

## **Clinical Observations and Notes**

April 28, 2004

### **Aids And Long Term Care**

With the improvement in the treatment of AIDS seen over the past several years, the condition has more and more come to resemble a chronic illness, where survival over a period of many years after diagnosis is now quite achievable. In fact, AIDS patients are living long enough and well enough that they are prone to the same other chronic illnesses that are seen in the rest of the general population.

There is increased recognition that patients who are middle aged and older may develop AIDS from sexual contact. Estimates have been made that perhaps 10% of the AIDS population is now over the age of 55.

Therefore, it should come as no surprise that the population of patients with AIDS in long term care (LTC) facilities is rising. There are many facilities in Maryland that now regularly care for patients with AIDS.

This office has recently investigated two complaints that have revealed important problems in the care of AIDS patients. In both cases AIDS drugs were involved. In one case the patient did not appear to suffer harm. In the second case, the patients appeared to be seriously harmed, perhaps permanently.

1. A 45-year old female patient with a long history of AIDS was transferred from a hospital to a Maryland long term care facility for care and rehabilitation of a skin lesion. At the time of discharge from the hospital, the patient was taking three different AIDS medications. Because of a lack of clarity in the transfer documents from the hospital, the patient was placed on only one of the three anti-AIDS drugs that had been provided to her in the past. In ensuing weeks, the attending physician asked for an Infectious Disease consultant to readjust the medication; but the consultant, for reasons that were unclear, never came to see the patient, and the request was not followed up. A nurse practitioner in the facility then noted the problem. Three weeks after this person's observation, the patient was seen at an AIDS specialty clinic where proper treatment was reinstated. The patient had thus been on mono-therapy instead of triple drug therapy for about 8 weeks.

Triple drug therapy was restarted by the AIDS clinic staff. Subsequent laboratory studies of the virus showed no important mutations had occurred as a result of the missed drugs. The patient showed a continuing response to therapy, seemingly not adversely affected by the prolonged interruption in her drug regimen in the long term care facility.

We can consider this patient to be fortunate. Interruption of part or all of an AIDS drug regimen frequently leads to the development of resistance by the AIDS virus to medications. The virus can mutate very quickly under such circumstances. This

frequently results in other anti-AIDS drugs needing to be substituted for those drugs not properly taken. This can be a very serious complication of inadequately treated AIDS.

2. A 38-year old female patient with a long history of AIDS was transferred to a long term care facility for rehabilitation. This patient was also on triple therapy for her AIDS. Several weeks after admission, the patient was noted to become lethargic and her food and drink intake markedly decreased. Renal function studies that had been normal, showed progressive deterioration over a period of 8 days. The attending physician was notified and a renal consultation was requested. As in the first case, the consultant did not come to see the patient and there was no follow up. The patient was seen in her regular AIDS follow-up visit where she was noted to be very unkempt and ill appearing. Blood tests drawn in the clinic that day did not return before the patient had been returned to the long term care facility where she was recognized to be acutely ill. She was transferred to a nearby emergency service that night where she was found to be severely dehydrated, with a BUN of 151 and a creatinine of 9.1. The patient was admitted and dialyzed. She remains on dialysis, months after this admission.

This patient needed extra oversight because of the drugs she was taking for AIDS as well as other chronic illness. AIDS drugs can cause serious side effects about which those administering the drugs must be aware.

**Comment:** The treatment of AIDS has become extremely complex, with some 20 drugs now approved and available for use in the United States. The philosophy behind the treatment has evolved over the past 8 years and now multi-drug cocktails are routinely prescribed, combining various classes of AIDS drugs. Close attention must be paid to certain blood tests, such as the CD4 and viral load. Patients may be put on various prophylactic drug regimens as these blood values change and if patients become symptomatic. The AIDS drugs themselves can cause interactions with other medications being taken by the patient. Further, these drugs can cause symptoms resembling AIDS.

The two cases above demonstrate important errors in care that should not have happened, whether or not the patients had AIDS. In both cases, important patient needs were identified, but there was no follow up by requested consultants and no obvious efforts to obtain consultants promptly. In case #1, weeks passed before a medication error noted by two health care practitioners was corrected by a visit to an outside clinic. In case #2, no consultant was called despite the apparent intention to do so and despite a rapid deterioration in the patient's clinical situation. In neither case did there seem to be an awareness of the importance of the anti-AIDS drugs being taken by the patients.

AIDS is a disease that will respond to treatment if the providers are current and skilled in the treatment of the condition. Where providers are not dealing with the disease on a regular basis, it is not reasonable to expect that they will be able to keep up with the changing treatment of the disease and recall how AIDS treatment may complicate other, more typical diseases found in long term care settings.

Another issue about which facilities need to be aware is that patients with AIDS have a much higher probability of either contracting tuberculosis de novo or of having old tuberculous infection activate. Facilities need to be sure of AIDS patient TB skin testing status as well as issues of non-reactivity that occur with AIDS. There may also be a need to give prophylactic anti-tuberculosis drugs.

The challenge then is for LTC facilities to determine how staff caring for patients with AIDS can be afforded expert consultation in a routine and effective way. A consultant expert in AIDS who sees patients in a LTC facility might help. Another method used by the Moore Clinic at the Johns Hopkins involves telemedicine between the Clinic and each Maryland state prison. The patient/prisoner sees and is seen by a Hopkins consultant, without the very expensive need to move the patient.

The need for staff education can be met by using resources available at Johns Hopkins and the University of Maryland where HRSA funded training programs provide training for staff about HIV and AIDS treatment issues. Program directors are Ms. Carrie Wallace at the University of Maryland training program (410-328-6330) and Ms Ellen Rappaport (410-614-2234) at the Johns Hopkins training program. Each program director has advised me that they are available to institutions that want to consider AIDS training and educational updates for their staff, at all levels. Bruce Gilliam, MD, Medical Director of the University of Maryland AIDS treatment clinics and Patricia Barditch-Crovo, MD of the Hopkins Training Program are available for phone consultation on specific patients.

A national “warm line” can be accessed at 1-800-933-3413 for answers to specific questions about care of individual AIDS patients. Another important information source is the Preventive Exposure Program (PEP) whose number is 1-888-HIV-4911, for questions relating to care of providers who may have been exposed to the AIDS virus. There is further voluminous and growing information on the Internet.

All of these services are available without charge.

The OHCQ expects that facilities will provide oversight on patients with AIDS that will permit them to receive current and timely care for this complicated but treatable condition. Physicians and other staff not caring for AIDS patients on a regular basis need to be provided support and regular updates. Help is readily available.

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