



***STATEWIDE HOSPICE CLERGY END-OF-LIFE
EDUCATION ENHANCEMENT PROJECT***

FINAL REPORT

**Prepared for the
Florida Department of Elder Affairs**

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I. ACKNOWLEDGEMENTS

The *Statewide Hospice Clergy Education Enhancement Project* was authorized by an appropriation signed by Governor Jeb Bush in July, 2002 with a completion date of July 2003. It could not have been accomplished without the assistance and commitment of many dedicated people who believe in the singular role clergy can play in assisting the dying and their families. On behalf of the Directors of Hospice Foundation of America (HFA), I am grateful to the individuals and organizations identified here and I am pleased to be able to recognize their contributions.

The Florida Legislature is to be commended for funding the *Clergy End-of-Life Education Project*, which became the more utilitarian name of the program. In 1999, the legislatively created *Panel for the Study of End-of-Life Care* issued its final report that called for legislative encouragement for "the ongoing development of innovative end-of-life educational programs...." The legislature rose to the occasion with concrete action motivated by a commitment to assisting the dying. The project was administered through the Department of Elder Affairs. Terry White, Secretary of the Department of Elder Affairs and Linda Macdonald, Senior Management Analyst, have been supportive and encouraging throughout the process.

The Advisory Committee to the project provided valuable insight into the educational, professional and personal needs of the clergy in counseling families, and generously offered manpower and printed materials for inclusion in the curriculum. The hospice members of the committee were very generous in offering their bereavement expertise and staff to the project and the committee's educational specialists offered valuable assistance in curriculum design and practical experience in clergy education. We are greatly indebted to the committee for its generosity of wisdom, collective and individual.

The initial group of regional trainers is to be commended for working under the pressure of organizing their clergy communities without seeing a complete final product. This group consisted of the executive directors of the local health councils and trainers recruited by them. We are grateful for their confidence in the program's management and their dedication to the project. The commitment of these trainers was instrumental in our reaching over 600 congregational faith workers in only a few months. The attachments list the original trainers, but there were also many who filled in locally who share responsibility for the success of the project. We want to also thank the local hospices and Council of Community Coalitions of the Florida Partnerships for End-of-Life Care for helping to identify skilled trainers.

The design and implementation of a statewide project required a complex set of skills and knowledge. The staff of the Health Council of South Florida, under the leadership of Sonya Albury, Executive Director, was instrumental in designing the training program as well as recruiting and training regional health councils to bring the project to the local level. Beyond being a partner in the project for two years prior to the appropriation, Ms. Albury has been generous with her time in developing the project's goals and objectives. Her encouragement was a strong influence to go forward with a project of this magnitude. Her personal commitment to serving dying people and her energy in bringing the project to fruition has been critical to its success.

A number of individuals have contributed their skills to the project. Irma Emery, HFA consultant, met difficult deadlines and created the trainer's manual in a few short weeks. Kathy Brandt, Director, Rallying Points Resource Center at The Hospice of the Florida Suncoast, has been a consistent friend to HFA and supported this project.

Kenneth J. Doka, Ph.D., M.Div., Professor of Gerontology at the College of New Rochelle, and Bereavement Consultant to HFA served a triple role in the program: overseeing the educational content, facilitating the important first meeting of the Advisory Committee and as a featured presenter in several counties. In 1995 Dr. Doka envisioned HFA's first effort in clergy education, the audiotape series *Clergy-to-Clergy*. He has urged us to do more in this area, and the *Clergy End-of-Life Education Project* is a direct result of his strong leadership.

Finally, we want to acknowledge the most important element of the clergy education project: those clergy members who have taken time to attend the regional workshops. Clergy men and women are busy people who work under considerable stress. Their demonstrated commitment to improve their skills by attending this program is testimony to their concern for the dying and their families in their communities.

David Abrams, President
Hospice Foundation of America

II. EXECUTIVE SUMMARY

The *Statewide Hospice Clergy End-of-Life Education Enhancement Project* was launched during the summer, 2002. The project was managed by the Hospice Foundation of America (HFA) on behalf of the Florida Department of Elder Affairs as part of a statewide effort to enhance care for the dying by improving the knowledge base of clergy and faith communities in end-of-life care. The goal of the *Clergy End-of-Life Education Project* (as the project became known) is to mitigate the deleterious physical and mental effects of futile aggressive care at the end of life by educating faith communities on end-of-life options, so that they may more effectively minister to families facing impending loss.

The project was specifically designed for professional clergy, lay leaders, and faith communities that would benefit from end-of-life education. The target audience included clergy, lay leaders, deacons, clergy in training, chaplains and directors of pastoral care services, hospital and home visitation ministry leaders and others who minister to the sick and the bereaved, and their families.

PLANNING

The launching of the educational sessions for the *Clergy End-of-Life Education Project* was preceded by multiple planning steps that encompassed a wide array of developmental and outreach activities. The planning steps for the program included:

Selection of subcontractor. Hospice Foundation of America selected the Health Council of South Florida (HCSF) as a collaborative partner to conduct the program on behalf of the State. The Health Council was selected because of its abilities in planning and evaluation, experience in the coordination of complicated projects, and its demonstrated commitment to improving care for the dying. The Executive Director of HCSF is President of the American Health Planning Association. That leadership would be an important factor in coordinating the involvement of other regional health planning councils.

Identification of Regions for Program Demonstration. HFA and HCSF identified nine counties as target areas for the *Clergy End-of-Life Education Project*. Key factors considered were the size of the population, availability of hospice support, urban and rural representation, and ethnic diversity to reflect the dynamic mix of Florida's communities. Six of the eleven local health councils in the State of Florida were chosen to serve as regional coordinators to conduct the educational sessions. They were chosen because of their local involvement in selected communities and the project team's efforts to include both urban and rural areas.

Formation of a Statewide Advisory Committee. Project oversight was provided by an Advisory Committee. The committee was comprised of 15 members representing hospice organizations, university ethics and gerontology programs, clergy members, and medical care providers. The Advisory Committee conducted two formal meetings to review the selection of regions, the work plan and products produced by the project management team. In addition, work in progress was reviewed by the committee via e-mail. The

committee provided valuable guidance on the projects direction, development of the curriculum and review of the final report.

Recruitment and Training of Regional Coordinators. The Health Council of South Florida recruited five regional health councils to participate in the project, in addition to itself acting as a region. The executive directors of these health councils became the project's regional coordinators. Each regional coordinator recruited two to three regional trainers. One of the trainers selected was required to be a local clergy person or a lay leader, the second trainer was a member from the local health planning council, and the third a hospice provider.

Development of Project Materials: All the materials for the clergy project were incorporated into a toolkit for simplified dissemination and program compliance. The toolkit items consisted of:

Curriculum Materials.

On the advice of the Advisory Committee, seven modules were suggested for the clergy participant's curriculum: *Cultural Considerations at the End of Life; The Dying Process; End-of-Life Options; The Grief Process; Assisting Families; The Role of Spiritual Care; Self Care for Clergy.* A trainer's manual containing learning objectives, curriculum, suggested training methodologies, case studies, definitions, handout materials and a slide presentation was developed and distributed to trainers.

Outreach/Marketing Materials.

A variety of materials were developed to announce and promote the statewide educational sessions. They consisted of an outreach brochure for direct mail, program flyer, a press release, a radio public service announcement, and a questions and answers document to be utilized as a guide for media interviews. These were provided to the regional coordinators on a compact disk and as hard copy.

Clergy Materials.

Each clergy participant was given a Participant's Manual that corresponded to the content information in the Trainer's Manual. Supplemental materials were also provided including an audiotape program entitled, *Clergy To Clergy: Helping You Minister To Families in Need*, a book, *Caregiving and Loss: Family Needs, Professional Responses* and one other book on grief and loss from the Hospice Foundation of America series.

Consumer (Family) Materials.

The project managers conducted a literature search and selected a variety of resources for individuals with a life limiting illness and their families to help them through the dying process and after. These materials were packaged in a folder and provided to clergy to give to the families they counsel. Three thousand kits were delivered to clergy for distribution.

Regional Coordinator Training. Over 30 regional coordinators and trainers from across the state were recruited for an all-day workshop held in Ft. Lauderdale on December 11, 2002. During the seven-hour intensive training session, trainers were given an overview of the Trainer's Manual and a sample of the outreach/marketing and consumer materials.

Creation of training calendar and outreach. Each regional coordinator identified three to five tentative dates and locations in his/her target counties for the educational sessions. A training calendar was created to guide the process and facilitate coordination between the regions. They identified and compiled a list of potential clergy, lay leaders, clergy groups/associations, clergy in training groups, places of worship, hospices, and leaders of community-based organizations to promote the *Clergy End-of-Life Education Project*. Approximately 6,000 outreach brochures were mailed to promote the educational sessions throughout the participating regions.

IMPLEMENTATION

The implementation phase of the project occurred between January and April, 2003. The first training session was held in Miami-Dade County by the HCSF to pilot test the format, agenda and materials for suitability, and to garner initial feedback from the participants. The pilot session was videotaped, reproduced and distributed to the other regions. A telephone conference call was facilitated by HCSF to discuss lessons learned from the pilot test. Two additional conference calls were held during the program period to share successful outreach techniques, presentation tips and administrative issues. Ongoing advice and assistance by telephone was also available through an identified HCSF staff member.

Between February 5th and April 23, 2003 twenty two educational sessions were conducted across Florida. Over 613 participants attended, of whom 54% were clergy or pastoral care personnel. The remainder included caregivers, social workers, bereavement and outreach workers, lay volunteers and church administrators. Fifteen of 22 sessions were held in churches. The average attendance in the church setting was 10% higher than those sessions held in other locations.

EVALUATION

To evaluate the outcome of the sessions, pre- and post-test self-reporting forms were developed. The 613 participants were given a strong incentive to complete the forms, resulting in a high response rate. The average age of participants ranged from 40 to 60 years old, but notably 10% were over the age of 70. Men and women were equally represented. Two-thirds of participants were White, about 13% African American, and 9% were Hispanic.

In terms of outreach, most participants heard of the educational sessions through the mail or by phone invitation. In Northwest Florida a PSA and television coverage may have generated a large turnout. It was also noted that positive word of mouth built momentum over time as news of the value of the program spread within the clergy community.

Pre-Test and Post-Test Summary. A high proportion of participants (80%) reported that they had a higher level of knowledge of end-of-life care issues upon completion of the training. It appears that trainees felt confident that the training had helped them understand medical and spiritual issues in a manner that would improve their ministry. In

addition, they expressed that the experience had helped them address personal issues. They also felt better informed about technical, procedural and legal issues than they had

prior to the training, but their responses did not express quite as high a degree of confidence in their mastery of these issues. The general unfamiliarity with legal and technical issues may be the reason that a number of participants asked for a longer program and more training.

All participants stated that they intend to utilize the curriculum and consumer materials in their communities. This intention appears consistent with the high utility score awarded to the consumer materials. This strong emphasis on useful materials for application in home communities suggests that maintenance of communication and updating of materials may be important post-training support mechanisms for the participants.

It is reasonable to anticipate that the impact of the training offered in 2003 will affect many communities and extend the value of the program delivered. The clergy and lay leadership were left with a body of knowledge, resources to draw upon and material to give their parishioners. The project was able to accomplish this at a low per unit cost. We expect this educational effort will reap benefits to the terminally ill and their families across the state for many years to come.

RECOMMENDATIONS

The Advisory Committee convened at the conclusion of the project and reviewed the logistics of the project and the evaluation results. The major recommendations coming from the meeting arise from the lessons learned. There were three lessons that stood out beyond all others: the need for cultural sensitivity in the curriculum; the importance of self care for clergy; the balance between didactic and participatory presentations.

Cultural components are difficult to incorporate directly into curriculum, but one good way to ensure cultural competency is to utilize local input and expertise to address issues distinctive to ethnic or cultural groups. It is important that clergy of other ethnic groups understand the taboos, rituals and customs of their neighbors. One of the most well received modules was self care for clergy. Many clergy indicated that the educational sessions were the first time that anyone validated the workplace induced stress they experience, and while that recognition helped greatly, the module should be expanded and included in future educational sessions. The project managers struggled to reach a balance between didactic presentations and participatory presentations. Both received high scores, but those regions that emphasized a more participatory approach saw less negative scores. This indicates that the agendas developed need to be reviewed with a goal of being more active.

