

**CENTER FOR PALLIATIVE CARE EDUCATION AND
ASSOCIATION OF NURSES IN AIDS CARE
PALLIATIVE CARE EDUCATION NEEDS ASSESSMENT**

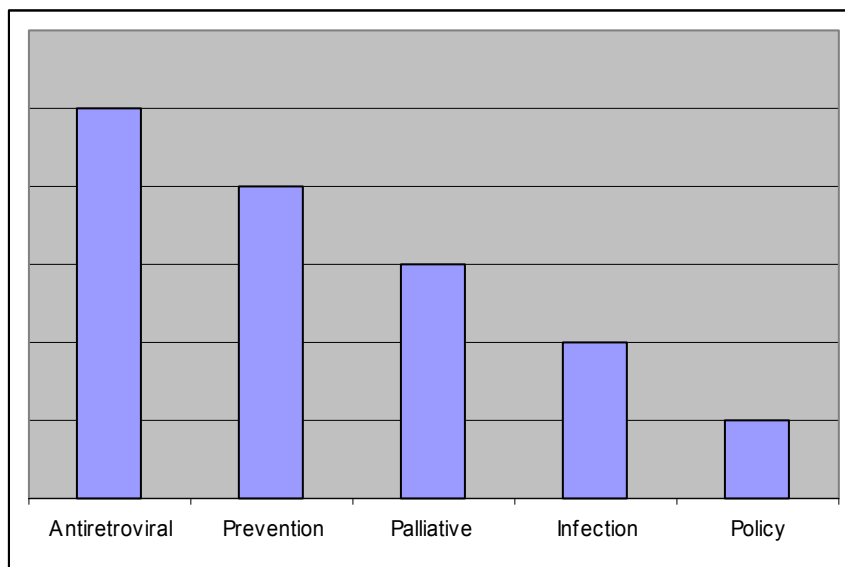
INTRODUCTION

In order to assess the palliative care training needs of nurses in HIV/AIDS care, surveys were distributed by mail to approximately 2000 members of the Association of Nurses in AIDS care in September, 2003. The information presented here is the result of analysis of data from 374 surveys which were returned as of November 6, 2003.

RANKING INTEREST IN TRAINING TOPICS

Respondents were asked to rank their interest in the following topics, in order of preference from 1 – 5: Antiretroviral therapy and adherence; Prevention for HIV positive persons; Palliative care; Treatment of opportunistic infections; AIDS policy and funding.

Responses indicated that palliative care was ranked third among the topics. Antiretroviral therapy and adherence, and prevention for HIV positive persons were ranked higher than palliative care.



TRAINING PREFERENCES

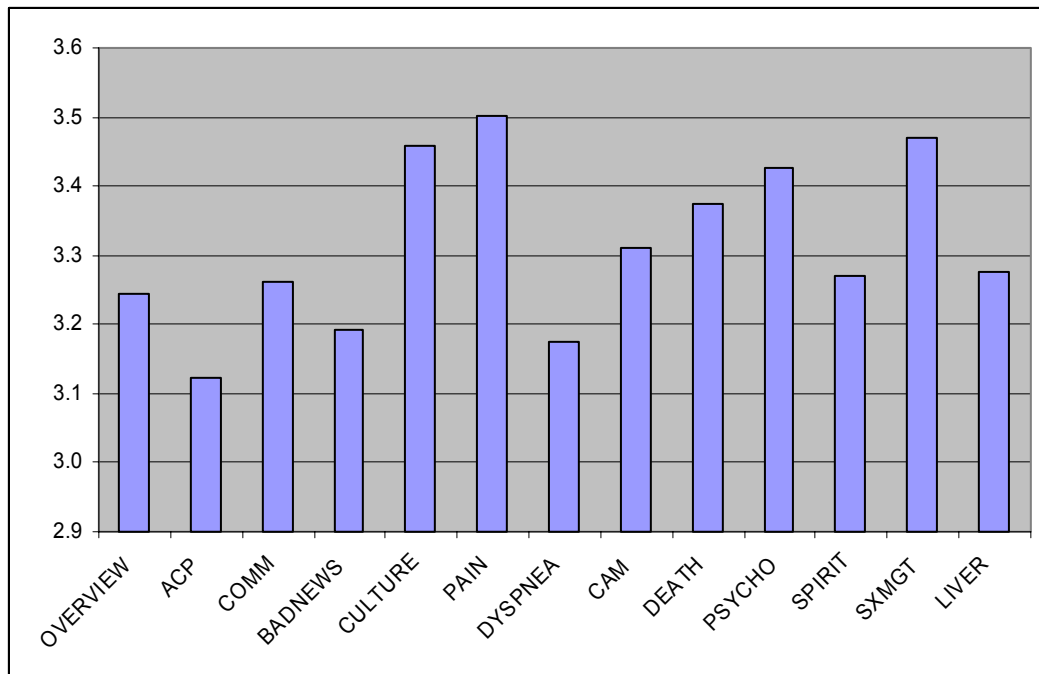
Training Topics

Respondents were asked to rate topics, in response to the question, “How helpful do you feel additional training would be for you in the following specific areas?” Responses were on a 1 to 4 scale, with 1 being “Not at all helpful,” 2 “Slightly helpful,” 3 “Moderately helpful,” and 4 “Extremely helpful.” The following training topics were listed:

