Fact Sheet

HIV-Associated Dementia Complex

Definition

HIV-Associated Dementia Complex (also known as AIDS Dementia Complex) is a progressive neurological disorder that can affect persons who are infected with the Human Immunodeficiency Virus (HIV). HIV-Associated Dementia Complex (HAD) is thought to be a subcortical dementia and is characterized by cognitive, motor and behavioral impairments severe enough to interfere with an individual's ability to function occupationally or socially.

Facts

Although the precise incidence and prevalence of HIV-Associated Dementia Complex is uncertain, it has been estimated that as many as two-thirds of individuals with AIDS will develop dementia or related neurological disorders. The leading hypothesis regarding HAD is that it is caused by direct infection of the brain by the Human Immunodeficiency Virus (HIV), the cause of AIDS. In 1987 the Centers for Disease Control included HIV-Associated Dementia Complex as a primary diagnostic condition that warrants a diagnosis of AIDS.

Symptoms

The early manifestations of HIV-Associated Dementia Complex may include:

- **Cognitive**: Memory loss (difficulty recalling appointment times, telephone numbers, or names), impaired concentration (trouble keeping track of conversations or completing thoughts), and mental slowing (not as “quick” as usual, slower at responding to questions).
- **Motor**: Difficulty with gait, balance, coordination, leg weakness, clumsiness and deteriorating handwriting.
- **Behavioral**: Impaired judgment (impulsive behavior, poor decision making), personality changes (apathy, social withdrawal, irritability), mood changes (extreme highs and lows, anxiety, emotional outbursts), and occasionally psychotic behavior (hallucinations, suspiciousness, grandiose thoughts).

As the disease progresses, people with HIV dementia may become increasingly confused, weak and lethargic, and develop severe memory loss. Each person experiences these changes at different rates and not everyone develops all of these manifestations. The onset and course of dementia is also variable, with some persons sustaining stable mild dysfunction for long periods of time, and others exhibiting steady worsening within a few months.

Diagnosis

The symptoms of HIV-Associated Dementia Complex can resemble those of other medical and emotional problems. Some of these problems arise from treatable opportunistic infections such as toxoplasmosis or cryptococcal meningitis or from other treatable disorders such as depression, anxiety, nutritional deficiencies, recreational drug use and the side effects of medication.

In order to diagnose HAD and treat any reversible causes of dementia, a thorough medical and neuropsychiatric evaluation is recommended for anyone suspected of having neuro-
logical complications related to HIV. The evaluation usually includes a physical and neurological exam, blood tests, neurological procedures (e.g., lumbar puncture, EEG, CT scan) and neuropsychological testing.

**Treatment**

Although there is currently no cure for HIV-Associated Dementia Complex, recent studies have shown that Azidothymidine (AZT) may help to improve attention, fine-motor coordination and memory. Additional antiviral therapies and the possible effectiveness of protease inhibitors are being explored.

In addition, a “treatment plan” usually consists of making the situation more manageable for the caregiver and the person with HAD. For instance, various strategies can be utilized to help individuals compensate for and minimize the impact of lost abilities. Providing memory aids (calendars, clocks, lists), structuring the environment to maximize safety and familiarity (keeping home uncluttered, placing photographs around the house), and using verbal and non-verbal cues (saying the person’s name, maintaining eye contact) are all ways to minimize over-stimulation and keep the person oriented.

Supportive and personal care services provided at home or in other residential settings are also available to aid families and friends caring for someone with HIV-Associated Dementia Complex. Respite care, day programs, transportation, housekeeping and related community resources can help provide for basic physical, social and emotional needs and assist in alleviating the burden of care.

Caregivers can often benefit from individual counseling, group therapy and/or support groups. Sharing information and discussing feelings of frustration, fear, loneliness, guilt and depression with others can help decrease feelings of isolation and validate the caregiving experience. Legal assistance also may be necessary to plan for the financing of care, arrange surrogate decision-making and to protect the rights of partners.

**Recommended Readings**


*Caring, Commitment, and Choices*, Yas Branden, et al., 1994, National Association of People With AIDS. Available from Bridge Builder Media, 150 S. Washington St., Suite 204, Falls Church, VA 22046-2921. (800) 878-8422.


**Credits**


Resources

Family Caregiver Alliance
425 Bush Street, Suite 500
San Francisco, CA 94108
(415) 434-3388
(800) 445-8106 (in CA)
Web Site:  http://www.caregiver.org
E-mail:  info@caregiver.org

Family Caregiver Alliance supports and assists caregivers of brain-impaired adults through education, research, services and advocacy.

FCA’s information Clearinghouse covers current medical, social, public policy and caregiving issues related to brain impairments. For residents of the greater San Francisco Bay Area, FCA provides direct family support services for caregivers of those with Alzheimer’s disease, stroke, traumatic brain injury, Parkinson’s, HIV dementia and other debilitating brain disorders that strike adults.

CDC National AIDS Clearinghouse
P.O. Box 6003
Rockville, MD 20849-6003
(800) 458-5231; (800) 243-7012 (TDD)

National AIDS Hotline
(800) 342-2437; (800) 344-7432 (Spanish)
(800) 243-7889 (TTY)

San Francisco AIDS Foundation
P.O. Box 426182
San Francisco, CA 94142-6182
(415) 863-2437

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