A number of other interesting recommendations are offered, including creating the curriculum in Spanish and the inclusion of a module on children and grief.

III. INTRODUCTION

Hospice Foundation of America is pleased to present this report to the Florida Department of Elder Affairs in fulfillment of the appropriation of the 2002 legislative session to conduct a statewide program of clergy education in bereavement and end-of-life care.

The *Statewide Hospice Clergy End-of-Life Education Enhancement Project* is the first statewide project of its kind in Florida, and one of the first in the nation, directed toward addressing the learning needs of clergy and faith community leadership so that they are empowered to minister effectively to families facing end-of-life issues. Its goal was to mitigate the deleterious physical and mental effects of futile aggressive care at the end of life by educating faith communities on end-of-life options, so that they may more effectively minister to families facing impending loss. As a method of expanding access to quality end-of-life information and care, this project, with its focus on specialized education, seeks to extend the traditional end-of-life education provided primarily by nurses and social workers to include clergy and faith community leaders as a resource for information in the health care decision-making process.

The project was a collaborative effort. Under the leadership of the Hospice Foundation of America it combined the statistical and planning expertise of the Health Council of South Florida, the community building skills of the Council of Community Coalitions of the Florida Partnership for End-Of-Life Care, the outreach and program planning abilities of regional health planning councils, the educational expertise of local hospices, and the clinical expertise of the Lamers Medical Group. An Advisory Committee, made up of an eclectic group of clergy, bereavement professionals, educational design specialists and hospice personnel, provided clinical and educational expertise and outreach advice.

Prior to entering into this project, the management team met with a number of organizations and individuals who had been involved in clergy education efforts. Every conversation produced the same admonition – the daily pressures upon clergy will seriously inhibit our ability to recruit clergy to attend the educational forums. We took that advice seriously, and placed our energies into program design at the management level, and labor intensive individual contact with clergy at the field level. Our participants numbered just over 600 clergy in 13 counties over a four month period. That amazing turnout is due to the concentrated energies of all the collaborators in the project.

If each of the 613 clergy or other faith community leaders who attended the educational sessions tend to a congregation of 300 people (not a particularly high estimate) we can potentially affect about 75,000 people over a period of time. However, clergy are in ministries for a lifetime, and we are unable to say how many hundreds of thousands of people can benefit from the information over a longer period of time.

In 1998 there were over 157,000 deaths in Florida. Studies have indicated that in many cases physicians do not know their own patients' wishes at the end of life, and many

people die in pain. Individuals look to clergy for guidance during spiritual and medical crises. Because of the role that clergy play, both in the lives of individuals and their communities, they can be influential in improving the way people die in Florida. Many clergy members of all faiths and denominations, however, do not always feel comfortable participating in these situations. Investigations throughout the country indicate that end-of-life subjects are not included in the clergy educational curricula regardless of faith or denomination.

The failure of seminaries to train their students, coupled with the inherent difficulty in conversing with the terminally ill and their families, the lack of knowledge of the legal issues, the daily demands placed upon clergy that hinder the pursuit of continuing education, and the marginalization of clergy by the medical community, all serve as barriers to the clergy's unique mission of service and charity.

Clergy members, whether in a small congregation or a large one, are usually understaffed and frequently under funded. A pastor, priest or rabbi must be many things to many people. The demands placed upon them are many. This was recognized by the Florida Legislature in the study completed by Florida's Panel for the Study of End-of-Life Care, which noted that "greater efforts are needed to help Florida's residents receive more compassionate, dignified care as they near the end of their lives...."

Hospice Foundation of America is committed to assisting those who cope, either personally or professionally, with terminal illness, death and the process of grief. The Foundation works as an advocate for the hospice concept of care by conducting programs of professional development and working for the inclusion of hospice principles into the broader health care system. The Foundation has extensive experience in presenting mass education projects based upon adult learning theories and practice. With these qualifications, the Foundation undertook the *Clergy End-Of-Life Education Project*, with the express intent of furthering the acceptance and viability of hospice as a cost-effective care option at the end of life.

Caring for the dying and their bereaved loved ones is particularly challenging because there is often little tangible evidence of the good that is being accomplished. Sometimes there is little that is even said. It is precisely this intangibility that makes clergy so helpful in ministering to the terminally ill, because they (perhaps more than anyone else) are best able to combine the mystery of spirituality with the search for answers. The interior explorations of the dying regarding life's meaning and purpose, their personal and spiritual transformations, and the evaluating of meaningful relationships can be aided by a clergy member who understands the person's spiritual beliefs and who is familiar with grief and bereavement issues.

The clergy participants in this project do so out of a natural propensity to care for the bereaved. The bereaved may be the dying, their families, members of a faith community, friends and even strangers. Underlying all the facts, observations and recommendations presented by this project is the simple truth that it is a personal presence that is the most important element in caring for the dying. When combined with a basic knowledge, the clergy become a powerful force for improving the way Floridians die in the future.

IV. PROJECT OVERVIEW

A. BACKGROUND

A 1996 Gallup Poll revealed that 90% of Americans, if faced with a life-threatening illness, would prefer to be cared for and die at home, free of pain, with symptoms under control, and surrounded by their loved ones. Subsequent surveys have not shown any decrease in that percentage. When news of a terminal prognosis is delivered by the attending physician, it is very common for the physician to leave the patient and family on their own to cope with important decisions at the end of life. At these times, many people turn to those who have been a source of comfort, advice and strength to them in the past – their faith community.

Traditionally, clergy members of all faiths and denominations receive little or no formal training in advising, assisting and supporting people through end-of-life crises. Members of the clergy are often called upon to minister to the dying and their families, offering counsel and support at moments of trauma and loss. Even today many theological schools provide minimal or no instruction in grief and bereavement.

There is a lack of information and frequent misunderstandings of options for care at the end of life. These misunderstandings are common among the general public and even among medical professionals. In faith communities, which many people turn to in times of crisis, the clergy have not been given the information needed to provide meaningful direction, care and comfort to their members. The hospice movement is painfully aware of the many individuals with a terminal illness or disease that is no longer responding to curative care who will continue painful, costly and futile treatments because of misinformation. For some there is the perception that their faith would not allow a less aggressive course of action. Beyond the patient, studies indicate that persons suffering from grief reactions are at increased risk for mental and physical illness and, in fact, have higher rates of morbidity. A well informed clergy can mitigate the deleterious physical and mental effects of grief and loss upon the family.

It has been suggested that the ripple effect of a single death reverberates to between three and seven people who are seriously affected by grief reactions. With over 56,000 funerals in Florida each year, hundreds of thousands of survivors would benefit from informed spiritual leaders able to use the proper words, avoid the wrong ones, and reach out with increased compassion and sensitivity to the special needs of the terminally ill and the bereaved.

With the overwhelming daily demands placed upon them, most clergy members have neither the time nor the energy to pursue extensive continuing education. Clergy need a convenient way to learn more about end-of-life options, grief and bereavement.

B. PROBLEM STATEMENT

Thanks in large measure to the foresight of its Legislature, Florida is at the forefront in its initiatives to promote good end-of-life care, particularly with the passage of laws that facilitate advance care planning. According to a recent report, *Means to a Better End. A Report on Dying in American Today*, published by Last Acts, (a national campaign to promote improvements in end-of-life care), Americans have no better than a fair chance of finding good care when facing a life-threatening illness. The report rated all 50 states and the District of Columbia on eight criteria as a basis for assessing the state of end-of-life care in this country. Comprehensive information on the project, reports and research findings are available on an interactive Special Report on The Robert Wood Johnson Foundation web site, located at <http://www.rwjf.org/special/betterend>.

Florida can be proud of its rating in the *Means to a Better End* report, particularly in the area of state advance directive policies. The ratings were from A through E with A being the highest and E the lowest. In response to the question: *Do state policies support good advance care planning?* Florida was rated "A" based on the quality of state advance directive laws passed in 2002. The state also was rated "A" in response to the question: *Do state pain policies encourage good pain control?*¹

There is, however, still work to be done to translate enlightened state policies into practice at the grassroots level. Florida's ratings regarding hospice use was "C" based on percentage of deaths with hospice stay in 2000 and "D" based on median length of stay in hospice. Experts agree that patients need at least 60 days of hospice care to realize its benefits, but stays range from 14 to 43 days.

Ninety (90%) percent of Americans say they would prefer to die at home, while nationally only 25 percent of deaths occur at home. About half of all deaths occur in hospitals but less than 60 percent of hospitals offer specialized end-of-life services. The *Means to a Better End* report rated Florida "D" in answer to the question: *What proportion of state deaths occur at home?* This would suggest that if Floridians mirror the national picture, many who wish to die at home are not seeing their wishes respected. In fact, the State was rated "E" the lowest rating based on the number of elders who spend a week or more in the ICU during the last six months of life. (Based on percentage of Americans over 65 with seven or more ICU days totaled across all admissions during the last six months of life.)

The State did not rate well when the application of its pain policies were viewed from the level of patient services. Few hospitals in the State of Florida report having hospice programs or palliative care programs. The hospitals were rated "C" on self-reported pain management programs. The report also suggests that there is work to be done at the nursing home level in terms of pain management. In response to the question: *How well do the state's nursing homes manage their residents' pain?* Florida was rated "C."

¹ **Means to a Better End: A Report on Dying in America Today*, published by Last Acts with funding from The Robert Wood Johnson Foundation.

As indicated in the study completed by Florida’s Panel for the Study of End-of-Life Care, greater efforts are needed to help Florida’s residents receive more compassionate, dignified care as they near the end of their lives. One of the principal recommendations in the study is to “encourage the ongoing development of innovative end-of-life educational programs and standardized training” for health care providers.

The *Clergy End of Life Education Project* addresses the development of a model that translates progressive policy into local practices by engaging faith communities in the process of promoting good end-of-life care. Because clergy historically have been influential in minority communities, we believe such education will positively affect populations that have been historically disenfranchised from this humane system of care for terminally ill people.

With the implementation of the *Clergy End-of-Life Education Project* Florida will move ahead of other states in its proactive efforts to improve care for the dying by educating a critical gatekeeper into the medical system and a strategic member of the family support system.

C. PURPOSE STATEMENT

The *Clergy End-of-Life Education Project* is a state-funded initiative that has as its goal increasing the knowledge and skills of clergy members to address end-of-life issues by educating them about bereavement and options for care at the end of life, so that they can minister more effectively to the dying and their families.

The *Clergy End-of-Life Education Project* is a statewide educational project implemented in 13 counties throughout the State of Florida. The project developed an extensive curriculum addressing key issues in end-of-life care, a toolkit of consumer information and state-wide series of educational workshops for clergy members. The project subcontracted with six local health councils serving the 13 counties under the leadership of the Health Council of South Florida to conduct outreach to local faith communities and to implement the educational programs. The project utilized a self-reported participant profile and a pre and post test survey of workshop participants to assess the impact of the educational offerings. Through input from local participants in each county, the local health councils were given latitude to determine the learning needs of the clergy in their communities and to tailor their workshop accordingly.

D. OVERSIGHT

Project oversight was provided by the *Clergy End-of-Life Education Project* Advisory Committee. The committee was comprised of 15 members representing hospice organizations, university ethics and gerontology programs, clergy members, and medical care providers. The Medical Advisor to the project was William Lamers, MD who serves as a Medical Consultant to Hospice Foundation of America. The Educational Consultant to the project was Kenneth Doka, Ph.D., M.Div., Graduate Professor of Gerontology at the College of New Rochelle, and a recognized leader in clergy end-of-life education.

The Advisory Committee conducted two formal meetings to review the work plan and products produced by the project management team. In addition, work in progress was reviewed by the committee via e-mail. The committee provided valuable guidance on the project's direction, selection of counties to participate, input into the development of the curriculum and review of the final report.

Its functions were three-fold:

1. To represent the communities involved and advise on the cultural appropriateness of all documents.
2. To provide guidance regarding the development of the curriculum and the professional and consumer materials.
3. To assist, as needed, with the pre and post test evaluation tools and make recommendations regarding the final report.

The *Clergy End-of-Life Education Project* Advisory Committee was comprised of the following members:

Samira Beckwith

President
Hope Hospice Palliative Care Center

Anthony Palumbo

President & CEO
Catholic Hospice

Michael Bell

VP Development/Community Relations
The Hospice of the Florida Suncoast &
Chair of the Partnership for Caring Coalitions

Marty Ratliff

Former Director, Education & Training
Project Grace

Kenneth Doka, Ph.D., M.Div.