- An overview of HIV/AIDS and palliative care
- Advance Care Planning
- Communicating with patients and families about end-of-life care
- Giving bad news

Cross-cultural communication and palliative care
 Assessing and managing pain in HIV/AIDS
 Palliative management of dyspnea in HIV/AIDS
 Complementary medicine and HIV/AIDS palliative care
 Helping patients to have a good death
 Psychiatric and psychological issues at end of life
 Spiritual issues at end of life
 Symptom management in HIV/AIDS
 Liver failure in HIV/AIDS patients

On average, respondents' ratings fell between 3 and 3.5, with the highest average ratings being in the areas of: Cross-cultural communication and palliative care, symptom management in HIV/AIDS, and assessing and managing pain in HIV/AIDS. Other ratings are shown below.



Additional topics of interest

Respondents were asked to list additional training topics of interest, and 88 of the returned surveys included responses to this question. Respondents indicated both palliative care topics of interest, and other specific HIV/AIDS care topics in which they would like to receive more training. Most frequently-cited palliative care topics included pediatric issues, including pediatric end of life care, as well as communication and planning for children of parents with HIV/AIDS. Co-infection with hepatitis C, and addressing substance abuse in pain management were also listed frequently. Among the general HIV/AIDS care topics most frequently listed were antiretroviral medication updates and adherence, and distinct populations including women, children and

adolescents. The following list summarizes the responses which were provided, organized into themes, with most frequently cited topics indicated.

Summary of topics listed

Palliative Care related topics

Communication and planning

Most frequent:

- *Disclosure, communication, planning re end of life issues with children*

Also listed:

- *Goal setting/clarification*

Patient and Family support

Most frequent:

- *Family care during advanced disease*
- *Grief support*

Also listed:

- *Coping with HIV as older teen/ young adult*

Palliative treatments

Most frequent:

- *Substance abuse and pain management*
- *Pediatric end of life care*

Also listed:

- *Care of HIV-infected patients undergoing cancer treatment and palliative care.*
- *Prophylactic pain management*
- *Palliative care for mentally ill*
- *Code status included in above topics. (listed in needs assessment)*
- *Renal failure in AIDS patients*

Systems of care

Most frequent:

- *Role of Hospice with HIV/AIDS*

Also listed:

- *Introducing palliative care to the professional providers and support staff – clearer understanding of the what, why, and how this aspect of the care process is important. Our patients are eager to be engaged – our providers are not necessarily eager to engage them on this topic.*
- *Role collaboration with other health care professionals and palliative care*
- *All of the above (topics listed in needs assessment) for application in low resource settings*

- *The role of hospice care and the hospice benefit – increasing participation and challenging the criteria, i.e. 6 month prognosis*

Ethical issues

Most frequent:

- *Ethical issues with palliative/end of life care*

Also listed:

- *Suicide*

Medication-related issues

Most frequent:

- *Medication update*
- *Adherence*

Also listed:

- *Stopping HIV medications*
- *Interpreting genotype/phenotype. Medications for B/P, elevated lipids, seizures and possible interactions with HIV meds*
- *Lipodystrophy update and treatment*
- *Neuropathy update and treatment*
- *Alternative therapies related to AIDS care*

Co-morbidities

Most frequent:

- *HCV and HIV co-infection*
- *Substance use in HIV/AIDS*

Also listed:

- *Diabetes in HIV patients and kidney failure*
- *TB, HCV*
- *Depression*
- *Harm reduction. Psychosocial issues and HIV (not just end of life)*
- *Liver transplantation in HIV+ patients*

Distinct populations

Most frequent:

- *HIV disease in children and adolescents*
- *Women and HIV*
- *Pediatrics*

Also listed:

- *Maturing perinatally infected children.*
- *Homelessness and HIV/AIDS*
- *Perinatal HIV*
- *HIV in correctional settings*
- *Pregnancy and HIV – decision to continue or terminate*

Other related topics

Most frequent:

