with acidosis but may be symptomatic. Severe lactemia, while not common, presents both with acidosis and symptoms and carries a high mortality rate.

The symptoms most often associated with lactemia are fatigue, nausea and vomiting. In severe lactemia, fatigue may progress to profound asthenia or lethargy accompanied by intractable nausea, vomiting and abdominal pain. Patients with severe disease and acidemia may develop acute hepatitis and/or hepatic steatosis with abnormal liver function

tests. Hyperglycemia and pancreatitis have also been described.

Lactemia and lactic acidosis are thought to be one of the manifestations of mitochondrial toxicity associated with the use of nucleoside reverse transcriptase inhibitors (NRTIs). While the mechanism of production of hyperlactemia is not well delineated, there is a considerable amount of data supporting the association with the NRTI class. The NRTIs most commonly associated with lactemia are didanosine and stavudine, particularly stavudine.

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Legal

Clinicians faced with more HIV+ women of child-bearing age

Stacey LaFleur-Spawn, JD

More and more women are finding out that they are HIV-positive when they are tested for the virus during their pregnancy. Some states, including Arkansas,¹ mandate that pregnant women undergo an HIV test. Once a woman tests positive, she is then advised of her treatment options. A pregnant woman's medical practitioner should take her CD4 count, viral load, and the gestational age of the fetus into account when advising her regarding treatment during her pregnancy.² Under the current standard of care, it is recommended that antiretroviral (ARV) therapy be administered to a pregnant woman, unless a

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Medicine

Severe lactemia, though uncommon, carries a high mortality rate

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The other NRTIs have also been implicated. The non-nucleoside reverse transcriptase inhibitors (NNRTIs) and the protease inhibitors (PIs) do not appear to be associated with this syndrome.

The prevalence of elevated lactate levels in patients treated with NRTIs has been looked at in a handful of cohort studies. Up to 21% of these patients had elevated lactate levels compared to 0-3% of patients on no therapy. In contrast, the percentage of patients with symptomatic lactemia was quite low at 2-3%. The overall incidence of lactemia is 1.5-2.1 cases per 100 patient-years of exposure to NRTIs. It is higher when stavudine is considered alone with an incidence of 2.3 - 2.6 per 100 patient-years of exposure to stavudine. Still, the incidence of symptomatic lactemia and acidosis with NRTI use remained low at 0.13 -0.8 cases.

Lactemia most often occurs within the first several months of NRTI exposure. Several possible risk factors for the development of the syndrome have been identified. These include pregnancy, female gender, older age, underlying liver disease, lower CD4 counts and length of antiretroviral therapy. While the exact mechanism of production of elevated lactate levels remains ill-defined, mitochondrial toxicity has been postulated to be the etiology of this syndrome as well as others including drug-associated

peripheral neuropathy, lipoatrophy, hepatic steatosis and osteopenia. Association of lactemia with more rapid progression to lipodystrophy, neuropathy and osteopenia has been reported in one patient cohort from Australia.

NRTIs are thought to cause mitochondrial toxicity by inhibition of mitochondrial DNA polymerase. Impairment of this enzyme interferes with mitochondrial oxidative metabolism by blocking the pathway that converts pyruvate to acetyl Co A needed for ATP production. This is postulated to shift the pyruvate pathway towards excess production of lactate and gluconeogenesis. Furthermore, unused acetyl Co A is thought to accumulate, serving as a substrate for fat synthesis. Reduced ATP production may contribute to fatigue.

Appropriate management of NRTI-associated lactemia is incompletely understood, but some consensus regarding certain aspects of management is beginning to emerge.

Management of severe lactemia (> 10 mmol/L) with or without acidemia and hepatic steatosis warrants immediate discontinuation of NRTIs and supportive measures as indicated. The latter may involve sedation and mechanical ventilation to ensure adequate tissue oxygenation. The efficacy of oral or IV bicarbonate remains unproven. In patients who survive severe lactemia it may take several months to a year for

the lactic acid levels to normalize. Most authors would not recommend re-challenge in patients who have had severe lactemia with NRTIs, or would recommend at least to avoid stavudine and didanosine and any other NRTIs that may have been causally implicated.

In patients with moderate lactemia, there is a risk for development of acidosis and hepatic steatosis, though exactly which patients will ultimately have these complications is unknown. Discontinuation or interruption of NRTIs in patients who have symptomatic moderate lactemia is advocated by a number of authors. Careful monitoring of lactate levels, HCO₃, and liver function should be considered in those who are asymptomatic.

Mild asymptomatic lactemia may not be associated with progression to more severe disease, but more data are needed to confirm this observation. Continuation of NRTI-containing regimens can be considered but should be coupled with appropriate clinical and laboratory monitoring.

Routine monitoring of lactate levels in all patients taking NRTIs is to date not recommended. It should be considered, however, in patients with risk factors including pregnancy, symptoms of fatigue, nausea or vomiting, abnormal liver function tests, unexplained low bicarbonate levels, lipoatrophy, osteopenia, peripheral neuropathy and, in the setting of re-challenge with



NRTIs, in patients with a history of lactemia.

The decision to re-challenge patients who have had moderate or severe lactemia with NRTIs can be a difficult one. In general, the consensus is that it is best to avoid this class of drugs in patients who have had symptomatic lactemia and rely on PI/NNRTI combinations. In reality, of course, this may not always be possible given the limited number of antiretroviral agents available and resistance issues, if optimal HIV suppression is to be achieved. In pregnant patients, most practitioners would avoid even the de novo use of didanosine and stavudine given the recent reports of three deaths associated with lactic acidosis in pregnant patients taking stavudine.

There is some recent data in small numbers of patients to suggest that substitution with abacavir, zidovudine or both in patients with prior stavudine-associated lactemia may be possible without recurrence of lactemia for at least up to six months.

Clearly, our understanding of the causes and consequences of NRTI-associated lactemia remains incomplete. More studies are needed to better delineate the etiology of this syndrome. Preliminary information regarding how to approach this problem is welcome and useful while awaiting more precise guidelines for optimal management. ❖

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Source of listings: Medscape Conference Schedule



Legal

What if an HIV-infected pregnant woman refuses treatment?

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known adverse effect to mother, fetus or infant outweighs benefit to the woman. If the woman consents to ARV therapy, the general practice is for her to take 100mg of zidovudine (otherwise known as AZT) five times daily after fourteen weeks of gestation and then intravenously during labor.³ She should also be counseled regarding the possible benefits of a cesarean section in lowering the risk of HIV transmission to her child and the risk of HIV infection through breast feeding.⁴

While these are good guidelines to follow, imagine the following scenario: A pregnant woman is present in your office for treatment. She agrees to take an HIV test and the results come back positive. The guidelines are followed and she is counseled regarding the benefits of ARV therapy for her and her unborn child. However, the patient is concerned about the potential side effects of the medication. She then decides not to receive the ARV therapy.

Is she allowed to refuse medical treatment?

Yes. The Supreme Court has determined that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment.⁵ This liberty interest is found in the Fourteenth Amendment and is weighed against any relevant state interests to determine whether a patient's constitutional rights have been violated.⁶

A pregnant woman generally has the same right to refuse medical treatment, unless a state claims that its interest in protecting the fetus is greater. One factor in determining whether treatment can be forced is the invasiveness of the procedure.⁷ Most courts have upheld the right of a pregnant woman to refuse to have a cesarean section, even if it means that her unborn child might be harmed.⁸ Some courts have even ruled in favor of the pregnant woman when less invasive procedures, such as blood transfusions, have been prescribed.⁹

The patient's right to refuse ARV therapy would thus depend on the degree of invasiveness of the therapy. At first glance it appears that the therapy is non-invasive in nature due to the fact that it involves taking medication five times a day. However, if the patient has to be physically forced to take the medication

five times a day for as much as five and a half months, or forced to take a drug intravenously during labor, ADV therapy might be considered substantially more invasive than a one-time blood transfusion.¹⁰

Can she be forced against her will to receive treatment regardless of her refusal?

There are currently no states that mandate that a pregnant woman receive treatment for HIV symptoms. A state can enact a law mandating medical treatment under its police powers if such a law has a real or substantial relation to protecting the public health and safety.¹¹ The state's police power has been upheld in the past to trump individual freedoms only when intervention is necessary to contain epidemics and other widespread outbreaks.¹² This has occurred in areas such as mandatory smallpox vaccination and the quarantine and isolation of persons with infectious and communicable diseases, such as pulmonary tuberculosis.¹³ In both of these instances the courts agreed that the states had an interest in preventing the spread of disease to the general population. The courts have also used this public health rationale in one AIDS-related case to uphold the shutting down of a bathhouse in New York.¹⁴ However, it can be argued that due to the way HIV is transmitted, pregnant women and newborns pose significantly less risk to the public than a bathhouse.¹⁵ Mandatory treatment therefore appears to go beyond what is necessary to protect the public, particularly when there are less intrusive means such as educational programs available.¹⁶

Can I have the woman arrested for intentionally exposing her fetus to the HIV virus?