Professor of Gerontology
College of New Rochelle

Elizabeth Rugg

Executive Director
Health Council of West Central Florida

Kenneth Goodman, Ph.D.

Center for Bioethics
University of Miami

Rev. Martha Rutland

Director, CPE
Vitas Healthcare Corp

Rabbi Earl Grollman

Author, Educator
EAG Associates

Carlos Sandoval, M.D.

Director, The Courtelis Center
University of Miami Hospital and Clinics

Barbara Jacobowitz

Executive Director
Treasure Coast Health Council

The Most Rev. Thomas G. Wenski

Archdiocesan Director
Catholic Charities

Dale Knee

President & CEO
Covenant Hospice

Rev. John White

Senior Minister
Mt. Hermon A.M.E. Church

Rev. Bob Miller

Director Education & Training
Vitas Healthcare Corp.

The Department of Elder Affairs provided oversight services by reviewing drafts and approving outreach materials for state compliance, and offering valuable advice on curriculum and family materials development. The Department shared its experience in the development of its own end-of-life materials and in directing us to other state agencies with publications and information important to the project.

V. PROGRAM DEVELOPMENT

A. PROJECT PLANNING

The *Clergy End-of-Life Education Project* was funded by the Florida Legislature and administered through the Department of Elder Affairs for the contract period beginning July 1, 2002 through June 30, 2003. The Hospice Foundation of America (HFA) was designated as the lead agency. The original amount of money requested in the proposal submitted in November 2001 was \$350,000 and had as a goal conducting educational workshops that would be within reach (a two-hour drive) of 90% of the clergy in the State of Florida. The final amount appropriated for the project was \$262,500.

The principle impact of the cutback in the amount of funding for the project was the need to refocus the project's intention to reach most of the counties in the State. The project managers looked at the best way to reach as many members of the clergy as possible with the available funding. Guiding criteria listed below were developed:

- (1) Population density – where could the largest number of people be reached with a mix of urban and rural representation while well as maintaining ethnic diversity?
- (2) Because outreach and delivery of the program would be drawing on the expertise of hospice staff, the availability and likely cooperation of local hospice organizations was considered.
- (3) Priority was given to areas where there had been an expressed interest on the part of the local health councils for end-of-life training. In consideration of these factors, and in consultation with the Health Council of South Florida, as the subcontractor on the project, six health planning districts throughout the state were chosen, with consideration given to the local health councils in those areas that had a strong presence in the community and the capability to mobilize an outreach effort. The health planning districts and the counties served by them were:

Districts 1 and 2: Leon, Escambia, Bay
Districts 5 and 6: Hillsborough, Pinellas
District 7: Orange, Brevard, Seminole and Osceola
District 8: Lee
District 9: Palm Beach, Broward
District 11: Miami-Dade, Broward

A map of the participating Health Council Districts and initial target counties as well as the expanded counties served is provided in Attachment A.

A detailed work plan was developed immediately following notification of the project's funding. The work plan proved valuable in the development of the contract with the Department of Elder Affairs, the agency providing contract management for the project. The identification of the deliverables defined in the contract steered the initial project planning efforts. Such matters as the evaluation instruments, drafts of outreach and

marketing materials, project training sites, elements for inclusion in the educational curriculum and the formation of an Advisory Committee were completed during the first three months of the project.

Careful consideration was given to the composition and structure of the Advisory Committee. The project management sought out individuals who had special expertise both in end-of-life issues and who understood the needs of clergy members who served on the "front lines" in communities throughout the state. Selection of representatives from the major faiths and mainstream denominations was given priority consideration as was clergy representation from the African American community. No one, it was deemed, could provide better insight into the learning needs of the clergy than clergy members themselves. Wherever possible, management tried to combine criteria from several categories so as to increase representation while keeping the committee size manageable. That approach is illustrated by the participation of Carlos Sandoval, M.D., a psychiatrist, Director of the Courtelis Center at the University of Miami Hospitals and Clinics, an EPEC (Education for Physicians in End of Life Care) trainer and an ordained Episcopal priest. Seats on the Advisory Committee were also designated for representatives from educational institutions who could provide meaningful input regarding ethical and educational issues. Dr. Kenneth Doka, a nationally known expert and published author on the subject of grief and bereavement, a professor of gerontology, an ordained minister and Bereavement Consultant to Hospice Foundation of America, served on the committee and played a key role in designing, developing and presenting the curriculum, as well as facilitating the first Advisory Committee meeting.

At the first Advisory Committee meeting, held on October 17, 2002, the committee was provided with an overview of the project, including the role of the lead agency, the Hospice Foundation of America and the Health Council of South Florida, serving as the principle subcontractor for the project. The project's organization established the interrelationship of the Department of Elder Affairs, the Hospice Foundation of America, the Health Council of South Florida and the participation of the five other local health councils was presented. Plans for the development of professional materials and a toolkit were described and the highlights of the work plan were discussed.

The Advisory Committee, in keeping with its mandate to provide guidance regarding the development of the project's curriculum, devoted time during its first meeting to the development of learning objectives that would guide project management in what finally became the *Clergy End-of-Life Education Project's* Trainer's Manual and the corresponding Participant's Manual. The ensuing discussion at the meeting led to the formation of 23 curriculum learning objectives. Dr. Kenneth Doka led the group through a prioritization process that subsequently combined and merged the objectives down to a more workable 19. The committee came to an agreement on those that were applicable to (a) the educational sessions and the consumer toolkit; (b) to the toolkit only; and (c) those that should be addressed only as time permitted.

Apropos of the significant element of community engagement that was a part of this project, Mr. Michael Bell led a discussion on community engagement. Mr. Bell has extensive experience in community organizing and is Chair of the Partnership for Caring

Coalitions in Florida. He outlined various resources that could be used to attract clergy to attend the educational workshops and strongly encouraged the groups to partner with other groups in the community, including:

- € Community coalitions
- € Summits or town hall meetings
- € Faith in Action grantees and networks
- € The Florida End-of-Life Coalition
- € The Florida Partnership to Improve End-of-Life Care
- € The media - by creating stories that involve following a family and its clergy member ministering to them through the dying process.

Mr. Bell recommended a strong presence from hospice at the community workshops, as well as hospitals, funeral homes, and the local Area Agency on Aging. He noted that marketing efforts could be advanced by collaborating with these groups.

The Advisory Committee discussed the appropriate length of the educational workshops and agreed that, in order to do the subject matter justice, a day long session was needed. Flexibility to break the curriculum into smaller segments to meet local needs was recommended. The committee agreed that the format should be less didactic and more participatory. It was suggested that advance care planning be an essential component of the program.

The Advisory Committee addressed the issue of sustainability and the next generation of the project. There was consensus that the toolkit must have all the component parts so that it could be replicated at the local level with minimum additional effort.

The project evaluation was addressed. Ms. Albury, the project evaluator, reviewed a set of draft evaluation questions. There were two types of research questions: one pertained to what the clergy learned as a result of the program and the other was what the project team learned from the clergy participants.

The Advisory Committee members suggested the following questions:

1. Rate your knowledge of end-of-life care options (on a scale of 1 - 10)
2. How would you rate the information you received/how much did you learn at the seminar? (on a scale of 1 - 10)
3. Will you change your practice? Yes/No
4. How did you hear about today's session?
5. Would you like more information? If so, what information?

The process of contracting and securing the commitment of five local health councils was initiated and completed in the initial phase of the project's development. With assistance from the Health Council of South Florida, each local health council identified a regional coordinator who was responsible for the implementation of the workshops in his or her district. They, in turn were asked to identify sites where the workshops would be held and local trainers who would lead selected elements of the project's curriculum.

A training workshop was planned and scheduled prior to the date for implementation of the statewide workshops. All the regional coordinators were invited to attend along with identified trainers from their regions. The purpose of that meeting was to introduce the project materials and to launch the implementation phase of the project. A list of regional coordinators and trainers is included as Attachment B .

The Regional Coordinators in each target area identified and recruited two to three regional trainers. One of the trainers selected was required to be a local clergy person or a lay-leader, the second trainer was a member from the local health planning council, and the third, a hospice provider.

B. DEVELOPMENT OF PROJECT MATERIALS

In our challenge to attract clergy, we felt we could be successful if we developed a curriculum of high quality, provided intervention techniques, offered practical tools to help clergy perform their jobs and packaged it all into an easy-to-use format. These principles guided the development of all the project materials.

The development of materials was a collaborative effort. The Advisory Committee members were forthcoming with suggestions, ideas and contacts regarding marketing, consumer and educational materials. Their input was incorporated throughout the process of compiling and creating materials for the project.

1. Outreach and Marketing Materials

The outreach and marketing of the workshops to clergy members throughout the State was a primary responsibility of the Health Council of South Florida. The Hospice Foundation and the Health Council of South Florida worked together successfully on a prior project funded by the Legislature, the *Hospice Medicaid Education Project*. Project management was able to draw on the materials and expertise gained from that experience which, like this one, involved statewide dissemination through local organizations. In addition, HFA has extensive experience in conducting outreach efforts on a national level for its annual satellite teleconference, *Living with Grief™*. In a truly collaborative undertaking, the combined talent of the HFA national staff and the statewide network created by the Health Council of South Florida contributed to a model outreach and marketing package that was made available to all the local participating health councils.

The outreach and marketing materials included the following: (See Attachment C)

- € Clergy End-of-Life Education Project marketing messages
- € Statewide press release
- € Regional press release
- € Educational session flyer
- € Project brochure
- € Radio public service announcement (PSA)
- € Questions and answers for interviews

The outreach and marketing packet of materials was presented to each of the participants at the Regional Coordinator's Training Workshop conducted in December 2002. A key feature of these materials was their adaptability to local markets by allowing for the

inclusion of local information. Each of the regional coordinators had the ensuing four weeks to comment on the materials. At the request of the coordinators, a CD containing the outreach material files was created so local information could be inserted easily.

To ensure that a consistent and clear purpose for the sessions would be communicated, the project's marketing messages were defined and given to each regional coordinator for distribution to the many trainers and program assistants who made the sessions happen at the local level.

The distribution of the press releases statewide was accomplished by posting it on the HFA and council websites as well as the website of the Department of Elder Affairs. In addition, HFA e-mailed or sent the press release to local newspapers with general circulation. Regional press releases were sent to local newspapers by the regional coordinators. HFA also released information on the clergy sessions through its e-newsletter that has a distribution of over 8,500 nationwide.

The template for an educational session flyer, suitable for mailing and community posting, was designed. It was posted on the Health Council of South Florida website. At the regional level, the education flyer information was displayed on the local health councils' websites, on co-sponsors' websites and newsletters, in local newspapers and sent as an e-mail to clergy groups and associations, places of worship and hospices.

A direct mail brochure announcing the seminar was prepared and given to each region. It was camera ready for printing and allowed the region to insert its specific dates, locations and sponsor logos. Regional coordinators sent this out as a direct mail piece to clergy groups and association, places of worship, hospices and lay leadership groups.

At the local level, coordinators were encouraged to obtain radio spots on local stations, especially those that broadcast religious programs. They were encouraged to seek out interview opportunities and were given a question and answer template to guide interviews with the media.

Each region did a mailing of the project marketing brochure and/or flyer to their respective target communities. Over 5,000 outreach brochures were mailed to promote the educational sessions throughout the participating regions. The South Florida region also conducted an initial mailing of more than 200 outreach brochures in south Miami-Dade County for the pilot test of the project.

2. Clergy Resource Materials

One of the keys to the success of the *Clergy End-of-Life Education Project* was the dissemination of high quality supplemental information to clergy. This included materials that added to their knowledge base and enhanced the educational experience of the day.

The clergy resource materials consisted of complimentary copies of HFA's audio tape set *Clergy to Clergy: Helping Clergy Minister to Families Confronting Illness, Death and*

Grief, and the books *Caregiving and Loss* and an additional book selection from the HFA *Living with Grief™* series.

The *Clergy to Clergy* tapes, published by Hospice Foundation of America, were edited by Rev. Kenneth Doka and moderated by Rev. Anita Bradshaw of Yale Divinity School, and feature nationally known members of the clergy from different faiths addressing everyday issues surrounding bereavement and grief. The series includes a lecture and discussion on the following topics:

- € Counseling Those with Life-Threatening Illness
- € The Funeral Ritual, Empowering Healing
- € When a Child Dies
- € Facing Illness as a Family
- € Complicated Mourning
- € What is Grief?