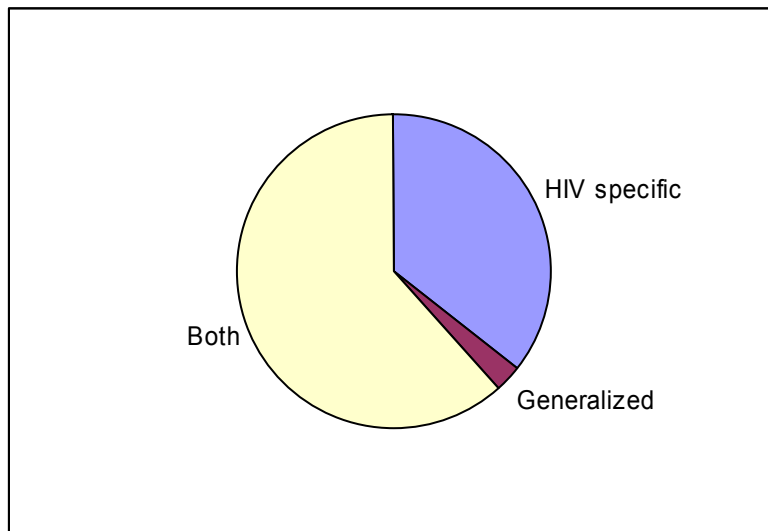
- *Prevention*
- *Nutrition*
- *Holistic treatment*

Also listed:

- *HIV effect on specific organ systems*
- *Cultural competency related to all care areas*
- *Therapeutic touch – energy medicine.*
- *Research*
- *Obtaining resources*
- *Good overview HIV/AIDS disease, treatment. Anal exam*
- *Patient increased involvement in his/her care and increase patient provider interaction*

Specific to HIV/AIDS?

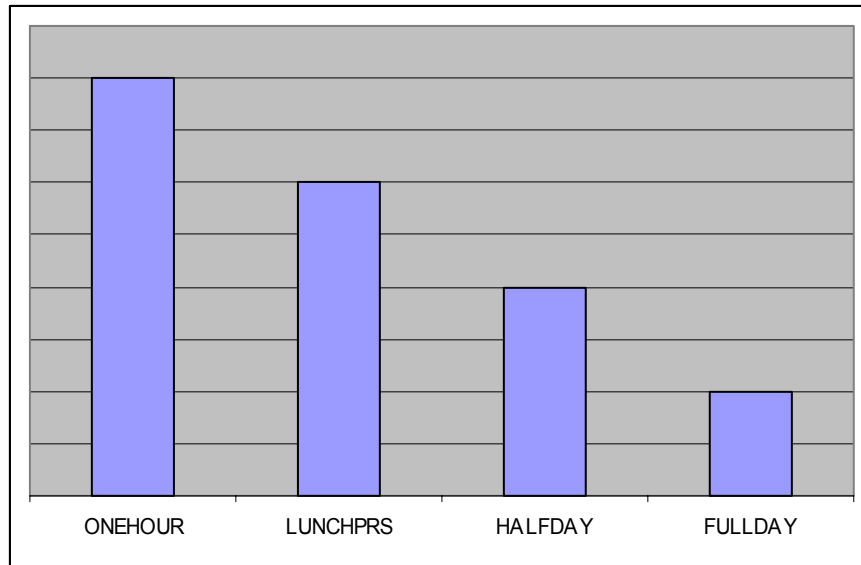
Respondents were asked to choose whether they preferred to attend trainings in which the material presented was specific to HIV/AIDS, whether they would prefer the content to be generalized to other illnesses, or whether they would like trainings to provide both HIV/AIDS-specific and generalized information. Results suggest that respondents strongly favor trainings which combine HIV/AIDS specific information with content generalized to other illnesses.



Types of trainings

Respondents were asked what types of trainings they would be interested in attending: 1-2 hour sessions as part of a conference; Full-day interactive workshop before

a conference; Half-day interactive workshop before a conference; 1-hour lunch presentation at or near your workplace. Results suggest that most respondents prefer shorter presentations: Both the 1-2 hour session at a conference, and workplace lunch presentations ranked higher than did half-day and full-day sessions. .



SUMMARY

Results of this assessment reveal an interest in receiving additional training in palliative care topics, particularly in the area of assessing and managing pain and symptoms in HIV/AIDS. Of 5 possible topics of interest, palliative care ranked 3rd, above treatment of opportunistic infections and AIDS policy and funding, but below prevention for HIV positive persons and antiretroviral therapy and adherence.

Respondents were asked to list additional training topics of interest. Most frequently-cited palliative care topics of interest included pediatric issues. Co-infection with hepatitis C, and addressing substance abuse in pain management were also listed frequently. Among the general HIV/AIDS care topics most frequently listed were antiretroviral medication updates and adherence, and HIV/AIDS in distinct populations including women, children and adolescents.

Respondents were interested in trainings which provided both HIV/AIDS-specific content and content generalized to other illnesses. Results suggested that respondents prefer shorter presentations: Both the 1-2 hour session at a conference, and workplace lunch presentations ranked higher than did half-day and full-day sessions.