Under Louisiana law, it is unlawful for someone to expose another person to the AIDS virus without the knowing and lawful consent of that person.¹⁷ Arkansas also criminalizes the exposure of a person to the AIDS virus through either sexual penetration or the parenteral transfer of blood or blood products.¹⁸ The Mississippi legislature has yet to enact a so-called intentional exposure statute.¹⁹

Prosecuting a pregnant woman for intentional exposure depends on whether

the statute in question covers unborn persons. Recently several states have encountered a similar issue in the context of women who took illegal drugs during their pregnancies. If the fetus was considered a legal person under the state's laws, the prosecutions were successful.²⁰ In Louisiana, a fetus is not considered a person for the state's homicide statutes, so it is unlikely that an unborn child would be considered a person for the intentional exposure statute.²¹ In Arkansas, the homicide statutes cover unborn children, but specifically exclude the mother from criminal liability, and other criminal statutes do not include fetuses as persons.²² In Mississippi, which does not have an intentional exposure statute, persons who test positive for HIV are often served with quarantine orders, but the typical order focuses on sexual activity and sharing blood products, not maternity.

What if I tell the patient that if she does not take this treatment while she is pregnant, her baby will also be HIV-positive?

In counseling a patient regarding ARV therapy, one must be careful to give all of the facts concerning treatment. Another doctrine of law, known as the right to informed consent to medical care, has developed to require that consent to all medical treatments be: 1) knowing; 2) voluntary; and 3) competent.²³ For consent to be knowing, information regarding treatment alternatives, including rejecting treatment, must be in language as simple as necessary for the particular patient to understand.²⁴ To satisfy the voluntary element of the informed consent doctrine, a doctor or other health care professional must not attempt to direct the result, nor must there be any evidence of coercion, duress, undue influence, or deceit.²⁵ Voluntary consent also means that doctors or other medical professionals must not withhold or give inaccurate information.²⁶ Lastly, the patient must be deemed competent to make an informed decision regarding her medical treatment. For example, if the patient denies that she is HIV-positive, despite documentation that confirms her positive status, she could be deemed incompetent to make informed medical decisions and treatment could be mandated for her benefit and the benefit of her unborn child.

If a patient is told that her child will be HIV-positive if she does not undergo ARV



therapy, she is not getting the whole picture. Because HIV antibodies cross the placenta barrier during pregnancy, all babies born to HIV-infected mothers will test positive for the virus at birth and for several months thereafter.²⁷ However, studies have shown that only 25% of children born to HIV-positive women who do not receive ARV treatment during their pregnancy will become infected with the virus themselves.²⁸ If a patient is not given complete information regarding ARV therapy and its impact on her unborn child, then her consent could not be considered voluntary, and therefore not informed. A better tactic, perhaps, would be to stress the benefits of taking the therapy on her and her unborn child, making sure to include possible risks and side effects.

What if she tells me that it is against her religion to take the ARV therapy?

Religious objections to medical treatment are protected by the Free Exercise clause of the First Amendment and therefore are usually honored, even for pregnant women. Most court decisions have involved the pregnant woman's refusing to have a C-section or a blood transfusion during labor. The courts have focused on the individual's right to refuse treatment and the right to informed consent, and generally have upheld the patient's wishes if the patient poses no risk of injury to another person (particularly if the person is a fetus).²⁹ Only in rare instances have courts compelled a pregnant woman to accept medical treatment when doing so violated her religious beliefs. Even when the woman's decision to refuse treatment could harm the fetus, some courts have honored the woman's decision.³⁰

Isn't it child abuse for the mother to refuse treatment during her pregnancy? Can't the state step in?

Probably not. Most jurisdictions do not consider fetuses children for these purposes. In Louisiana, children are defined as natural persons in the Children's Code, so a fetus is not covered.³¹ In Mississippi, infants and minors are also defined as natural persons, thereby excluding unborn persons.³²

Doesn't the unborn child have legal rights?

Only to a limited extent. The landmark Supreme Court case of *Roe v. Wade* that held that a woman had a fundamental right to privacy and to an

abortion also recognized that a state has a compelling interest in both the safety of the mother and the well being of the fetus.³³ *Roe* established the doctrine that the state has an important and legitimate interest in potential life at the time a fetus becomes viable.³⁴ An abortion can only be performed after viability if it is necessary to preserve the life or health of the woman.³⁵ Subsequent cases have replaced *Roe's* trimester framework with an undue burden standard, which is less strict.³⁶ It could be argued that forcing a woman to take medication five times daily in the guise of protecting the fetus would be unduly burdensome on the mother.³⁷ Moreover, even though there is a state interest in a developing fetus, a woman who chooses to continue her pregnancy and not abort does not give up her right to control her own body.³⁸

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If this patient continues to refuse ARV therapy for her child after it is born, can she be charged with child neglect and the baby be taken away from her?

Probably not. A competent parent is generally empowered to consent to medical treatment for an unemancipated minor.³⁹ Parents can be charged with child neglect or child endangerment if they deprive their children of adequate health care.⁴⁰ The courts, however, will scrutinize closely the basis for the parent's decision. In 1997, the state of Maine attempted to get a child protection order seeking custody of *Nikolas E.*, a four-year-old boy who was HIV-positive, because his mother (who was also HIV-positive) refused to permit her son to participate in highly aggressive anti-retroviral therapy (HAART).⁴¹ *Nikolas'* mother had consulted extensively with two doctors regarding the therapy prior to making her decision.⁴² She also had the experience of having another HIV-positive child die while taking the same drug therapy.⁴³ The Maine Supreme Court determined that the mother's decision was rational and

reasoned and since the benefits of the therapy were unclear, it was up to the mother to make the informed choice to delay the therapy. Therefore, the mother's decision to delay drug therapy did not constitute serious parental neglect that merited a child protection order.⁴⁴

A similar problem emerges however, when the parent denies treatment to her/his child due to religious reasons. This issue has not been encountered directly as of yet, but the general rule is that the right to practice religion freely does not include liberty to expose the child to ill health or death.⁴⁵ A state may be able to force treatment depending upon the degree of harm to the child or community if the procedure is not performed.

What if the patient is in denial of her child's HIV status?

If a patient denies that her child is HIV-positive despite supporting evidence, she might be deemed incompetent to make medical decisions for her child and the state might be able to order her to submit the child for treatment. This was the case in *A.D.H. v. State Department of Human Resources*, where the state of Alabama ordered a mother to submit her child for HIV treatment.⁴⁶ The court concluded that the mother was incapable of making a well-reasoned, rational decision regarding treatment that was in the best interest of her child due to her adamant belief that her child was not infected with HIV.⁴⁷

Conclusion

As more and more women of child-bearing age test positive for HIV, clinicians will be faced with questions concerning proper treatment for both the mother and the child. In most cases, the clinician will be limited to advising the mother about treatment options, and will have only limited recourse if the mother decides against receiving treatment during pregnancy. Clinicians may urge the mother to receive treatment, but misrepresenting the benefits of treatment or the pitfalls of failing to take medication arguably will invalidate the patient's consent. Attempting to have the pregnant woman arrested for intentional exposure or some sort of child abuse will probably not be successful without some change in statutory law which in any event might run afoul of Constitutional guarantees. Even after the child is born, it will be difficult to force a parent to approve treatment for the child, unless there is

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good reason to believe that the parent is incapable of making informed judgments about the child's well-being.❖