One packet including the six tapes and the accompanying resource guide was given to each clergy member who attended the sessions. Additional copies of the tapes were made available at a 50% discount. Participants were directed to listen to the tapes at their convenience and reminded that one tape included the death of a child, since this was not included as part of the curriculum due to time constraints.

Over the years, the Hospice Foundation has published a series of books generated out of the participation of leading national end-of-life experts who have spoken at its *Living with Grief™* satellite teleconferences. Each participant was given two books from the series. Everyone received *Caregiving and Loss: Family Needs, Professional Responses* (2001). In consultation with their co-sponsors, the regional coordinators were asked to choose one additional book, appropriate to its constituents, from the following list: (See Attachment D)

- € *Living with Grief: Loss in Later Life* (2002)
- € *Living with Grief: After Sudden Loss* (1996)
- € *Living with Grief: When Illness is Prolonged* (1997)
- € *Living with Grief: Who We Are, How We Grieve* (1998)
- € *Living with Grief: At Work, At School, At Worship* (1999)

The total retail value of the audio tapes and the two books is between \$61 and \$70.

Throughout the project, management was mindful of the importance of maintaining flexibility and local relevance. To that end, a format was developed and the local health councils compiled a list of local end-of-life resources that were provided to the clergy participants at each of the sessions.

3. Consumer Materials

An important product of the project was the creation and dissemination of consumer oriented educational materials that clergy could give to the families to whom they minister. These materials would have to be user friendly and comprehensive in scope.

Project management conducted an extensive library and Internet search to ascertain what information was currently available that could be provided, reproduced and disseminated

by the clergy in their faith communities. The search, conducted by the staff of the Health Council of South Florida, yielded a vast amount of material. Project management reviewed what was available and made the determination of what would best meet the needs of the end users.

Samples of the consumer packages were distributed at the Regional Coordinator Workshop session in Ft. Lauderdale and each regional coordinator had a period of time for comment. The consumer materials consisted of information on advance care planning, dealing with end-of-life care options, and/or undergoing grief and bereavement after the loss of a loved one. They were instructed that these materials could be reproduced and disseminated to members of their respective faith communities. The consumer packet included the following: (See Attachment E)

- € The Medical Futility Guidelines of South Florida – A Guide for Patients and Their Families, Health Care Surrogates, or Proxies
- € Florida Do Not Resuscitate Order
- € What You Should Know About Advance Directives
- € Florida Living Will
- € Florida Designation of a Health Care Surrogate
- € When Someone You Love Dies (brochure)
- € How to Talk About End-of-Life Concerns
- € Helping a Child Deal with Loss
- € Web-based Resources
- € End-of-Life Care Resources (by county)
- € Glossary of End-of-Life Terms

At the regional education sessions, each clergy participant received three folders containing the consumer materials. In all, 3,000 packages of the consumer materials were reproduced for the regional coordinators to distribute at the sessions. A total of 70,000 pieces of material for distribution to families were duplicated.

The regions were offered the expertise of national experts to present on the various topics included in the curriculum. Dr. Kenneth Doka spoke at four of the sessions in South Florida and one in Pensacola. Dr. Grollman was the keynote speaker at one of the Ft. Myers sessions.

4. Training Curriculum Materials

An important product developed by the *Clergy End-of-Life Education Project* was the seven-module Trainer's Manual and accompanying Participant's Manual. The formulation of the overall learning objectives and seven training modules that came out of those objectives were developed under the guiding hand of the Advisory Committee with considerable input from Dr. Kenneth Doka, members of the committee, as well as Dr. William Lamers, Medical Consultant to HFA.

The determination was made that the training sessions would be done in a one-day workshop format (approximately six instructional hours) with the option to do half-day session to meet local preferences.

The final mission statement was defined as follows:

The mission of the Clergy End-of-Life Education Project is to increase the knowledge and skills of clergy members to address end-of-life issues by educating them about bereavement and options at the end of life so that they can minister more effectively to the dying and their families.

The overall learning objectives were defined as follows:

- ∄ To provide an understanding of the physical and psychological changes brought about by the dying process.
- ∄ To enhance clergy members' ability to provide assistance to families facing the dying process.
- ∄ To provide an understanding of the advance care planning process and the care options available to persons with terminal illnesses.
- ∄ To enhance the understanding of clergy regarding the grieving process.
- ∄ To support clergy in fulfilling their role in providing spiritual care at the end of life.
- ∄ To increase the clergy's sensitivity to the need for self care.

The seven modules included the following:

Module 1.	Cultural Considerations at the End of Life
Module 2.	The Dying Process
	A. Medical
	B. Psychological Issues
Module 3	End-of-Life Options
	A. Advance Care Planning
	B. Service Options
Module 4	The Grief Process
	A. Typical Grief Reactions
	B. Complicated Grief
	C. Anticipatory Grief
Module 5	Assisting Families
Module 6	The Role of Spiritual Care
Module 7	Self Care for Clergy

(See Attachment F for the learning and content outline for each module.)

Irma Emery, consultant, was retained to compile and edit the educational materials submitted, and assemble it into a trainer's manual format that included trainer notes regarding suggested methodologies such as discussion questions, case studies, role plays and similar adult learning techniques. PowerPoint slides were developed for the modules and provided to the regional trainers on a CD. For those who chose to use them,

overhead transparencies of each slide were provided. Handout materials, suitable for reproduction, were prepared for all of the modules.

In keeping with the mandate to provide a program with the greatest possible flexibility at the local level, the Trainer's Manual included additional text material for review and use by the regional trainers as they saw fit. The content of the material in each module intentionally included more than could be presented in the time allotted to the subject matter so that the trainers could select those key points they wanted to emphasize.

One important note regarding the curriculum should be made. It was uppermost in the minds of the Advisory Committee members that cultural and ethical considerations play an important role in end-of-life decisions. When we approached the subject, it became clear that we could not address all the many cultures that comprise Florida's population. The determination was made to provide material that addressed cultural sensitivity in a general sense, and not specific cultural practices. The evaluation materials will show that trainers and workshop participants wanted information specific to the ethnic groups with whom they interact. In some sessions this became a very important issue.

VI. IMPLEMENTATION

A. IMPLEMENTATION METHODS

The implementation phase of the project occurred during the months of January through April 2003. Technical assistance calls were conducted throughout the project to assist the regional coordinators and troubleshoot any problems with recruitment, logistics, or evaluation procedures as they arose. Ongoing advice and assistance by telephone was also available through an identified staff member to provide technical assistance support.

B. PROGRAM LAUNCH

1. Regional Coordinators Training Workshop

The launching of the regional educational session began with the Regional Coordinators Training Workshop, a full-day session held in Ft. Lauderdale in December 2002. Over 30 regional coordinators and regional trainers from across the state were in attendance. They served as the project's representatives in the local communities in which the educational sessions were held. The purpose of the day's activities were threefold: (1) to acquaint the regional coordinators with the materials that had been developed to assist them in their outreach and marketing efforts, (2) to introduce the training curriculum, and (3) to outline the administrative procedures for implementation of the statewide sessions. (See Attachment G)

Each participant left with the outreach and marketing materials, the consumer toolkit, evaluation materials and draft versions of the Trainer's Manual.

The curriculum was presented by inviting speakers to present several of the modules as they might occur at a regional session. Given the time allowed, it would not have been possible to take participants through all the modules thoroughly, but, at a minimum, an overview was presented of all the curriculum content. Workshop participants were able to review a draft of the entire Trainer's Manual. In this instance, as in so many sessions to follow, response to the subject matter depended a great deal on the presentation skills of the trainer in front of the room.

Participants were asked to evaluate the training workshop and suggest recommendations for improvement in the proposed format and materials. Several suggested that the focus for the training should have been on training issues rather than content. Suggestions with regard to the curriculum content were made, including further development of the materials presented, and improvements to the module on cultural considerations. Almost 90% of the participants felt either somewhat or fully prepared to facilitate the educational sessions at the end of the one-day training workshop. The evaluation results were used to design/refine the pilot test program. As the project moved forward with implementation of sessions around the state, valuable lessons were learned and suggestions were provided through the technical assistance and evaluation efforts of the Health Council of South Florida.

The expectation at this point was that the regional sessions would be one day events. (See Attachment H) Certain modules had been designated by the Advisory Committee as "core" modules – those topics that were deemed essential to basic knowledge regarding end of life. It was, therefore, recommended that these modules be given priority in all training sessions. However from the first pilot session forward, response to the information on clergy self care (not a core module) was very positively identified by participants as among the most important information gained from their participation. In light of this feedback, and in keeping with the project's commitment to maintain flexibility, the recommendation to give priority to what management deemed as "core" was dropped in favor of the expressed needs of clergy in the community.

2. Tentative Dates and Sites Identification

Following the Regional Coordinators Training, each regional coordinator identified three to five tentative dates in the target counties for the educational sessions. A training calendar was created to guide the process and facilitate coordination among the regions.

The regional coordinators were also asked to recruit additional trainers who could provide diversity and augment the competencies of the trainers who attended the workshop. Regional trainers were strongly urged to collaborate with their local hospices and end of life coalitions. Information about the project was disseminated to the local coalitions through the Florida Hospice and Palliative Care Organization.

3. Recruitment of Participants for Educational Sessions

In order to inform the local clergy and to promote sessions, each regional coordinator identified and compiled a list of potential clergy, lay leaders, clergy groups/associations, clergy in training groups, places of worship, hospices, and leaders of community-based organizations. Each region conducted a mailing of the project marketing brochure and/or flyer to their respective target communities. Almost 5,800 outreach brochures were mailed to promote the educational sessions throughout the participating regions. The South Florida Region also conducted an initial mailing of more than 200 outreach brochures in South Miami-Dade County for the pilot test of the project. (See Table 1)

Table 1: **Distribution of Outreach and Marketing Materials by Region**

Regional Coordinator(s)	Region (Target Counties)	Pieces Distributed
Health Council of South Florida, Inc.		
€ Pilot Test	Miami-Dade	214
€ Educational Sessions	Miami-Dade Broward	1,873
Health Planning Council of Southwest Florida, Inc.	Lee	750
Local Health Council of East Central Florida, Inc.	Orange	379
Northwest Florida Health Council, Inc./Big Bend Health Council, Inc.	Escambia Leon	900
Suncoast Health Council, Inc./Health Council of West Central Florida, Inc.	Pinellas Hillsborough	1,259
Treasure Coast Health Council, Inc.	Palm Beach	420
TOTAL		5,795

The recruitment process included:

- € Identification of clergy groups/associations, community based organizations, places of worship and lay leaders.
- € Selection of potential participants for the clergy sessions and mailing list development.
- € Dissemination of outreach/marketing materials: mail-outs, follow-up phone calls, publication of press releases, flyers and announcements in local newspapers and religious bulletins/publications, Public Service Announcements on local radio stations, and posting the flyers on the local health councils' websites.
- € Pre-registration of participants.

4. Curriculum Pilot Test

A pilot test of the curriculum, presented as a one-day workshop was conducted on January 13, 2003 by the Health Council of South Florida. Twenty-one people attended the program including ministers, chaplains, pastors, caregiver support staff and bereavement counselors. The pilot test confirmed that the program format, agenda, schedule, including the time allotments for material coverage were suitable for the educational program. The content of the modules was also extremely well received and the evaluations of the trainers received favorable scores. The Dying Process was considered the most useful program component. Based on pre-test and post-test results, about half of the participants indicated an increase in their overall knowledge of end-of-life care issues. By the end of the session, however, using a retrospective assessment of knowledge, nearly two-thirds of participants indicated an increase in their overall knowledge of end-of-life issues. They indicated that the program was of particular

interest because it included not only information about death and dying, but also the options available for those at end of life, caregiving and needs of the dying, followed by self care for clergy. Many participants remarked that few programs include the importance of the clergy taking care of themselves. (See Attachment I)

C. TECHNICAL ASSISTANCE

The pilot test program format, agenda, schedule and summary results of the evaluation were presented to the regional coordinators in a technical assistance conference call on January 17, 2003. This information was provided so that the coordinators could benefit from the lessons learned and the challenges faced during the recruitment phase and pilot educational program. A video of the pilot program was prepared and disseminated to the regions. It provided highlights of the five-hour pilot test session. It showcased some of the modules as presented by the featured speakers, captured interaction with the participants and modeled how to summarize the materials presented. Other topics covered in the technical assistance calls included the outreach and marketing materials, consumer materials, regional coordinators' toolkit, contract review and regional deliverables. Timelines and procedures were discussed in full detail. The regions were encouraged to tailor their sessions in length, time of day, and module content to the respective communities' needs and interests.

