

29. **Robert M. Wachter, John M. Luce, Phillip C. Hopewell, Critical Care of Patients With AIDS, JAMA- India, Vol. 10, No. 6, 543-522, 1992**

### **Decision making about Intensive care for Patients with AIDS**

Since the beginning of the AIDS epidemic, we and others have recommended that informed patient refusals of life-sustaining treatment be respected. Such guidelines are consistent with the ethical principle of respecting patient autonomy and the legal requirement of informed consent. In San Francisco, many patients with AIDS have expressed their preferences regarding life-sustaining treatments and these preferences have usually been decisive. However, it is not known how many patients with AIDS who receive critical care were, in fact, given the opportunity to forgo such care. We do know that with other diseases and in other geographical areas, patient preferences about life-sustaining treatments are often not elicited or respected.

It is an accepted tenet of biomedical ethics that physicians are under no obligation to provide futile care. The application of this principle is problematic, however, since reasonable patients and clinicians may disagree as to whether a given situation represents futility. In the case of life-sustaining treatments for patients with PCP and respiratory failure, the outcome is now better than that of other situations for which clinicians routinely offer ICU care. Therefore, with uncommon exceptions (such as a wasted hypoalbuminemic and demented AIDS patient with severe respiratory failure from recurrent PCP), critical care for AIDS patients cannot be deemed futile unless we are willing to alter our concept of futility when caring for patients with other diseases carrying similar prognoses. The point is that futility is defined by prognosis and not by disease.

When patients are incompetent to make decisions and therefore unable to make known their preferences regarding critical care (and when such care is not futile), physicians should act according to the previously expressed wishes of their patients. Since these wishes are best ascertained when patients have completed a living will or selected a surrogate decision maker, all AIDS patients should be encouraged to make their preferences known before the need for life-sustaining treatment arises. In cases where an incompetent patient has not made his or her preferences known and no reasonable surrogate is available, clinicians should be guided by the patient's best interests.

Patients or clinicians, knowing that withholding support is ethically and legally no different than not initiating it, may opt for critical care at first, reassessing its benefits and burdens over time. Such a strategy is perfectly reasonable. However, all parties involved in such decisions should understand that, with the exception of patients who deteriorate soon after bronchoscopy, an ICU stay of less than 10 days is probably inadequate to predict the outcome of mechanical ventilation for PCP and respiratory failure. If the decision is made to discontinue mechanical ventilation, the patient's comfort becomes the overriding concern. In these cases, abandonment, pain, and dyspnea must be combatted as aggressively as was PCP before the choice was made to withdraw life-sustaining support.

## **Future Issues in the Critical Care of AIDS Patients**

It is difficult to predict whether the number of admissions for AIDS patients with PCP and respiratory failure will continue to rise. On the one hand, the widespread availability of effective antiviral therapies and PCP prophylaxis should lead to fewer new cases of PCP. On the other hand, the number of AIDS cases is still rising and will continue to do so for at least the next decade. Although zidovudine and PCP prophylaxis are available, such therapy is only partially effective, and life-long compliance with medicines cannot be assured. Perhaps most important, the new optimism shared by patients and clinicians about the outcome of critical care for PCP specifically and AIDS generally (because of effective antivirals and opportunistic infection prophylaxis) can be expected to result in more clinicians offering, and more patients accepting, life-sustaining treatment when such treatment is medically indicated. On balance, we expect the increase in ICU admissions for AIDS and respiratory failure to be moderated, but not abolished, by the availability of effective therapies.

Moreover, as antiviral therapy and prophylaxis against opportunistic infections improve and the life expectancy for people with AIDS lengthens, AIDS patients may require intensive care for increasingly diverse indications, including tuberculosis, other bacterial infections, lymphomas, and neurological events.

The ICU is the most expensive site for the provision of medical care. In one study, while the average hospitalization for AIDS treatment cost \$9024 (in 1984 dollars), the average hospitalization that included at least 1 day in the ICU cost \$23360. Therefore, the extent to which critical care is used for AIDS patients will have an important impact on health care costs. Because nearly one fourth of AIDS hospital admissions are "self-pay," which generally means the patients are without insurance, communities at the epicenter of the epidemic will find it increasingly difficult to find adequate resources to pay for the care of persons with AIDS, especially when such care includes use of the ICU.

With the cost of health care in the United States continuing to increase, pressure to ration the availability of expensive critical care will undoubtedly grow. Such rationing decisions involve complex social choices and should be debated openly and based on a reasoned assessment of the benefits and burdens of alternative uses of scarce health care resources and not on prejudice against certain classes of patients or on fear of transmission in the health care setting. The recent improvement in the outcome of intensive care for patients with AIDS represents a small victory, one that will be Pyrrhic if such care is denied to patients for whom it is indicated and desired.