FOOTNOTES

1. Ark. Code Ann. '20-16-507 (Michie 1997). A medical practitioner who treats a pregnant woman must draw blood from her to test for syphilis, HIV and hepatitis B. If the woman objects to the test, then her objection must be documented in her medical record.
2. Guidelines for Use of Antiretroviral Therapy in Pregnancy, from material developed by the National Pediatric and Family HIV Resource Center (NPRHC), New Jersey, December 2000.
3. Id. There are other acceptable regimens.
4. Id.
5. Cruzan v. Director, Missouri Department of Health, 479 U.S. 261, 278 (1990).
6. Cruzan, 497 U.S. at 279.
7. Samantha Catherine Halem, At What Cost?: An Argument Against Mandatory AZT Treatment OF HIV-Positive Pregnant Women, 32 Harv. C.R.-C.L. L. Rev. 491, 506 (Summer 1997).
8. See In Re A.C., 573 A.2d 1235 (D.C. Ct. App. 1990) and Baby Boy Doe v. Mother Doe, 260 Ill.App.3rd 392; 632 N.E.2d 326 (Ct.App. April 1994).
9. Fetus Brown v. Darlene Brown, 689 N.E.2d 397 (Ill.App. 1997).
10. Halem, 32 Harv. C.R.-C.L. L. Rev. at 508. Halem also notes that the only way to enforce treatment would be with a parole-type situation.
11. Jacobson v. Massachusetts, 197 U.S. 11, 25, 31 (1905).
12. 32 Harv. C.R.-C.L. L. Rev. at 509.
13. See Jacobson and In re Halko, 54 Cal. Rptr. 661 (Ct.App. 1966).
14. See City of New York v. New Saint Mark's Bath, 497 N.Y.S.2d 979 (NY Sup.Ct. 1986).
15. In fact, HIV-positive pregnant women will only pass the virus on to their newborn 25% of the time without treatment. 32 Harv. C.R.-C.L. L. Rev. at 511.
16. Id.
17. La. Rev. Stat. Ann. '14:43.5.
18. Ark. Code Ann. '5-14-123 (Michie 1997).
19. So far the only such conviction under Mississippi law has occurred in a case where the defendant was charged with violating a health department quarantine order. See Carter v. Mississippi, No. 1998-KA-01497-COA, 199 WL 1034827 (Miss. App. 1999).
20. Whitner v. State of South Carolina, 492 S.E.2d 777 (S.C. 1995) and In Re Unborn Child, 683 N.Y.S.2d 366 (N.Y. Fam. Ct. 1998), held that a fetus was a person, while Wisconsin ex rel. Angela M.W. v. Kruzicki, 561 N.W.2d 729 (Wis. 1997) and Commonwealth of Kentucky v. Connie Welch, 864 S.W.2d 280 (Ky. 1993), held that a fetus was not a person under that state's laws. The court in Reinesto v. Superior Court of the State of Arizona, 894 P.2d 733 (Ct.App.Az. 1995), declined to uphold a child abuse charge for conduct that harmed a fetus (injecting heroin).
21. See State of Louisiana v. Gregory Keller, 592 So.2d 1365 (1st Cir.1991).
22. Ark. Code Ann. '5-1-102 (13) (B) (Michie 1997).
23. Suzanne Sangree, Control of Childbearing by HIV-Positive Women: Some Responses to Emerging Legal Policies, 41 Buff. L. Rev. 309, 364 (Spring 1993).
24. Sangree, 41 Buff. L. Rev. at 366.
25. 41 Buff. L. Rev. at 369.
26. Id. See also Olga Salgo v. Leland Stanfor Jr. University Board of Trustees, 317 P.2d 170, 181 (CA Ct. App. 1957).
27. Jennifer Brown, A Troublesome Maternal-Fetal Conflict: Legal, Ethical, and Social Issues Surrounding Mandatory AZT Treatment of HIV Positive Pregnant Women, 18 Buff. Pub. Interest L.J. 67, 69, (2000).
28. Brown, 18 Buff. Pub. Interest L.J. at 70-71.
29. Francis J. Fosmire v. Denise J. Nicoleau, et al., 551 N.E.2d 77, 81-82 (Ct.App. 1990).
30. See A. C., 573 A.2d 1235 and Baby Boy Doe, 632 N.E.2d 326, 330. The Appellate Court of Illinois went

- so far as to say that the potential impact of the woman's decision on the fetus is not legally relevant. Doe, 632 N.E.2d at 332. Courts have differed with regard to blood transfusions and pregnant women. Some like In Re Fetus Brown, 689 N.E.2d 397, have held that a blood transfusion is an invasive procedure and thus a state cannot override a pregnant woman's decision.
31. LSA-Ch.C.art.603.
 32. Miss. Code Ann. '1-3-21, 1-3-27, 1-3-39.
 33. Roe v. Wade, 410 U.S. 113, 162-163 (1973).
 34. Roe, 410 U.S. at 163-164.
 35. Id.
 36. See Planned Parenthood v. Casey, 505 U.S. 833 (1992).
 37. 32 Harv. C.R.-C.L. L. Rev. at 519-520. To mandate treatment under the abortion line of cases might also invoke a slippery slope wherein states could forcibly regulate all aspects of a woman's pregnancy, such as making sure a woman does not smoke or drink alcohol while pregnant.
 - 38.18 Buff. Pub. Interest L.J. at 85.
 39. See Miss. Code Ann. '41-41-3 (2001).
 40. See LSA-Ch.C. Art. 655.
 41. In Re Nikolas E., 720 A.2d 562, 563 (Me. 1998).
 42. Nikolas E., 720 A.2d at 563.
 43. Id.
 44. 720 A.2d at 565, 567.
 45. Prince v. Massachusetts, 321 U.S. 158, 166-167.
 46. AD.H. v. State Dept. of Human Resources, 640 So.2d 969 (Ala.Civ.App. 1994).
 47. A.D.H., 640 So.2d at 971.

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by James Zachary, MD, Delta ETC faculty member and staff physician, MCL HIV Outpatient Program (HOP) Clinic

Palm Platform Guide to Antiretroviral Dosing, including Food and Drug Interactions

by James Zachary, MD, Delta ETC faculty member and staff physician, MCL HIV Outpatient Program (HOP) Clinic



Pharmacy

Some foodborne pathogens can hasten progression of HIV

Tina Edmunds-Ogbuokiri, PharmD, FASCP

Infections from common foodborne pathogens are responsible for a large number of AIDS-related illnesses. These illnesses range from mild to very severe and even to life threatening. The human body ordinarily is well equipped to deal with these bacteria, but in patients who are immunocompromised such as those with AIDS and HIV, a far greater risk of serious illness exists. Once contracted, these infections, with their severe symptoms of vomiting and diarrhea, can be difficult to treat and may reoccur. This can weaken the immune system, hasten the progression of the HIV infection and prove fatal for persons with AIDS.

The progression of HIV can be hastened by gram negative enteric pathogens which are responsible for a large portion of foodborne illnesses. Monocytes and macrophages produce the cytokine human tumor necrosis factor alpha (TNF α), in response to bacteria. This cytokine can cause activated expression of HIV-1. It has been suggested by several workers that TNF causes or contributes to the severe cachexia which is seen in the HIV wasting syndrome. It has also been determined that gram negative enteric pathogens, including those present in food, are triggering agents of other illnesses including reactive arthritis and Reiter's syndrome, possibly due to these induced levels of TNF α . Other studies have suggested that neurological conditions like Guillain-Barré can be triggered by *Campylobacter jejuni*. Therefore, these potent pathogens existing in food can greatly increase the level of morbidity and mortality by activation of HIV-1 infections, induction of reactive arthritis, Reiter's syndrome, and possibly Guillain-Barré syndrome.

The bacterial pathogens responsible for providing the most prevalent threat to persons with AIDS and HIV include *Salmonella enteritidis*, *Listeria monocytogenes*, *Campylobacter jejuni*, *Escherichia coli* and *Vibrio vulnificus*. *Salmonella* bacteria, especially *S. enteritidis*, are the most common causes of foodborne illness. Salmonellosis occurs almost 100 times more frequently in persons with AIDS than in healthy individuals. In AIDS patients, *Salmonella*

infections can be difficult to treat and are more likely to lead to serious complications. Symptoms of infections are flu-like with vomiting, nausea, abdominal cramps and diarrhea. These can appear in 6-48 hours after exposure and last up to one week. Foods most associated with salmonellosis include raw or undercooked meat, poultry, fish and eggs.

Listeriosis is caused by *Listeria monocytogenes* and can be acquired from a variety of foods, including soft cheeses that are unpasteurized, and some ready-to-eat foods like hot dogs or deli meats. *Listeria* infections in AIDS patients are usually severe and are often fatal. Symptoms are flu-like with chills, fever, headache, and possibly nausea and vomiting. These early symptoms can appear 2-30 days after exposure and result in bacteremia, meningitis or encephalitis.

Campylobacter jejuni causes campylobacteriosis which presents as an acute abdominal pain, diarrhea, nausea, headache, muscle pain, and fever. Symptoms can begin two to five days after eating contaminated food and last usually seven to ten days. This illness occurs 35 times more frequently in persons with AIDS. *Campylobacter* is most commonly found in raw or undercooked poultry, unpasteurized milk and non-chlorinated water.

Escherichia coli is a major cause of bloody and non-bloody diarrhea, resulting in as many as 20,000 cases and 250 deaths per year in the United States. Additionally, *E.coli* O157:H7 infection is the most common cause of the hemolytic uremic syndrome, the leading cause of acute kidney failure in children in the United States. The syndrome is associated with long-term complications including endstage renal disease, hypertension, and neurologic injury. *E.coli* is found in undercooked ground meat, lettuce, raw cider, raw milk, and untreated water.

Vibrio vulnificus is a naturally occurring bacterium in coastal brackish waters of the United States. *V. vulnificus* is present in high numbers in seawater that has a temperature greater than 20° C and salinity between 0.7%-1.6%. During the summer months, the incidence of infection rises dramatically. Patients with HIV are at an unusually high risk of infection that leads to severe morbidity and mortality in 45%-75% of patients. *V. vulnificus* damages the gastrointestinal wall and is

transported rapidly across to invade the blood stream and cause primary septicemia. Symptoms include fever, chills, skin lesions, nausea, vomiting, diarrhea, hypotension and shock. Raw oysters, other raw shellfish, and open wounds exposed to seawater are the primary source of *Vibrio*.