A second technical assistance conference call occurred on February 25, 2003. This call provided technical assistance to the regional coordinators on the presentation of the summary reports and the educational session evaluation results. The training calendar was reviewed for clarity and coordination. Attendance at the preliminary sessions was discussed and suggestions were provided on different proven recruitment strategies to buttress attendance. The format for the evaluation reporting process was described for the first set of deliverables as contained in the interim report. A two-page model reporting format was distributed to each region and the well-attended Hollywood Hills evaluation results were provided as a model for compiling the evaluation data for each educational session.

A third and final technical assistance call was held on April 9, 2003. An extensive debriefing occurred on the implementation of the educational sessions. A discussion was held on the profile of the participants in sessions, the best practices for recruitment such as the use of local media (TV and radio), the needs of the clergy participating in the sessions, and areas for future exploration such as advance care planning and practical guidance on how to complete the various forms (e.g., living wills, health care surrogates, durable power of attorney, etc.). Specific reporting requirements and project deliverable deadlines were also covered.

In terms of reporting tools, instruments were developed both for the regional coordinators and the statewide regional coordinator that codified the technical assistance and project oversight during the field experience. Selected items are contained in Attachment J.

D. REGIONAL EDUCATION SESSIONS

Following the pilot test (on January 13, 2003), 21 educational sessions were conducted in the six regions across the state from February 5, 2003 through April 23, 2003. (See Attachment K for a list of the sessions as displayed by health planning district.)

Each region held between three and four sessions. All sites offered the program at different locations with the exception of Treasure Coast Health Council which conducted two at its office and were later combined as one session/site. Three regions determined that it was necessary to cancel a single session, largely due to the need to allow more time for advertisement and recruitment to take place. Only one cancelled due to poor registration in March.

Momentum was generated as the program became publicized across the local communities. “Word of mouth” advertisement in particular, prompted a surge in overall participation. During the initial 11 sessions there were 236 participants and two cancellations. In the latter sessions, there were 377 participants with a single cancellation, and an increased participation rate of nearly 60%. This informal advertisement complemented the distribution of the program flyers and encouraged more clergy to attend. As momentum grew, the project team began to realize a greater return on its investment and generated a stronger outcome of increased program participation.

VII. EVALUATION

A. EVALUATION METHODS

To evaluate the outcome of the sessions, two evaluation instruments were utilized: the Participant Profile and the Session Evaluation Forms. (See Attachment L)

The Participant Profile Form, which was distributed at the beginning of the session, includes participant information (name, title, degree, organization, and contact information); role/position in the faith community; demographic information (age, gender, race, and ethnicity); level of knowledge of end-of-life care, and how the individual learned about the educational session.

The Session Evaluation Forms were distributed for collection at the end of the session. The evaluation forms were collected prior to the presentation of the Certificate of Attendance to generate a high response rate. The evaluation instrument asks for comments on what was the most/least helpful part of the program, suggestions for future educational sessions, rating of the individual components of the program, perception about being better prepared to minister to their faith community at the end of life, and the level of agreement/disagreement with statements related to modules covered during the educational session. A major feature is the question that asks the participant to rate his/her level of knowledge of end-of-life care both pre-session and at the end of the program.

The evaluation results cover the entire project implementation from January through April 2003. They represent findings based on 22 education sessions and the compilation of results from all participant surveys filled out by the participating clergy, lay leaders and other attendees from faith communities in the six regions across the State of Florida. A total of 613 clergy and lay persons attended the sessions with an average number of 28 people at each program. While nine counties were originally targeted for implementation, a total of 13 were actually included in the project upon its conclusion. In addition, many of the participants attending the 22 sessions resided in surrounding counties, increasing the statewide coverage to a total of 28 counties, or 41.8% of all Florida counties. A summary of the evaluation instruments completed by the participating regions is provided in Attachment M.

B. VENUE

Of the 22 sessions, 15 were held in church settings representing 68.2% of the total. Another 7 or 31.8% were conducted in secular locations such as hospices, a local library, a community college and a local health council. Average attendance was 10.4% higher in sessions held in church venues.

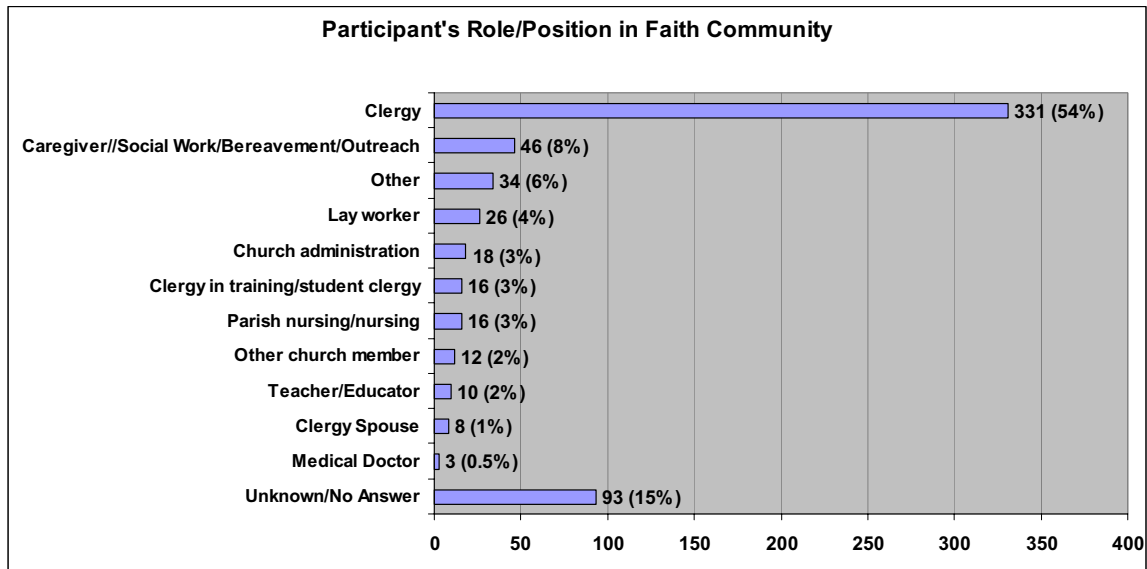
C. PARTICIPANT PROFILE RESULTS

Role/Position

A total of 536 attendees completed the participant profile at the beginning of the education session. Of these responses, a majority (54.0%) reported themselves as being clergy. These are inclusive of chaplains, deacons, ministers, rectors, reverends, priests,

and rabbis. They also include assistant and associate ministers. The next most frequent participant types included caregiver/patient relations/social worker and bereavement/outreach workers (7.5%); lay workers (4.2%); and church administrators (2.9%). All others rated less than 2.6% each. (See Figure 1.)

Figure 1

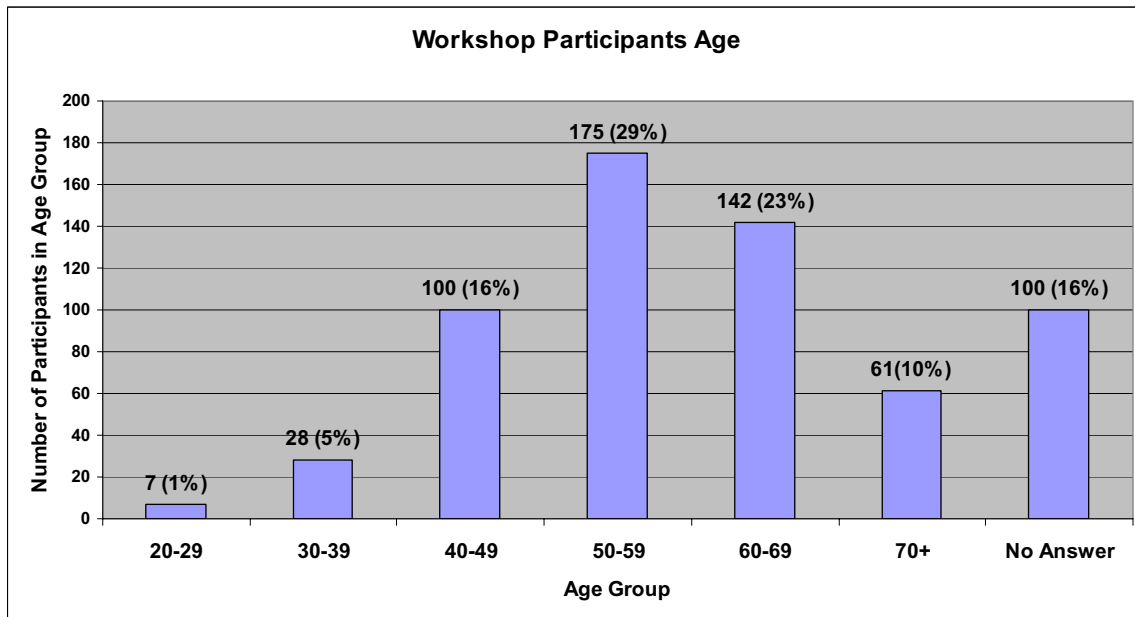


Regions tended to follow a similar pattern with the exception of Northwest Florida/Big Bend which had a high turnout of lay workers (16%) and South Florida with a good turnout of clergy in training (7.9%).

Age

The average age of clergy/caregiver/lay worker participants was generally in the middle ranges. (See Figure 2.) While people of all ages attended, the largest group was between the ages of 50-59 years (28.6%); followed by 60-69 year olds (23.2%) and the 40-49 year olds (16.3%). Together they represented 68% of the participants. A striking 10% were over the age of 70 years, and 4.6% were ages 30-39. All regions showed a clustering in the middle age groups. (See Figure 2.)

Figure 2



Gender

No major gender differences were observed. Both men (45.0%) and women (43.7%) were represented. Only Treasure Coast (54.3%) and South Florida (52.4%) had a majority of female participants.

Race and Ethnicity

Nearly two-thirds of the participants were White (64.6%). About 13% were African American, compared to 14.6% in Florida overall. However, a large segment of this total was from South Florida which had a 25% African American participation rate. Hispanics comprised 9.1% of the respondents, a smaller proportion than that found in the general Florida population (16.8%). It should be noted that over half of the participants did not respond to this question.

Geographic Location

The largest portion of participants reported that they lived in suburbia (31.7%). Another 18.1% reported they resided in an urban area. Only 7.0% reported living in a rural community. Once again, however, many respondents did not answer this particular question. No marked differences appear by region.

Means of Hearing about the Session

Over a third of the participants (34.6%) heard about the session through the mail or received an invitation. A little over 10% received information from a flyer. Another 6.7% heard about the session they attended via a religious publication. Well over a third (35.6%) indicated another means of notification. By region, over 38.7% in the

Northwest Florida/Big Bend area reported an “other” source of hearing about the session. This may be due to the television and radio coverage they received which was not listed as one of the possible responses. South Florida also had a large “Other” response (45.1%) as it relied heavily on media, word of mouth and email/personal contacts when traditional means of notification were not as successful.

Participant Summary

Of the 613 participants most were clergy leaders of different faiths and groups across the state. Many also had caregiver responsibilities as part of their professional or lay ministry. The vast majority of the participants were between the ages of 40 and 69 years, and there seemed to be a near even distribution among men and women. While nearly two-thirds of the participants were White, a fairly representative group of African American clergy participated, particularly from South Florida. Many of the participants reported that they resided in a suburban or urban area. While mail and invitations were the means by which over a third of the participants heard about the session, a sizeable portion also learned about the program from other means, which could include media, word of mouth, e-mail and other personal contacts, to name a few. (See Attachment N.)

