

APPENDIX C

Proposed Research Agenda

- I. Organization and Delivery of Care Studies:
 - A. Models of care, including home care, day care, assisted living and skilled long-term care (including cost effectiveness studies of different models, using quality-adjusted outcome measurements and total costs, including expenditures averted, prevention of lost work time by caregivers, etc.):
 1. Availability/accessibility of hospice care to people with HIV/AIDS;
 2. Availability/accessibility of non-hospice palliative care to people with HIV/AIDS.
 - B. Use and impact of interdisciplinary teams on all phases of HIV management.
 - C. Development of reliable, valid measures for:
 1. Access to services;
 2. Quality of care and family/caregiver support; and
 3. Costs.
 - D. Local and regional patterns of gaps in available services.

- II. Clinical Care Studies focused on disease in post-HAART era:
 - A. Evaluation of prevalence, prevention and management of symptoms related to use of antiretroviral therapy during induction, maintenance and salvage therapy, and how these impact adherence as well as quality of life.
 - B. Guidelines for withdrawal/cessation of HAART and prophylaxis of opportunistic infections in late-stage HIV disease.
 - C. Clarification of important psychological and emotional decision making junctures in management and demonstration of optimum methods for accomplishing this communication.
 - D. Clinical epidemiology of advanced HIV/AIDS and death-related data, e.g., cause of death and place of death.
 - E. Prognosis and surrogate markers for late-stage HIV disease.
 - F. Evaluation of appropriate timing, method and documentation of end-of-life planning.
 - G. Documentation of appropriate prognostic indicators to assist decision making during advanced and end-stage disease.
 - H. Delineation of clinical issues and therapeutic responses to timing and setting of death, grief and bereavement.
 - I. Patient preferences for care in advanced AIDS, including:
 1. Desire for/benefits of continuing HAART; and
 2. Features/qualities/location of palliative care.
 - J. Caregivers for people with advanced AIDS: their needs and priorities.
 - K. End-of-life care in people with chronic substance abuse and HIV/AIDS.
 - L. End-of-life care in people with end-stage liver disease and HIV/AIDS.
 - M. End-of-life care in people with end-stage renal disease and HIV/AIDS.

- N. Treatment of specific symptom complexes:
 - Chronic pain, including neuropathic pain;
 - Gastrointestinal symptoms: nausea, anorexia, diarrhea;
 - Weakness and fatigue; and
 - Cognitive dysfunction and psychiatric symptoms in palliative HIV care.

- III. Quality of Life and Family Experience Studies:
 - A. Refinement of existing and development of new interventions to improve quality of life, including interpersonal, emotional, social and spiritual domains of human experience.
 - B. Measurements of quality of life with advanced HIV disease that encompass interpersonal, emotional, social and spiritual domains of human experience.
 - C. Efficacy of palliative interventions that improve quality of life in advanced HIV disease.
 - D. Measurement of caregiver experience (stress, burden and quality of life).
 - E. Community attitudes toward dying with AIDS.

- IV. Studies on impact of Ethnicity and Culture on End-of-Life Research

- V. Documentation of and clarification of models to identify and relieve patient/family and staff-related stress and burnout related to caregiving and to accumulated multiple loss.
 - A. Meaning of palliative care to AIDS providers; also their knowledge, attitudes and beliefs about it.
 - B. Educational experience and needs in palliative and end-of-life care of HIV care providers.

- VI. Reimbursement and Access to Care Studies:
 - A. Descriptive studies;
 - B. Interventions; and
 - C. Demonstration projects.

- VII. Educational Needs Research:
 - A. Professional training and development;
 - B. Patient education tools; and
 - C. Public engagement studies.