Food safety counseling for the HIV-positive patient should be provided to each and every patient as the risk from foodborne illnesses from these pathogens can be greatly reduced by a small number of precautions in the selection, preparation and storage of foods. It is of even greater importance as the knowledge of this risk seems to be lacking among the HIV population. In a survey published in *AIDS Care*, only 25% of HIV-infected patients reported receiving information on food safety, despite the fact that 74% of the subjects had modified their diet since learning of their HIV status (mainly for nutritional reasons). Therefore, the importance of food safety information for immunocompromised patients should not be underestimated. It is a powerful tool for decreasing illness and morbidity in HIV infection.

The critical points of counseling include shopping for safe foods, correctly storing food, proper cooking techniques and preparing safe leftovers.

Shopping for safe foods

When shopping for raw and cooked perishable foods, it is very important to make sure the food is being stored at a safe temperature in the store. Perishable items should not be selected from a non-refrigerated aisle display. Torn or leaking packages should not be chosen. When ordering foods from the deli counters, make sure the clerk washes his hands between handling raw and cooked items, or wears plastic gloves. Cooked ready-to-eat items should not be touching raw items or displayed in the same case. Persons at risk may want to avoid the deli counter altogether. The sale of food products with damaged packaging, the unsafe displaying of products (such as cooked shrimp in the same bed of ice as raw seafood), workers with poor personal hygiene, and unsanitary store conditions can increase the risk of foodborne illness. Not only should these products or even stores be avoided, the conditions should be reported to the local health authorities.

See Foodborne illnesses next page



Foodborne illnesses, from pg. 7

For persons with AIDS, it is especially important to read food labels to select foods that pose the least risk of food poisoning. For example, all milk and cheese products should have the word "pasteurized" on the label. Products that contain any raw or undercooked meat or dairy products should be avoided. Any "use by" and "sell by" dates should be observed. Of course, products should not be used past the expiration date.

Also, the order and manner in which items are placed in the shopping cart are important. It is a good idea to put packaged meat, poultry or fish into a plastic bag before placing the items into the shopping cart. This prevents drippings from coming in contact with other foods, reducing the risk of cross-contamination (bacteria from one food contaminating another food). The refrigerated or frozen items should be placed in the cart last, and taken home immediately. These cold items should be placed in the coolest part of the car for the trip home. If the items are held in the car for more than 30 minutes, store in an ice chest to keep cold.

For shelf-stable foods, cans that are dented, leaking, bulging or in cracked glass jars should not be purchased. All tamper-resistant safety seals should be intact and safety buttons down without making a clicking noise when pushed.

Correct storage

Chilled and frozen foods should be placed in the refrigerator or freezer as soon as possible. Storage of foods in the car, office, or carrying them with you for even a few hours can raise the temperature of foods enough to allow the bacteria to grow. Refrigerator temperature needs to be at 40° F or below and the freezer temperature needs to be at 0° F. An important tool for the HIV/AIDS patient in achieving food safety is the purchase of several thermometers. This is extremely cost-effective advice, as it can lead to prevention of costly illness and/or hospitalization.

Proper storage in the refrigerator involves routinely checking the thermometer for the correct and safe temperature. Also, the patient needs to make sure thawing juices from meat and poultry do not drip on other foods. Eggs need to be left in their carton for storage and not placed in the door of the refrigerator. Ground meat, poultry, and fish can be stored in the refrigerator for one or two days, other red meats for three to five days. The refrigerator needs to be kept clean.

Proper storage in the freezer again involves routinely checking the thermometer for the correct and safe temperature. Freezing foods keeps food safe by preventing the growth of microorganisms that cause both food spoilage and foodborne illness. However, once the food begins to thaw, the microorganisms again become "alive" and can cause an illness if not properly thawed. Therefore, when thawing food always place the food in the refrigerator as bacteria multiply rapidly at temperatures of 40°F to 140°F.

For proper storage in the pantry, canned foods and other shelf stable products should be stored in a cool, dry place. These items should never be placed above the stove, under the sink, in a damp garage or basement, or any place exposed to high or low temperature extremes. Highly acidic foods such as tomatoes and other fruit can be stored up to 18 months while low acid foods such as meat and vegetables can be stored for two to five years.

Safe cooking techniques

Hands, utensils, can openers, cutting boards, sponges and countertops should be washed with hot, soapy water before and after contact with raw meat, poultry or fish. It is especially important to wash all utensils and your hands with soap and hot water after handling one food and then handling another. This helps prevent cross-contamination. The kitchen towels and cloths also should be washed in hot water in the washing machine.

Plastic or glass surfaces should be used for cutting raw meat, fish and poultry as wooden cutting boards are difficult to clean thoroughly, allowing cross-contamination to occur. Different cutting boards for other foods such as fruit and bread is a good idea. Cutting boards need to be washed with hot, soapy water after each use, then air dried or patted dry with clean paper towels. Wooden, glass and plastic cutting boards should be sanitized with a solution of one teaspoon liquid chlorine bleach per quart of water. The surface is flooded with the bleach solution and allowed to stand for a few minutes, then rinsed and dried.

Properly cooking food allows the heat to kill the bacteria. The meat thermometer is an important tool to ensure complete cooking has occurred. Meat, fish, eggs, and casseroles should reach at least 160°F; whole poultry at least 180°F and poultry breast at least 170°F. Juices in done ground meat and poultry will run clear when thoroughly cooked. Cook the stuffing for turkey or chicken separately

from the poultry instead of inside the bird. Brown paper bags should not be used for roasting as they are not sanitary. Avoid very low oven temperature roasting methods (below 300° F) and long overnight cooking of meats, as this encourages the growth of bacteria before cooking is complete. When basting or applying a sauce during grilling or broiling, the sauce should be brushed on cooked surfaces only. Care needs to be taken to avoid contaminating fully cooked meat with a brush used on partially cooked food.

Any raw or undercooked meat, poultry, fish or eggs should not be eaten. This includes sushi, oysters on the half-shell and foods containing raw eggs like Caesar salad. Fresh fruits and vegetables should be washed and placed in the refrigerator to reduce spoilage. Pasteurized eggs should be used in place of shell eggs when making homemade ice cream, eggnog or mayonnaise. When cooking eggs, the yolks and whites are firm, not runny. Several cooking times and temperature for eggs include:

- Scrambled—1 minute at a medium stovetop setting (250°F for electric frying pans)
- Sunny side—7 minutes at medium setting (250°F) or cook covered for 4 minutes at 250°F
- Fried, over easy—3 minutes at medium setting (250°F) on one side, then turn and fry for another minute on the other side
- Poached—5 minutes in boiling water
- Boiled—7 minutes in boiling water.

Microwave cooking requires special precautions as a "standing time" is necessary after the cooking period to ensure an even temperature throughout the food. Additionally, many microwave dishes must be removed from the oven and stirred from time to time. Therefore, it is important to heat pre-cooked foods evenly and thoroughly, whether in an oven or a microwave to obtain sufficient heat uniformly.

Preparing safe leftovers

Bacteria on food left out at room temperature will quickly begin to multiply at temperatures between 40°F and 140°F. This temperature range is called the "danger zone." Food will become unsafe in a matter of hours and therefore should not be left out for more than *two hours*. Leftovers should be divided into shallow containers to ensure rapid, even cooling. Airtight lids, plastic wrap or aluminum foil should be used to cover the containers. Leftovers need to be stored in the refrigerator at 40°F and used within three to four days.

To reheat leftovers, thoroughly heat in a conventional or microwave oven or on the stove top. It is very important when reheating in the microwave to cover, rotate and stir foods once or twice. All leftovers should be heated to 165°F. A meat



thermometer tested in several places of the food should be used to ensure all areas reach at least 165°F. Sauce, soup and gravy should be reheated to a rolling boil for at least one minute. Even though the food was once cooked, bacteria from the air or people's hands can contaminate the food.

Food safety while dining out

Dining out can also pose a serious threat of infection for the AIDS patient. Persons with AIDS need to avoid the same foods in the restaurants as they would at home. Always order food well done and do not eat anything medium or rare. To determine if meat is done, cut into the center of the meat. If it is pink or the juices are not clear (bloody), the meat should not be eaten. Fish should be flaky, not rubbery when cut.

Caesar salad should not be eaten as it has raw eggs. Fried eggs should be cooked on both sides, not sunny side up. Any scrambled eggs which are runny should be avoided.

Raw seafood should be completely avoided. This includes oysters on the half-shell, raw clams, sushi and sashimi. Lightly steamed seafood, such as mussels and snails, should also be avoided.

Food safety while traveling abroad

Persons with AIDS need to take additional precautions when traveling abroad as the same high standards of hygiene used in the United States are not applied everywhere. All water needs to be boiled before drinking. Only beverages made with boiled water or canned bottled drinks are safe to consume. Ice should be made only from boiled water. Any uncooked vegetables and salads should be avoided. All fruit should be peeled. Cooked foods need to be eaten only while still hot.