D. PRE-TEST AND POST-TEST EVALUATION RESULTS

Changes in Knowledge of End-of-Life Issues

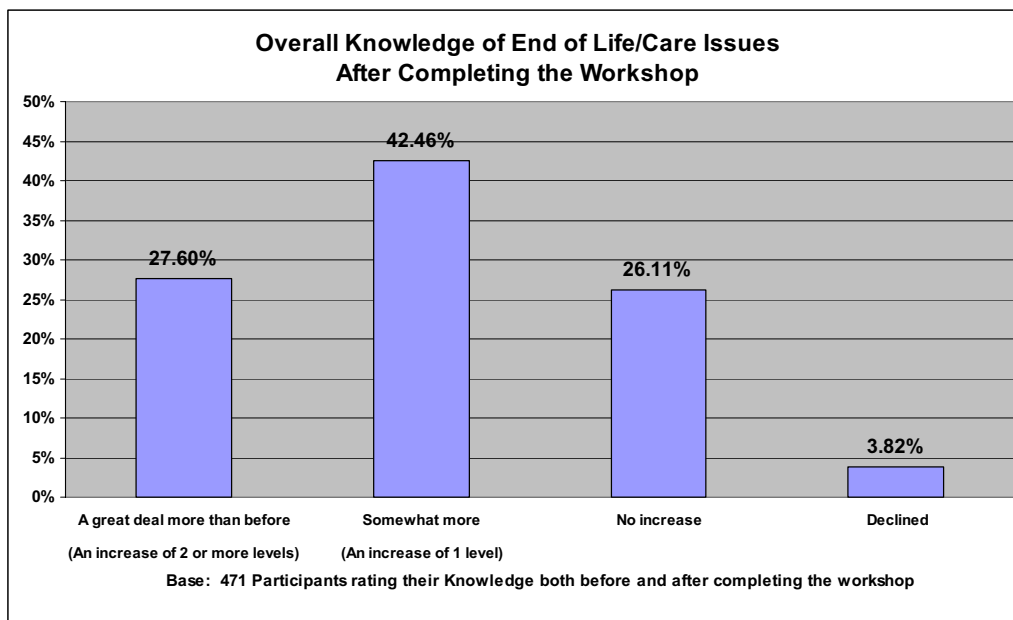
Table 2 and Figure 3 show that approximately 70% of those participants who completed both the pre-test and post-test reported a higher level of knowledge of end-of-life care on the post-test than they did on the pre-test. Of those who felt that their knowledge of end-of-life issues had room for improvement (i.e., those who had not already rated their knowledge as “excellent” in the pre-test), 80% reported a positive change. Given that both measures occurred on the same day, it seems difficult to attribute this change to the impact of causes other than the educational session. (See also Attachment O.)

Table 2

**Knowledge Level of End of Life/Care Issues
Following the Workshop**

Grand Total (All Regions)		
A great deal more than before (An increase of 2 or more levels)	130	27.60%
Somewhat more (An increase of 1 level)	200	42.46%
No increase	123	26.11%
Declined	18	3.82%
Number of participants rating Knowledge both before and after the workshop	471	100.00%
Northwest Florida/Big Bend (Districts 1 and 2)		
A great deal more than before (An increase of 2 or more levels)	34	28.81%
Somewhat more (An increase of 1 level)	51	43.22%
No increase	31	26.27%
Declined	2	1.69%
Number of participants rating Knowledge both before and after the workshop	118	100.00%
Suncoast/West Central Florida (Districts 5 and 6)		
A great deal more than before (An increase of 2 or more levels)	11	18.33%
Somewhat more (An increase of 1 level)	22	36.67%
No increase	19	31.67%
Declined	8	13.33%
Number of participants rating Knowledge both before and after the workshop	60	100.00%
East Central Florida (District 7)		
A great deal more than before (An increase of 2 or more levels)	18	33.96%
Somewhat more (An increase of 1 level)	22	41.51%
No increase	13	24.53%
Declined	0	0.00%
Number of participants rating Knowledge both before and after the workshop	53	100.00%
Southwest Florida (District 8)		
A great deal more than before (An increase of 2 or more levels)	17	26.56%
Somewhat more (An increase of 1 level)	21	32.81%
No increase	23	35.94%
Declined	3	4.69%
Number of participants rating Knowledge both before and after the workshop	64	100.00%
Treasure Coast (District 9)		
A great deal more than before (An increase of 2 or more levels)	12	26.67%
Somewhat more (An increase of 1 level)	27	60.00%
No increase	5	11.11%
Declined	1	2.22%
Number of participants rating Knowledge both before and after the workshop	45	100.00%
South Florida (District 11)		
A great deal more than before (An increase of 2 or more levels)	38	29.01%
Somewhat more (An increase of 1 level)	57	43.51%
No increase	32	24.43%
Declined	4	3.05%
Number of participants rating Knowledge both before and after the workshop	131	100.00%

Figure 3



As shown in Figure 4, there were differences among the six regions in the proportion of participants who reported a higher level of knowledge at post-test. For example, roughly 87% of participants in the Treasure Coast regional training reported a higher level of knowledge at post-test, versus only 55% of those in the Suncoast/West Florida region. However, as noted below, these differences in outcomes may reflect the backgrounds of the trainees rather than regional differences in the quality of the educational experience.

Figure 4

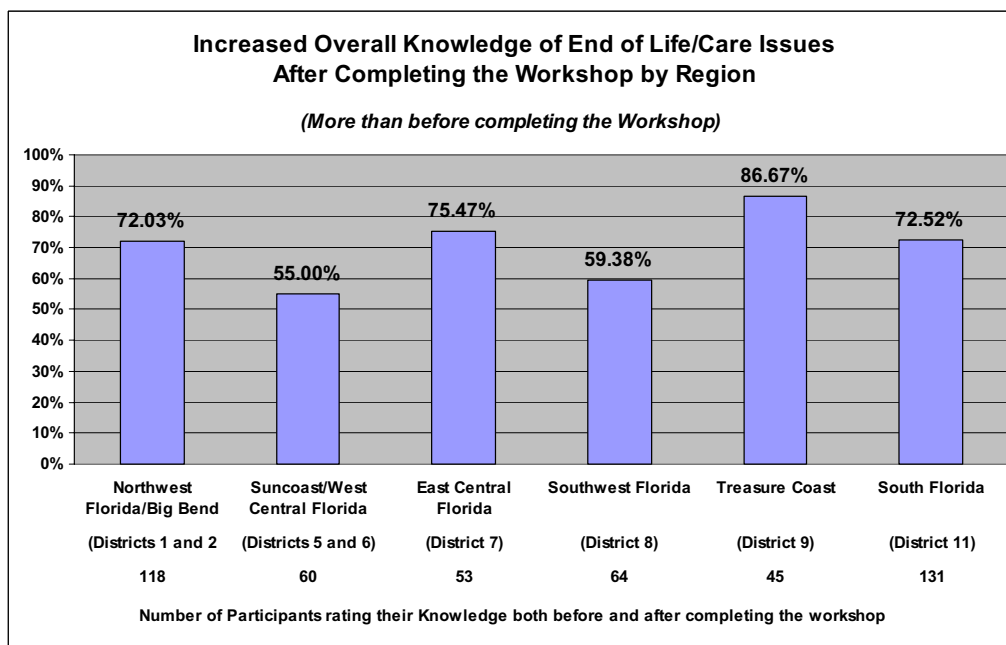
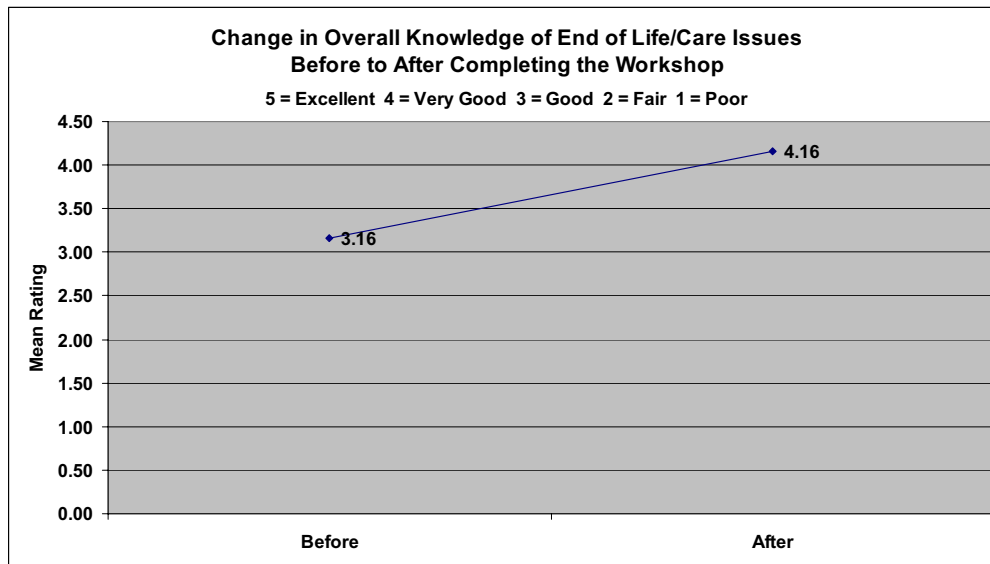


Table 3 and Figure 5 illustrate the change from pre-test to post-test in the average level of knowledge for the entire group and for each region when this knowledge is expressed as the mean (or “average”) value of the participants’ responses. As the figure shows, the mean score for all participants showed a change from a “good” level of knowledge to a “very good” level of knowledge.

Table 3
Knowledge of End of Life/Care Issues
Mean Rating
 (Excellent = 5 Very Good = 4 Good = 3 Fair = 2 Poor = 1)

	Pre	Post	Shift
Grand Total (All Regions)	3.16	4.16	1.00
Northwest Florida/Big Bend (Districts 1 and 2)	3.05	4.07	1.02
Suncoast/West Central Florida (Districts 5 and 6)	3.40	4.02	0.62
East Central Florida (District 7)	3.02	4.20	1.18
Southwest Florida (District 8)	3.17	4.11	0.94
Treasure Coast (District 9)	3.13	4.31	1.18
South Florida (District 11)	3.22	4.26	1.04

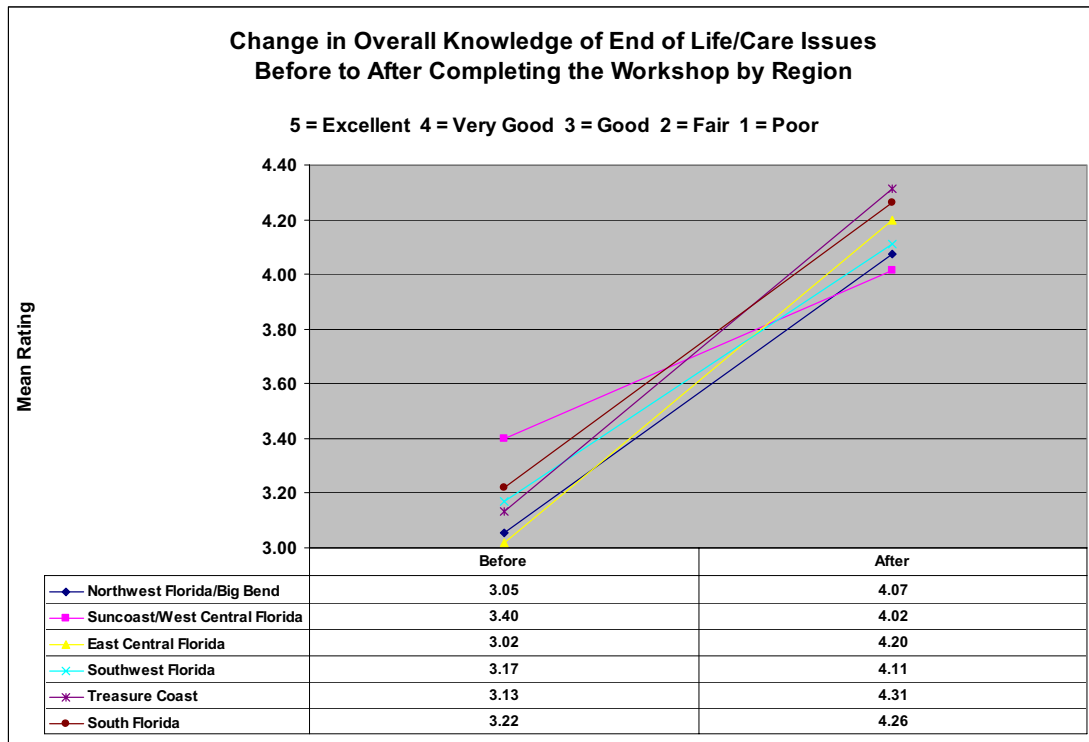
Figure 5



In part, the regional differences in outcomes reflected in Figure 6 may be a function of differences in the baseline level of participants’ knowledge across regions at the time of the pre-test. As an example, the Suncoast/West Florida region, which showed the smallest increase in average score, includes those participants who reported the highest average level of knowledge at pre-test. Thus, the apparent differences in the program’s

impact on knowledge across regions, as shown in the figures, appears to reflect, at least in part, differences in the prior training and background of the participants in different regions.

Figure 6



A final perspective on changes in self-perceived knowledge of end-of-life issues is offered by noting the substantial changes from pre-test to post-test in the percentage of persons who described their knowledge as “fair” or “poor” and as “excellent”. At pre-test, roughly one in four participants (25.5%) described their knowledge as only “fair” or “poor” whereas at post-test only five participants (0.8%) described their knowledge at these low levels. Similarly, participants describing their knowledge as “excellent” grew from 10.4% at pre-test to 24.5% at post-test. If non-respondents are excluded, the proportion describing their knowledge as “excellent” among those who completed both questionnaires is even higher (30.3%).

Preparation for End-of-Life Ministry

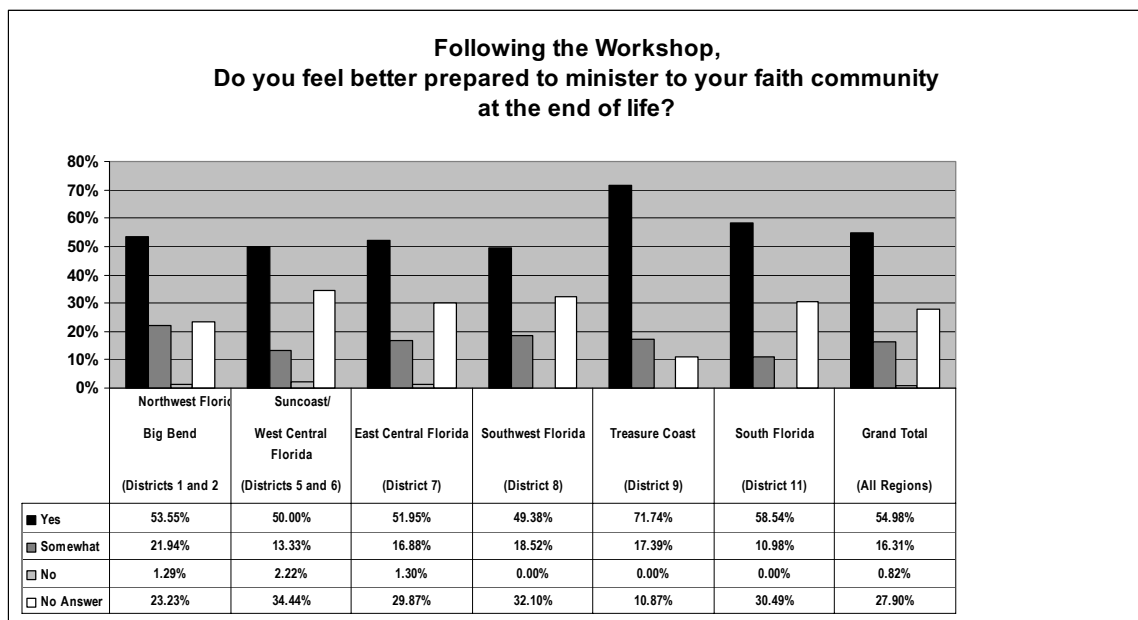
Following the training, participants were asked whether they felt prepared to minister to their faith community at the end of life. As shown in Table 4, 171 participants did not answer this question, but among the 442 who did answer it virtually all felt prepared or “somewhat” prepared. Only five participants (1.1% of the 442 participants who answered the question and 0.8% of all participants) answered “no”. Affirmative responses included “yes” (76.2% of those who answered the question and 55% of all participants) and “somewhat” (22.6% of respondents and 16.3% of participants).

Feelings of being prepared were constantly high across the regions, ranging between 49.4% and 71.7%. (See Figure 7.) In fact, many expressed during the sessions that once they reviewed all the handout materials including audio tapes and books, their knowledge would increase even more.

Table 4
Following the Workshop,
Do you feel prepared to minister to your faith community at the end of life?

	Yes	Somewhat	No	No Answer	Participants
Grand Total (All Regions)	337 54.98%	100 16.31%	5 0.82%	171 27.90%	613 100.00%
Northwest Florida/Big Bend (Districts 1 and 2)	83 53.55%	34 21.94%	2 1.29%	36 23.23%	155 100.00%
Suncoast/West Central Florida (Districts 5 and 6)	45 50.00%	12 13.33%	2 2.22%	31 34.44%	90 100.00%
East Central Florida (District 7)	40 51.95%	13 16.88%	1 1.30%	23 29.87%	77 100.00%
Southwest Florida (District 8)	40 49.38%	15 18.52%	0 0.00%	26 32.10%	81 100.00%
Treasure Coast (District 9)	33 71.74%	8 17.39%	0 0.00%	5 10.87%	46 100.00%
South Florida (District 11)	96 58.54%	18 10.98%	0 0.00%	50 30.49%	164 100.00%

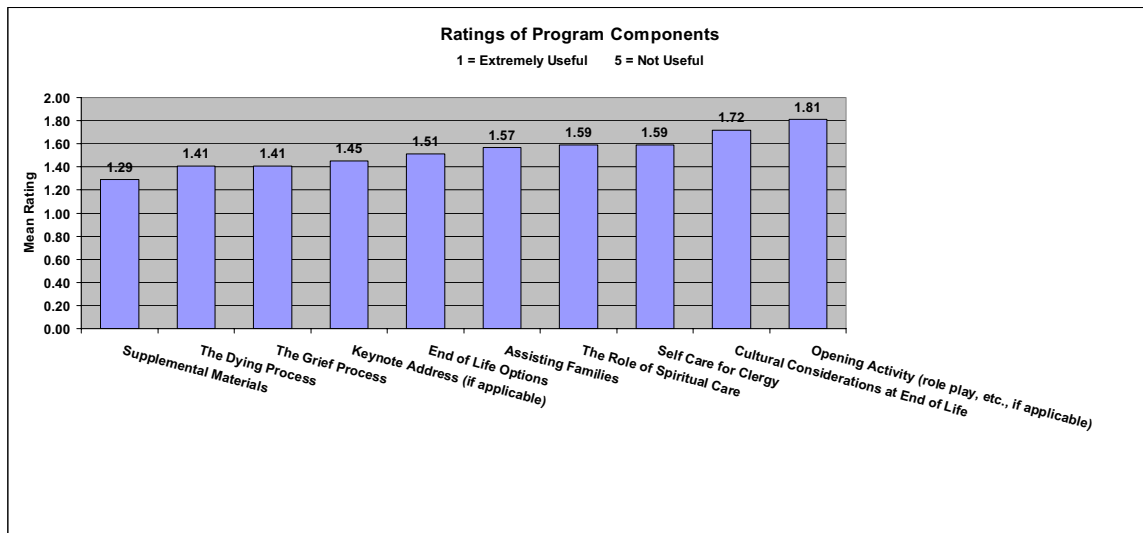
Figure 7



Evaluation of Program Components

Participants were asked to rate the utility of ten different components of the educational program on a five point scale where one indicated “extremely useful” and five denoted “not useful”. Generally, all components were perceived as very useful with average scores between 1.29 and 1.81. (See Figure 8.) At each training, the supplemental materials were rated as the single most useful component. Other components with very high scores on utility were “The Dying Process” and “The Grief Process”. Perceived as least useful were components on “Cultural Considerations at the End of Life” and the “Opening Session/Role Play”. The ranking of components was highly consistent across the multiple performance sites. (See Attachment P)

Figure 8



When participants were asked on the post-test to name the most useful components of the curriculum, a wide variety of responses were offered with many indicating that “the entire program/everything was helpful” (17.4%). However, the two specific components most often identified were “the dying process” (17.4%) and “the grief process” (13.2%). (See Figure 9.) When asked which component was least useful, the modal response was that all parts were useful (42.5%). However, among those who identified least useful components, the most common responses were “the role playing” (9.0%) and “the role of spiritual care” (7.6%). (See Figure 10.)

Figure 9

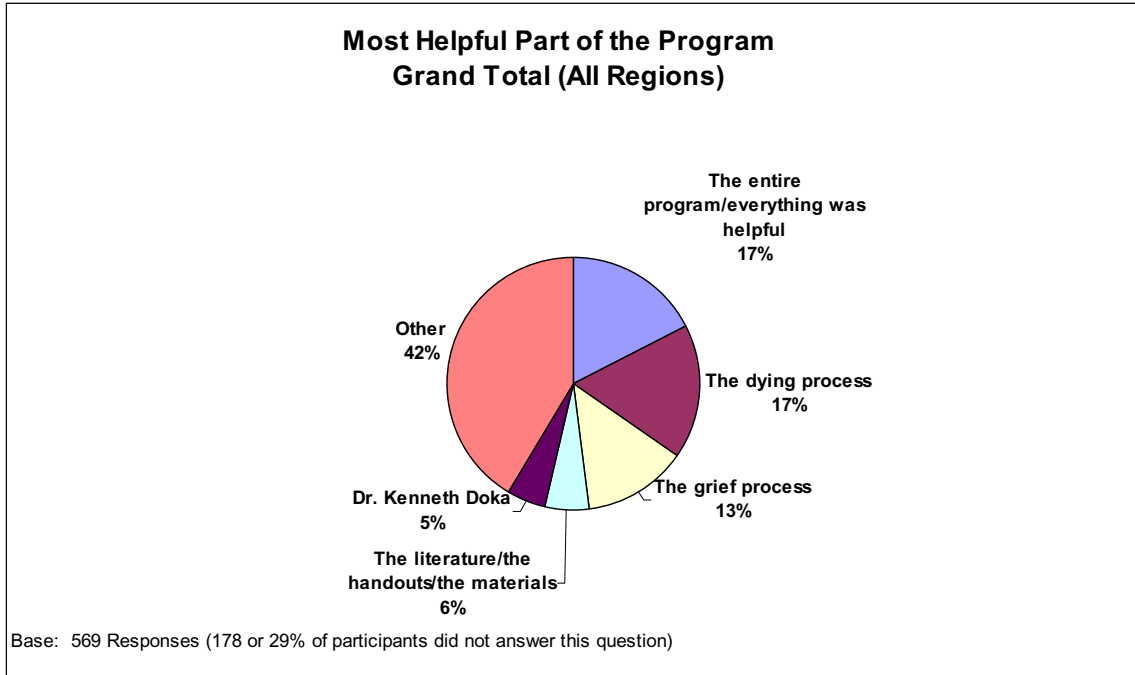
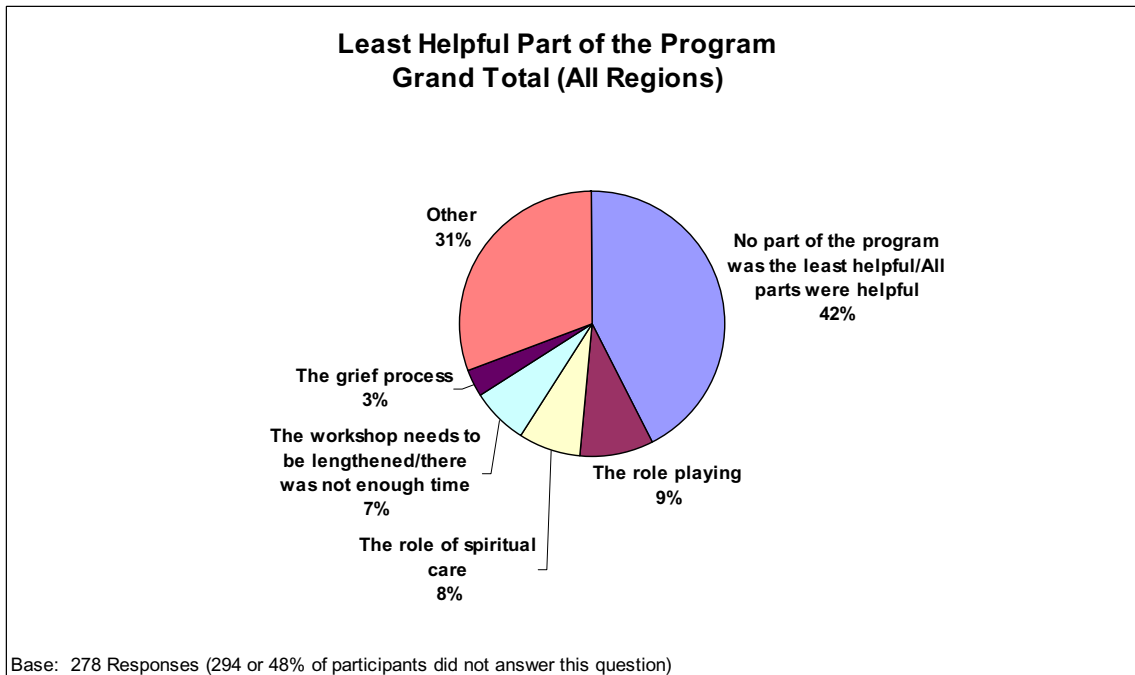
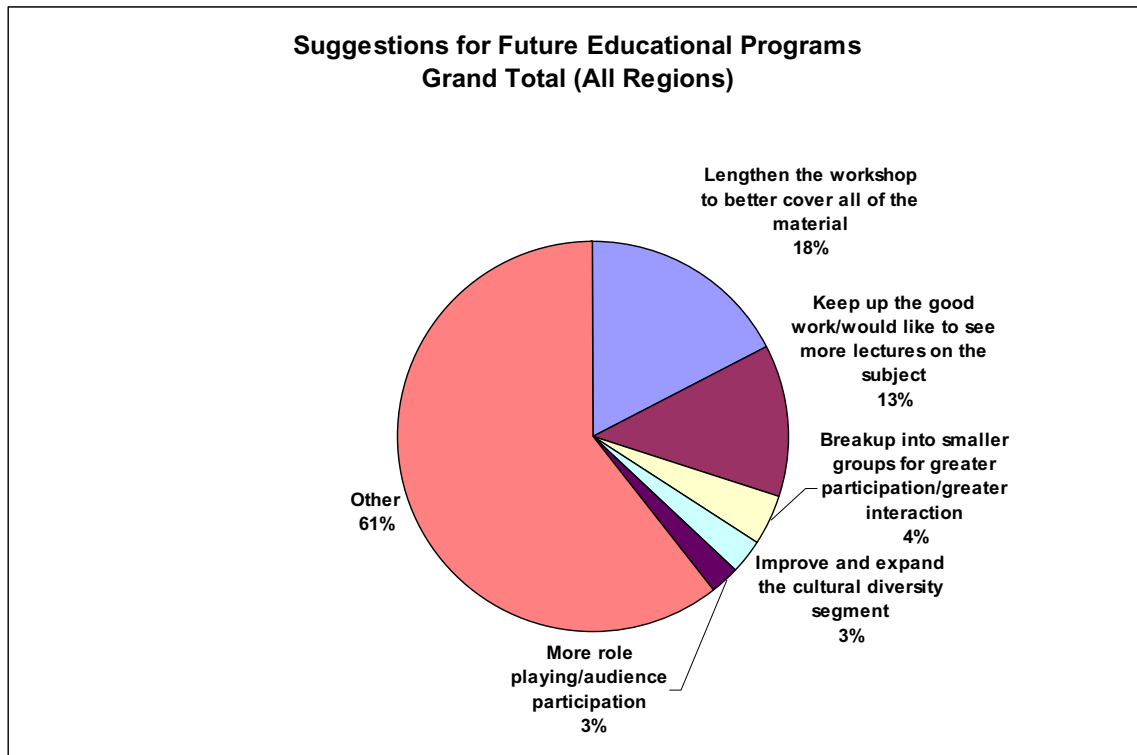