Good rule of thumb: Boil it, cook it, peel it or forget it!!!

Safe water

Additionally, drinking safe, clean water is especially important for persons with AIDS. Water can also be a source of microbes which can cause illness. Using bottled water instead of tap can be a good choice depending on the quality of the bottled water. Bottled water is regulated by the U.S. Food and Drug Administration (FDA) and is labeled bottled water only if it meets or exceeds federal, state and industry standards. For a list of the bottled water exceeding government standards, patients can call 1-800-WATER-11.

One of the microbes that can be present in water is *Cryptosporidium*, a single-celled microorganism residing in animals. The animals serve as carriers which enable it to contaminate the water supply. In humans, it can cause cryptosporidiosis, a devastating illness of explosive diarrhea and cramping after a 7 to 14 day incubation period. Death can be the end result, especially for an immunocompromised individual.

To make sure bottled water does not contain this organism, water should be treated with one or more of the following methods: reverse osmosis, micron filtration or ozonization. Reverse osmosis forces water under pressure through membranes that remove 90% of dissolved minerals and contaminants. Micron filtration is a process that moves water through extremely fine filters to remove the particles. However, a one micron filter is needed to adequately remove *Cryptosporidium*. Ozonization uses ozone gas instead of chlorine to clean the water without leaving a taste, color, or odor in the water.

Important points to remember for safe bottled water:

- Always check with the bottled water company to determine the processes they are using.
- Use safe, bottled or boiled water for ice cubes, concentrated fruit juice, coffee and tea.
- Water should be taken with you to restaurants, work and when you visit other people.
- Be careful of fruit juices, drinks made from concentrates and soda fountain drinks when out.
- All filters should be changed in the water purification systems according to the instructions to prevent a backwash of contaminants.
- All point-of-use water filters must be labeled "NSF-certified 53 for cyst removal" to ensure the removal of *Cryptosporidium*.

Additional information can be obtained by calling Centers for Disease Control (CDC) National AIDS Hotline-toll free 1-800-342-2437 (7 days a week, 24 hours a day).

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Psychosocial, from pg. 10

Rarely did a week go by without discussing hospice care with someone or preparing significant others for the impending death of their loved ones. This is not to make death seem like an insignificant issue today, however the sheer volume of patients dying nine years ago made it seem more overwhelming.

The future

"In the future, authors will take a long time to get to the point. That way the book looks thicker"—Dilbert, 1997.

OK, so what's MY point (aside from seeing my name in print)? Clearly mental health services have changed in the past nine years and these have coincided with changes in the disease. (I know, you're thinking I must be some kind of genius to have figured this out!) There really is no point other than to share some observations of my experiences over this time frame. I can only speculate that most of the changes in mental health services are in some way connected to the shift in the mind set from viewing HIV as a terminal disease to now being a chronic disease, whether the evidence supports this or not. We're talking perception here. Clients seem less motivated to examine their lives and make major changes in personality and behavior. Therapy is less insight oriented and less existential for the same reasons. The provision of mental health services at HOP now seems to be more crisis oriented, with brief therapy being the order of the day. This is often an exciting and challenging method of providing therapy, and isn't unusual in the private sector of mental health treatment, with many managed care providers limiting clients to brief therapy. This also isn't necessarily a bad thing if you consider that many of the services offered nine years ago were so centered on death and dying. Now we just have to worry about the Borderline Personality Disordered client whose only goal is to disrupt and split the staff while maintaining the victim persona while all crumbles around him/her! That is a good thing, right?

Now, about my slides from the Smoky Mountains...

Danny Sansovich is a Mental Health Specialist in the HIV Outpatient Program (HOP) of the Medical Center of Louisiana.



Psychosocial

Much has changed in the last nine years at one HIV clinic

Danny Sansovich, MSW

I've just recently started my 10th year as a social worker at the HIV clinic where I work. While consolidating office items to move to a new location (you know, throwing stuff away, like all those unread journal articles that seemed so important to keep!), I came across a file containing the names of patients seen for psychotherapy during my first couple of years at the clinic. It was interesting to see how things have changed so much over the past nine years relative to mental health services and I thought it might be worth sharing observations about these changes. Of course it may turn out that this retrospective look is just as boring to readers as looking at my vacation slides from the Smoky Mountains, so be forewarned. This is your last chance to turn back!

Brief history

So, you've decided to take this ride after all, eh? When I first started at the clinic, there were approximately 1400 full time patients receiving care for HIV/AIDS. About half had an AIDS diagnosis based on either a CD4 count of less than 200 or a history of an AIDS-defining opportunistic infection. HAART therapy was non-existent with AZT the primary treatment to combat the HIV virus. Patients at the clinic *looked* very sick and they were. KS was very common, as was wasting, PCP, CMV, dementia, cryptosporidium, and other diseases that had noticeable physical symptoms. The building that was used for HIV care was one of the oldest buildings on the campus. Exam rooms were shared by two to three primary care providers at the same time. Privacy was limited to the thickness of the curtains pulled around the exam tables. Approximately 15-20 patients died every month, with some months having as many as 30 deaths. These were the ones we knew about.

Today there are approximately 3300 patients being treated at the clinic. About a third meet some criteria for an AIDS diagnosis. HAART therapy is the rule for most. Patients look better. Spending a day in the HIV patient waiting areas might look like any other clinic waiting room in the hospital system. Diseases with obvious physical symptoms do still occur but they are much less visible. The clinic

now has 18 private exam rooms for primary care, in addition to areas for procedures, lab work, IV treatments, x-ray and dental referrals. The clinic even has its own pharmacy. There are about 10-12 deaths a month. This may still sound high, but considering the much higher patient count, this number is a considerable improvement.

Mental health services

In the old days (when I had to walk to school 15 miles in the snow, we only had three TV stations, ...oops, wait...that's for another article!!), mental health services were provided by social workers and clinic psychiatrists. The psychiatrists were mainly providing medication management of psychiatric symptoms. The social workers were doing psychotherapy, primarily through individual or group formats. Almost all of the social workers did psychotherapy. Referrals for psychotherapy came through primary care providers, psychiatrists or social workers.

Group Therapy

There were five to seven active social work-led therapy groups in the first four years I worked at the clinic. My "group practice" alone routinely had 15-20 weekly participants. Most of the therapy groups were open ended non-thematic groups, with occasional closed topical therapy groups such as victims of sexual abuse. Other social workers doing groups had similar levels of participation. Many of the therapeutic issues focused on self esteem and the stigma of HIV, grief, death and dying, other feelings of loss or abandonment, and anger associated with all of the above. There was a feeling of urgency to resolve personal issues for many of the patients in group therapy because so many patients were dying and many didn't want to die angry and bitter. Ironically for some, this heightened sense of mortality was motivation to seek help for changing self-destructive behaviors and instill a desire to have some sense of "peace" in their lives before they died.

Currently, there are no active psychotherapy groups and it's probably been about four years since the last therapy group ended. The clinic does have support groups, including two for addiction, a men's group, and a palliative care group which at best attract a combined total of about 20 participants.

The actual number is more often closer to 12 combined regulars.

Individual therapy

The changes in the number of clients receiving or seeking individual therapy mirror the same characteristics described above for groups. Most of the social work staff (four to nine years ago) had individual clients who had issues similar to the group therapy population, but who felt more comfortable in an individual therapy setting.

Presently, there are one social worker and one psychologist doing individual therapy, and four psychiatrists who primarily provide psychopharmacological services with occasional opportunities for individual therapy. Many of the referrals to the mental health social worker (moi) are for initial psychiatric assessments with follow up referrals to psychiatry.

Substance abuse

Addiction and substance abuse have always been factors in the lives of many clinic patients. What has changed over the last nine years is the mortality rate of patients with polysubstance use and abuse issues. Initially, many of the patients with drug and alcohol problems weren't living long enough for substance abuse therapy. Frequently, patients with addictive disorders were "clean" by default simply because they became too critically ill to use. Today, patients with drug and alcohol problems are living longer. The number of patients seeking treatment has remained consistently low relative to the number of patients with problems. Our clinic currently has a psychiatrist who is also an addictionologist offering addiction support groups. Although tools for addressing addiction have increased, it remains perhaps the single most stressful issue facing providers in every discipline at our clinic.

Grief, death and dying

Perhaps no category of mental health services has changed more over the last nine years than issues surrounding death and dying. This is not a bad thing! Many of the clients in individual and group therapy were faced with the fear of their own death, or were dealing with the death of partners, friends, and family members. Often these clients were dealing with multiple losses in a short period of time.

See Psychosociabn page 9



Mental Health

HIV clinicians face special issues in the area of informed consent

Penelope W. Dralle, PhD

The Acute Response Team of the Medical Center of Louisiana in New Orleans' (MCLNO) Ethics Committee answers requests for consultations throughout the hospital system. One of the most frequently occurring consults concerns issues surrounding a patients' ability to give or refuse to give consent for medical interventions.

During the last century, a number of legal cases have been initiated by patients and/or their families against physicians and health care providers demanding that they (the patients) have the right to say what treatments they will or will not accept. Beginning with the case of *Mary E. Schloendorff v. the Society of the New York Hospital* (1914), the courts have generally upheld the right of individuals to make their own decisions. In this case, the patient agreed to an examination under anesthesia but not to the removal of the tumor. The surgeon removed the tumor against her specifically expressed wishes and was found guilty of committing assault. (For a brief review of the history of informed consent, see Hana Osman, MSSW, *History and Development of the Doctrine of Informed Consent*, Vol. 4:41-47, 2001, *The International Electronic Journal of Health Education* site at (<http://www.iejhe.org/paid/2001/osman.htm>).

The underlying ethical or philosophical principle of consent is based on the concept of autonomy, which is derived from the Greek words *autos* meaning self and *nomos* meaning rule, or governance. Two conditions are usually required for autonomy: liberty or independence from controlling influences and agency or the capacity for intentional action. (See Tom Beauchamp and James Childress's Chapter 3 in *Respect for Autonomy in Principles of Biomedical Ethics Fourth Edition*, Oxford University Press, New York 1994, for a more complete explanation.) The legal or constitutional guarantee of this right is based on the right to liberty and the protection of privacy. As the relationships among physicians and patients have changed over the decades, the nature and form of agreements to treatment have also changed. Today physicians are generally required to involve their patients in decisions about their care and to inform them of options and consequences of these options. The doctrine of informed

consent now serves as the standard for health care decision making rather than the standard of care based on benevolent decision making by physicians alone.

The necessary elements for informed consent listed by Beauchamp and Childress (1994) are: 1) disclosure of information; 2) understanding; 3) voluntariness; 4) competence; and 5) consent. Although each of these elements is an important topic for discussion, competence is the one that appears to be most difficult to assess in many health care settings and one that deserves special attention in an HIV-infected population. Competence is the ability to perform a task and may also be a legal determination made by a judge. Usually adults are considered competent unless otherwise determined by a judge. In determining competence in medical settings, it is useful to think of specific tasks that are involved rather than trying to make a determination of competence in general. Most often in cases of informed consent in a health care setting, the relevant issues revolve around the persons' abilities to express or communicate preferences or choices, understand their situation and its consequences, understand relevant information, give reasons for their choices, preferably rational reasons that are related to the risk/benefit of the various options, and reach a reasonable decision. The relevant issue then becomes evaluating the patients medical decision-making capacity.

Marc Tunzi, M.D., provides a number of illustrative cases and highlights four instances in which health care providers should be more thorough in their assessment of capacity to make relevant decisions. ("Can the Patient Decide? Evaluating Patient Capacity in Practice," July 15, 2001, *American Family Physician* site at www.aafp.org/afp/20010715/299.html).

The four cases are: 1) when there has been a sudden or abrupt change in mental status; 2) when patients refuse recommended treatments without being willing to discuss their reasons or reasons are misinformed or irrational; 3) when patients consent to extremely risky or invasive procedures with no consideration of risks and benefits, and 4) when patients have a known risk factor for poor or impaired decision-making, such as certain neurologic or psychiatric conditions, limited cognitive skills or educational level, significant language or cultural differences,

an acknowledged fear or suspicion of health care institutions or are below 18 years or above 85 years of age.

When considering the demographics relating to cultural and language issues of HIV-infected clients and the progression of HIV disease and symptoms, it becomes clearer why health care providers working with these patients need to be highly attuned to issues of informed consent and decision-making capacity. For example, of the 42,156 patients with AIDS during the year 2000, 47% were black non-Hispanic, 19% were Hispanic, and about 2% were other minorities (CDC-NCHSTP-DHAP:HIV/AIDS Surveillance Report-Vol. 12, No.2). In addition, a major mode of transmission has been and continues to be injection drug use. There is also a higher than average comorbidity with use of other intoxicating drugs which impairs cognition and judgment both acutely and chronically. Finally, there are multiple neurologic and psychiatric symptoms that can appear during the course of HIV infection, including a prevalence of AIDS Dementia Complex of up to 66% of patients in advanced AIDS cases.

Thus there are many cultural and language issues that could be barriers to true informed consent. In addition, high rates of cognitive impairment, especially in persons in more advanced stages of HIV-disease progression and those with a history of or continued use of substances, necessitate a careful and on-going assessment of capacity to make informed choices regarding treatment options. One other consideration that is particularly applicable in the HIV-infected population has to do with choices of surrogate decision makers if and when patients are no longer able to make or express their desires. Hospital policy dictates the relational status of surrogate decision makers when no legal documents such as Medical Power of Attorney have been completed. This list does not address the specific needs of same sex couples. In a follow-up article, I will review some practical guidelines for determining decision-making capacity and suggestions for determining thresholds applicable to different types of medical decisions. ♦

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Nursing

Advanced HIV care planning: how to begin “the” conversation

Harlee Kutzen, MN, ACRN

Death remains a taboo subject in our society. It is unpleasant for most adults to discuss while we are healthy and strong, and few health care professionals are comfortable discussing the possibility of death with a person who is not well. Maybe that is just it, we talk about death as if it were a “possibility” and not a certain outcome for each of us at some time.

Working within HIV care, we discuss many forbidden subjects. We think nothing of demonstrating the details of female condom insertion, teaching ways to reduce transmission risk during anal and oral sex, counseling victims of domestic abuse, rape, and incest, and are aware of the extensive criminal and drug use histories of many of our patients. Yet, do we know how they wish to die? Where they wish to die? What life goals are more important to them than their adherence to antiretrovirals? If you do not know the most recent answers to these questions, you may need to improve your skills in advanced HIV disease planning.

It is important for HIV care professionals to learn how to initiate a discussion on end-of-life planning and patient-determined goal setting. It is equally important to know what to do with that information once it has been shared. This article will explore both issues.

There are many myths about discussing end-of-life issues which perpetuate our avoidance of such planning. Understanding such myths, and learning the facts about advanced disease planning will help decrease the common barriers to palliative care.

Myth: Discussions about the seriousness of our patient’s condition should be withheld until all viable treatment strategies have been exhausted.

Fact: Some patients do not live long enough for all viable treatment options to be completed. Factors such as patient intolerance of medications, limited adherence to the medication regimen, knowledge capacity of patient to comprehend scheduling and need for medications, viral resistance to current treatments, and lack of interest in complex antiretroviral and infection treatment strategies affect overall prognosis. There are also life threatening co-factors such as

substance use, co-infections and social factors which can affect the length of a person’s life. Some of our patients die of sudden onset conditions even though their viral load is suppressed and immune status is improved. Recently, many of our newly diagnosed patients are presenting very ill at their time of diagnosis, compounding the complexity of initial care planning.

Myth: Patients and families do not think about the possibility of death unless we tell them to do so.

Fact: Most patients who are diagnosed with HIV fear death as a final outcome of their infection. They worry about wasting, and about not being able to hide their advancing condition. They worry about their changing levels of energy and their ability to care for themselves as well as their dependents. They fear pain and other uncontrolled symptoms, dependence on others, caregiver burden, and being alone in their final days.

Myth: Health care providers are comfortable initiating discussions on end-of-life planning.

Fact: Often physicians, nurses, and social workers defer death-related conversations until the patient’s condition is very advanced. It is also common to transfer the responsibility of this conversation to one specific team member who has demonstrated interest and/or skill in discussing approaching death. Unfortunately, when the discussion gets deferred over time, planning needs may be inaccurately assessed, and families may regret not being informed of expected changes.

Myth: Physicians give truthful and direct answers to the patient’s request for prognosis estimation.

Fact: Often out of nervousness, the physicians and primary care team members may stumble over end-of-life planning discussions and explanations of hospice care. Physicians frequently avoid open and ongoing discussions about prognosis, advancing disease, and end-of-life care planning. Physicians with more clinical experience are generally more familiar with the natural course of advanced HIV disease and tend to integrate end-of-life planning in their primary care approach.

Myth: Discussing end-of-life issues are painful and will upset the patient and family.

Fact: Health care providers generally desire to reduce harm and pain. Fearing emotional reactions of patients and families perpetuates avoidance behaviors and nervousness regarding end-of-life discussions. This myth serves as a barrier to the families’ understanding and acceptance of palliative care and hospice services. Often when patients question their prognosis, providers may tell them to “Think more positively” or “Let’s wait for the next viral load result before we start talking about *that*,” or “If you would just take your medications as prescribed, you will get better and live longer.” Most often, providers have been known to tell their patients, “Stop thinking like that now,” or bargain with patients to “Take your medicines or else you will die!” The frank truth remains, there is no cure for HIV and many of our patients *will* die.

Myth: Explaining hospice care is the best way to address end-of-life planning options with patients and families.

Fact: In our society, hospice care continues to mean giving up all medications and getting ready to die. If the health care providers begin a conversation about hospice care without first learning the patient’s perception of the current status, there is a great chance of the patient and family refusing such care. There is more to learn about regarding the patient’s and family’s preparation for increasing disability and dependent care than simply referring to a hospice. For example: Has the patient drawn up a will and assigned a health care proxy? Does the patient have a living will? If so, who has a copy? Is the physician willing to honor this document? Is there a plan for child, dependent adult, or pet care when the patient is no longer able to provide this care? Is there designated guardianship for children? Does friction exist between the patient’s family of origin and family of choice? If so, what are their concerns?

Even the most end-of-life experienced team members should not go into the patient’s room and introduce themselves with an introductory speech about how wonderful hospice care is. If the family does not have a chance to explore their own issues, develop a rapport with their health care team member, most referrals will be refused. When this occurs, the patient and



family frequently deny their need for palliative support, cling to hope for a miracle, or shut down emotionally and avoid further discussion.

This next section provides a scripted question guide to be used for patient and family assessment and planning for advanced disease care and end of life decision making.

End-of-life planning discussions should:

- Assess patient's and family's knowledge of diagnosis and prognosis, fears and concerns regarding advancing HIV disease, and meaningful goals
- Facilitate patient and family discussion of responses to questions
- Acknowledge this conversation as the beginning of a process of understanding changing needs and desires in care planning
- Identify unmet needs and facilitate appropriate referrals
- Engage the interdisciplinary team in care planning guided by the patient's priorities
- Provide support and assurance for optimal quality of life now and at end of life for both patient and family
- Lessen patient and family anxiety about end-of-life clinical decisions

The responsibility for initiating advanced disease and end-of-life planning does not reside with any specific discipline of the interdisciplinary team. Learning how and when to discuss these issues is an essential skill for all team members.

Begin by sitting down near the patient and family, preferably at eye level. Explain that you understand they have been living with HIV for some time and that you would like to know how they are "really" doing. Explain that understanding more about their feelings and concerns will help the team plan for their expressed care priorities.

"What has your medical team told you about your condition? What does this information mean to you?"

The patient's and family's responses to these questions are generally very revealing. Often the patient may state that he/she is getting worse, or not getting better, but the medical team is telling the patient to expect to get better. If the patient responds with little emotion or simply restates the medical team's words, ask "What is your body telling you about how you are doing?" This question prompts a more introspective response and guides future questions for additional information. For example, it is

increasingly common for individuals to experience the desired response to antiretroviral therapy regarding their immune markers, yet feel a diminished quality of life secondary to chronic pain or profound fatigue. In these cases, individuals often state, "My doctor is very pleased with my lab results, but I still feel like I am dying."

"Tell me about your good days... What are you able to do on those days?"

The content of this response is very important because the patient and family will let you know what gives them pleasure in their lives. By explaining unique points of enjoyment and meaning, the health care team can learn how available such pleasurable activities are to the patient and family. It is also a way for them to face the realities of how long it has been since they have had several consecutive "good days."

For example: When a patient identifies a deep satisfaction in attending church activities several times a week, we should know if and when he/she has recently been able to attend these activities. If the patient and family identified barriers such as transportation, fatigue, or fear of social stigma as inhibiting access to church, the interdisciplinary team can assist. Note, we can gain trust and understanding with our clients by acknowledging the loss of a meaningful aspect of their lives and arrange assistance with transportation to church. Most importantly, we gain understanding of how removed the patient and family are from important replenishing activities.

"When is the last time you had a day like that in the past two months?"

This question is really assessing the degree of changes in physical strength, independence, and endurance over time. It can help patients to refer back to the most recent holiday, since that is often a period of time that stands out for most people (such as Easter, Christmas, birthdays, etc.). They can recall where they were, what they wore, ate, and how they felt at the end of their activities. Because prognosis estimation is often connected to increasing weakness, assisting the patient and family to answer this question aloud helps them state in their own words how and in what ways things may be different now. This begins the patient and family's personal process of self disclosure of important changes in energy and needs in the present tense, thus enhancing realistic planning.

"Have you had any bad days lately? What makes them bad?"

Today, health care providers are concerned with viral load, tolerance and adherence to medications, and weight stability. We sometimes forget to ask the patient what defines their hard times. Listening carefully to the response, we learn not only about the patient's and family's priority concerns, but about chronic symptoms impairing quality of life that we may not have been aware of prior to this discussion. The response also lends to identification of need for outside assistance such as on-call nursing support, child care and respite assistance.

"What kind of assistance do you need on days when you do not feel well?"

In general, most individuals and families do not like to depend on other people for care and assistance. They are often concerned about being a burden, inconveniencing others, and fearing they will use up their "personal favors" too soon. Give the patient and family permission to fantasize about what kinds of things may be helpful. It may be as simple as a community case manager's arranging for the patient's children to be picked up at school when the patient does not have the endurance for this task, or as complex as arranging 24-hour care for several days while the caregiver attends to health or out-of-town personal business.

"If your condition worsens, do you wish to go back to the hospital?"

Traditionally, we tell patients, "If you get worse, go to the Emergency Room." This is fine if there is an acute infection or an event that will respond well to emergency attention. But the person with advanced HIV who has been hospitalized a number of times may not want to go back to the hospital. In fact, many people in more advanced stages of HIV disease often admit that they went back to the hospital only because their caregivers were scared or not ready for them to die.

"What are your most meaningful goals at this time in your life? Is there anything we can do to help you achieve them?"

Adults and children all have meaningful life goals. Some people are very open to discussing their goals, others have barely whispered them to their closest confidant, if at all. This is the time to learn what is most important to this patient. Identifying the patient's immediate and important goals will entirely guide care planning. We only need to ask about them.

See Advanced planning next page



Advanced planning, from page 13

CASE EXAMPLE:

From 1985-1999, our clinic provided HIV primary care to an incredibly courageous, soulful, and smart young lady named "Codi." At 16 years of age, she had already lost her father, mother, and common-law stepfather to AIDS, and was becoming very advanced in her illness. She was frequently hospitalized, self administered her 28 different medications, and was not ready to die until her most personal wish had been fulfilled. Most healthy adults think a young lady of her age would want to go to the prom, or have a first date, or graduate from high school. What "Codi" wanted most of all was to have her first menstrual period, so that when she died, she would die a "woman." Much to her pleasure, she was able to start on hormones. After a short period of time, she developed signs of the secondary sex characteristics she so desperately desired, including her first menstrual cycle, and died a "woman."

From a different perspective, a patient who is very clear about a desire to attend an adult child's wedding in three weeks may benefit greatly from several blood transfusions to optimize physical strength and attention. In every case, learning the patient's desires will guide care, treatments, and community referrals.

"In the event of your death, is there anyone or anything that you are worried about?"

When thinking of the possibility of our own death, sometimes it is less stressful for us to think of the needs of others rather than ourselves. This pertains to children and other loved ones, including cherished pets, plants, or any other kind of life form that would suffer during a patient's hospitalization, long term placement and the patient's death. Sometimes, a hospital stay provides a trial run for future custody or referral information. At other times, discussing these concerns is simply a way for the patient to express anticipatory grief for meaningful aspects of life and the need to know that these will be cared for. When both a patient and his/her partner are living with advanced HIV, the partner who believes he/she is going to die first always worries about who will care for the other partner. This is important information that can be included by advising a hospice referral about the availability of hospice bereavement. It may be a great

comfort for the patient to know that the loved one will be supported.

"Where would the patient like to die? Where would the family like the patient to die?"

Most people have a clear idea of how they wish to die, and also how they would not like to die. In an effort to reduce near death emergency crises, it is important to learn of each person's fantasy and fears about death. Some people may wish to die at home in their own beds, but the family may feel they may never be able to sleep in the house again if death occurs there. In this case, the family may wish to honor the patient's desire to stay at home as long as possible, but want to take the patient to the hospital or a setting outside the home when he/she is very close to death.

"Have you ever heard of a medical power of attorney or a health care proxy?"

Assignment of a health care proxy to make medical decisions on their behalf is an important safeguard for patients to assure their end-of-life wishes will be honored. The patient should select a person who knows and understands his/her personal desires for quality of life decisions that will affect the direction of care. More important than a living will, decisions made by the health care proxy (as designated by the Medical-Power-of-Attorney document) must be honored by law.

Living wills are merely a statement of desires in case the patient is no longer able to participate in this decision making, but the decisions do not by law have to be honored by the physician. A living will does not always address the complex decisions required in situations of initiation or withholding of dialysis, antibiotic or other therapies. Primary medical providers for the patient need to know the health care proxy. Providers should inform them of the patient's condition and options for care so they can make decisions from the most informed perspective possible.

"Do you have a living will? Who in your family is aware of it and has a copy?"

Although a living will is not the best means of communicating end-of-life decisions, it is very helpful for the patient, the health care proxy and the provider. The act of completing the living will form demonstrates a clear and deliberate desire to not have life prolonged beyond its natural limits, and holding of invasive life-

sustaining interventions. A true copy of this document should be placed in the patient's chart in the hospital, group residential facility, extended care, and home-based care settings.

"Are you having any chronic pain or distressing symptoms?"

Most health care providers hope to control quality of life-impairing chronic symptoms, however, we must not forget to regularly reassess the symptom needs. At an advanced stage of any disease, chronic symptoms not only serve as a reminder of advancing illness and provide a negative distraction from enjoying the limited length of life available, but also become internalized as an intense task of spiritual work. Almost every person who experiences chronic distressing symptoms for any length of time begins to wonder, "Why this is happening to me?" With all the HIV-related stigma issues, guilt and fear of transmission, life review of past events, leaving loved ones behind, and facing an untimely limitation of life expectancy, it is important to free one's body of distractions to accomplish whatever soul work is necessary. It becomes impossible for a person to relish quality time with loved ones or to complete important tasks while constantly struggling with nausea, pain, diarrhea, itching, or other uncontrolled symptoms. We have an obligation to relieve physical suffering in order to enable the soul work to be addressed.

"What can we do to make your life more comfortable/manageable?"

Listening to the patient's and family's responses, repeating back their words and letting them know you have heard them provide a powerful act of validation for patient and families when clear, reasonable requests have been stated. It is most important to respond with concrete assistance for identified needs as quickly as possible. It may be as simple as letting the patient return home before the weekend to be with family and completing future tests on an outpatient basis. Or it may be as complex as arranging for minors to visit in a room with contact isolation. Be prepared to take notes on the patient's expressed desires and bring them to the interdisciplinary team for discussion on ways to meet these wishes and needs.

Once all of the above questions have been explored, explanations of hospice, home care, assisted living resources, and other options for advanced disease care can be discussed. Gleaning from the content of this conversation, health care providers should have learned about the



patient's and family's concerns about the burden of care, approaching death, the presence of distressing symptoms, and after-hour on-call needs. By listening to the patient and family recall the frequency of good days versus bad, the pace of progression to death can be estimated.

By using the patient's and family's words, personal examples of concerns, and personal priorities, the same wording can be used in explaining hospice, home care and long term care. For example:

"Hearing that you wish to stay home and not return to the hospital, we would like to refer you and your family to a program of care designed specifically for patients and families in your condition."

"This program is designed especially for people who are living with advanced illness, who wish to stay home, and may need after-hour on-call assistance to stay comfortable. Nurses are available 24 hours a day for support and guidance. They are specialists, knowing how to help individuals and families be as comfortable and as strong as possible at home."

"This service offers a nurse who is an expert in pain and symptom management, and knows how to prevent symptoms from getting out of control. The nurse will help educate you and your family on what to expect with time. Sometimes learning what is natural and expected can be very calming."

"There is also a social worker who specializes in care of people who have been living with HIV for a long time. They will provide support and referrals to community resources as you need and desire. Home health aides are also trained to work with people with weakness and advanced disease. They can assist with bathing, changing of bed linens and other personal care several times a week. Spiritual support services are also available as desired. All of the services are designed to support your comfort and confidence at home. Additional services of spiritual support, volunteers, and bereavement are also available. You also maintain your primary relationship with your doctor or nurse practitioner."

"This special program is called hospice. We believe this program is just right for your needs at this time. If your needs change and you no longer need this special support, you may be discharged. If you receive services and you decide this is not the type of care you want, you may be discharged at any time. But for right now, we believe this program is right for you at this time."

These questions offer an orderly sequence to patient/family assessment of advanced disease planning needs. For the newer clinician, using a guide such as this may be helpful whereas more experienced clinicians have developed their own style of patient and family interview on these matters.

Sometimes, patients and families refuse hospice care at the time it is offered. This is frustrating for the referrers because they often want the patient to benefit from the clinical expertise, on-call availability, support services and anticipatory grief work prior to the active phases of dying. In these cases, we must evaluate the degree to which we have given the patient and family the freedom to choose between home care and hospice with their full understanding of the differences.

If we allow patients and families to refuse hospice care prior to our assessment and discussion of their needs and hopes for care, we have done them disservice. Sometimes, we can take the approach of actually writing out a prescription for hospice care. Sometimes it is helpful to remind patients with whom we have long-term care relationships that

we continue to be as invested in their best interest as ever.

Because of the terminal nature of hospice care, young people are often comforted by knowing that if hospice care does not feel right, they can leave the program. It is important to remind patients and family members of the fact that HIV is an unpredictable disease, and that "at this time" we believe hospice care is best to meet their needs. The mere acknowledgment of a "living discharge" from hospice can reduce the greatest barrier to hospice acceptance. If in the future they become stronger, or if they no longer need or wish to continue the hospice services, they may be discharged. ❖

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PalCare Pocket Guide: Initiating Advanced HIV Disease Option Planning

What has your medical team told you about your condition? What does this information mean to you?

Tell me about your good days. What are you able to do on those days?

When is the last time you had a day like that in the past two months?

Have you had any bad days lately? What makes them bad?

What kind of assistance do you need on days when you do not feel well?

If your condition worsens, do you wish to go to the hospital?

What are the meaningful goals for you at this time? Is there anything we can do to help you achieve them?

In the event of your death, is there anyone or anything that you are worried about?

Where would you like to die? Is that okay with your family? Where does your family want you to die?

Do you have a medical power of attorney assigned, or a health care proxy to make decisions if you cannot?

Do you have a living will? Who in your family is aware of it and has a copy?

Do you have chronic pain or any distressing symptoms?

What can we do to make your life more comfortable?



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▲ Origins of the Desire for Euthanasia and Assisted Suicide in People with HIV-1 or AIDS: a Qualitative Study [Lavery JV et al. *Lancet* 2001;358:362]

▲ Value of Patient Self-Report and Plasma Human Immunodeficiency Virus Protease Inhibitor Level as Markers of Adherence to Antiretroviral Therapy: Relationship to Virologic Response [Duong, M., et al. *CID* 2001;33:386]

▲ Effect of Cessation of Highly Active Antiretroviral Therapy during a Discordant Response: Implications for Scheduled Therapeutic Interruptions [Hawley-Foss, N. et al. *CID* 2001;33:344]

▲ Clearance of Fungal Burden during Treatment of Disseminated Histoplasmosis with Liposomal Amphotericin B versus Itraconazole [Wheat, L.J., et al. *AAC* 2001;45:2354]

▲ Postoperative Morbidity Associated With Cesarean Delivery Among Human Immunodeficiency Virus-Seropositive Women [Rodriguez, E.J., et al. *Am J Obstet Gynec* 2001;184:1108]

▲ The Etiology of Community-Acquired Pneumonia at an Urban Public Hospital: Influence of Human Immunodeficiency Virus Infection and Initial Severity of Illness [Park DR et al. *JID* 2001;184:268]

▲ Antiretroviral Treatment Simplification with Nevirapine in Protease Inhibitor-Experienced Patients with HIV Associated Lipodystrophy [Ruiz L et al. *JAIDS* 2001;27:229]

▲ Detrimental Effects of Continued Illicit Drug Use on the Treatment of HIV-1 Infection [Lucas, GM, et al., *JAIDS* 2001;27:251]

▲ A Pilot Trial of Indinavir, Ritonavir, Didanosine, and Lamivudine in a Once-Daily Four-Drug Regimen for HIV Infection [Mole L et al. *JAIDS* 2001;27:260]

▲ Nelfinavir, Efavirenz, or Both After the Failure of Nucleoside Treatment of HIV Infection [Albrecht MA et al. *NEJM* 2001;345:398]

▲ Hepatitis C Virus Infection-Related Morbidity and Mortality among Patients with Human Immunodeficiency Virus Infection [Monga HK et al. *CID* 2001;33:240]

▲ The importance of bacterial sepsis in intensive care unit patients with acquired immunodeficiency syndrome: Implications for future care in the age of increasing antiretroviral resistance [Rosenberg AL et al. *Crit Care Med* 2001;29:548]

▲ Growth Hormone Shrinks Fat Deposits in HIV Lipodystrophy [Internal Medicine News 6/15/01 page 29]

▲ Risks to Health Care Workers in Developing Countries [Sagee-Moses C et al. *NEJM* 2001;345:538]

▲ Influence of Human Immunodeficiency Virus Infection on the Course of Hepatitis C Virus Infection: A Meta-Analysis [Graham CS et al. *CID* 2001;33:562]

▲ Investigation of Primary Human Immunodeficiency Virus Infection in Patients Who Test Positive for Heterophile Antibody [Walensky RP et al. *CID* 2001;33:570]

▲ Implants Limit HIV Wasting Facial Change [Walsh N. *Internal Medicine News* 8/15/2001 p. 24]

▲ Effect of Mutations in Pneumocystis carinii Dihydropteroate Synthase Gene on Outcome of P. carinii Pneumonia in Patients with HIV-1: A Prospective Study [Navin TR, et al. *Lancet* 2001;358:545]

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