Figure 10



When asked for suggestions for improvement of the trainings, the most frequent responses that the participants suggested were: “lengthen the workshop to better cover all of the material” (17.5%), and “would like to see more lectures on the subject” (12.5%). Others suggested breaking up into smaller groups (4%), expanding the cultural diversity segment (3%) and engaging in more role playing/audience participation (3%). (See Figure 11 and Attachment Q.)

Figure 11



Self-Reported Outcomes/Impacts

Participants were asked to respond to seven Likert-type questions in order to assess their own perceptions of impact and their plan to utilize materials. All responses clustered in an area from “somewhat agree” into the “strongly agree” range, indicating quite positive outcomes. The strongest agreement was with the item that stated “Being able to address my own personal issues concerning end-of-life issues will help me to minister more effectively to others”. The vast majority (71.5%) of the 424 persons who responded to this question strongly agreed and not one respondent disagreed, (i.e., no responses of 4, 5, or 6 were recorded on the six point response scale.) Conversely, participants were least likely to agree strongly with the statement “I am better able to discuss end-of-life issues with individuals of diverse ethnic/racial backgrounds.” Only 37.3% of those answering the question agreed strongly, although most showed some level of agreement. Eighteen

participants who answered this question (4.3%) disagreed to some degree with this statement. It is worthy of note that this response is consistent with the somewhat lower level of approval received by this curriculum component. It may be that participants remain somewhat ill at ease in addressing end-of-life issues in communities culturally distinct from their own.

The large majority of respondents agreed that they were “better informed about issues related to the end of life (spiritual, medical or psychological)” after training, with 57% agreeing strongly and less than 1% disagreeing. However, when questions addressed specific types of knowledge, agreement was not quite as strong. An item measuring increased knowledge about “advance care planning, including do not resuscitate orders, health care surrogates and advance directives” drew responses of strongly agree from only 47.3% with 4.1% disagreeing. Similarly, an item measuring a “better understanding of the process of grief and the intervention approaches available at the time of death and throughout the grief process” drew strongly agree responses from about 50% and disagree responses from only 1.4%. A similar proportion agreed strongly that they had a clearer understanding of “my role in ministering to dying persons and their families.” (48.7% agreed strongly and 2.4% disagreed).

A single item measured intent to use “the curriculum and consumer materials within my local community.” Fifty-five percent of respondents agreed strongly with this statement and 100% expressed some degree of agreement. (See Table 5 and Attachment R.)

Table 5

Statement Agreement/Disagreement

Grand Total (All Regions)	Strongly Agree (1)	Somewhat Agree (2)	Agree (3)	Disagree (4)	Somewhat Disagree (5)	Strongly Disagree (6)	No Answer	Responses	Participants	Mean Rating
I plan to utilize the curriculum and consumer materials within my local community.	230	66	124	0	0	0	193	420	613	1.75
Being able to address my own personal issues concerning end of life issues will help me to minister more effectively to others.	303	37	84	0	0	0	189	424	613	1.48
I am better able to discuss end of life care options with individuals of diverse ethnic/racial backgrounds.	155	115	127	16	2	0	198	415	613	2.02
I am better informed about issues related to the end of life (e.g., spiritual, medical and/or psychological).	241	82	96	3	0	0	191	422	613	1.67
I have a better understanding of the process of grief and the intervention approaches available at the time of death and throughout the grief process.	210	91	110	5	1	0	196	417	613	1.79
I have a clearer understanding of my role in ministering to dying persons and their families.	204	86	119	7	3	0	194	419	613	1.85
I am more knowledgeable about advance care planning, including do not resuscitate orders, health care surrogates and advance directives.	195	80	120	14	2	1	201	412	613	1.91

Pre-Test and Post-Test Summary

In summary, a very high proportion of participants reported that they had a higher level of knowledge of end-of-life care issues upon completion of this training. It appears that trainees felt most confident that the training had helped them address personal issues and understand medical and spiritual issues in a manner that would improve their ministry. They also generally felt better informed about technical, procedural and legal issues than they did prior to the training, but their responses did not express quite as high a degree of confidence in their mastery of these more complex and detailed components. The complexity of these issues may also be reflected in the number of participants who asked for expanded time and more training.

It appears that the training offered at these six locations will affect many communities throughout Florida. All participants (100%) stated that they intend to utilize the curriculum and consumer materials in their communities. This intention appears consistent with the very high utility score awarded to the supplemental materials. This heavy emphasis on useful materials for application in home communities suggests that maintenance of communication and updating of materials may be important post-training support mechanisms for the participants.

VIII. RECOMMENDATIONS

The purpose of this section is to go behind the pure numbers presented in the evaluation section and combine the statistics with the on-site observations of the Advisory Committee, trainers, regional coordinators and project management.

In this section we have looked back to capture what we learned and looked forward toward potential expansion and improvement of the products developed by the *Clergy End-of-Life Education Project*. We share some the lessons learned during the course of the project and suggest things that worked well and those that we would do differently in the future. With the help of the Advisory Committee, we have taken a look forward and developed recommendation for future endeavors to educate the faith communities of Florida.

A. Lessons Learned

The project managers learned many valuable lessons in the course of planning, designing and implementing this ambitious statewide project over a relatively short period. While the evaluation clearly indicates a high level of success, future clergy education programs can achieve even greater results. Attempts to educate clergy in end-of-life issues should build upon the recommendations which grow out of our experience. The best way to optimize results is to conduct a candid assessment of the lessons learned.

Curriculum.

The curriculum received high scores for comprehensiveness by participants. When asked what else they would like to have included, they responded “more of the same.” The project created a curriculum that was relevant to the needs of the clergy. We would not omit any part of the curriculum. There are parts that would benefit from further development, as outlined below, but the concepts of the program have proven their worth and relevance to the target audience.

Cultural Issues. The issues of cultural and ethnic differences are of key importance. The beliefs of particular cultures inform attitudes throughout the range of end-of-life decisions, from the point of advance care planning through the dying process, death rituals, and the time of grieving. The issues are as diverse as the cultural and ethnic mix of the population in any given area. In a program of this scope and duration, it would not have been possible to provide answers to all the questions that participants will have about cultural differences, nor to present all the cultural facets of an issue. It is, however, important to provide resources and direction so that local faith communities are prepared to serve their members in culturally appropriate ways. In several presentations the lack of cultural relevance was noted, and in other sessions the presenters felt it was just below the surface. Because the cultural mix is specific to a given locality, this component of a

clergy education program must be designed in concert with members of the cultural and ethnic groups living in the area. Extra time must be allowed to cover the topic. The

literature on the subject is increasing and can be added to the resource materials for the program.

Self Care. The project staff was surprised by the strong positive response to the inclusion of self care as a module. Many participants noted that it was the first time anyone had paid attention to it and they were pleased to learn that they were not alone in their stress. It clearly struck a cord with clergy members present at the sessions and should be developed more fully as a key component for any future programming.

Spiritual Issues. The experience of the field training staff indicated a high level of tolerance and respect for the religious beliefs of other participants at the session. In the course of the development of the program, the staff may have approached this topic with some reservation for fear that controversy might arise during the presentation. The topic of spiritual issues at the end of life is receiving increased recognition by end-of-life service providers and one to which members of the clergy have an important contribution to make. We would do well to empower and embolden clergy participants to explore their own and their constituent's spiritual issues around death and dying in order to serve them better.

Resource Materials. The plan to include take-home materials for further study and distribution within the participants' faith communities was an excellent one. Participants left the sessions with a broad array of resources to draw upon. Their appreciation and gratitude was much in evidence. Any future programming would include the same level of resources, subject only to inclusion of updated materials as they become available.

Program Length. Lengthening the workshop to cover more of the material, suggested by some participants (18%), may provide a richer experience and would permit the inclusion of additional modules suggested by the Advisory Committee. However, the one day session resulted in a 70% increase in knowledge and lengthening the session may preclude some clergy from being able to attend and receive the "full value" of the program. Moreover, the cost of lengthening the session into a day and a half or two day conference would significantly increase the cost of producing the program.

Didactic vs. Participatory Approaches. Greater audience participation and the use of illustrations/stories was a repeated suggestion for improvement. This was suggested by participants at the pilot test and later sessions as well as by the program's creators and the Advisory Committee. Some of the project team leaders felt a strong need to convey the curriculum and relevant materials in a structured manner. This, coupled with the abbreviated time frame, led to the decision to emphasize a didactic approach. Several regions amended their programs to permit greater interaction and felt that this enhanced the overall program's efficacy. One option for future local replication of the program might be to conduct the program through a series of discussion sessions led by featured presenters and trained facilitators. This series could be held over a longer period if more than one session is required, although the cost factor in this approach is again raised.

Project Management

Train-the Trainer Approach. From the beginning project managers were concerned about the uniformity of presentations in the various sessions. We found that participant response to the presentations reflected the skills, knowledge and sensitivity of the trainers. The project learned an important lesson from this experience. It had been a part of the work plan to present the curriculum statewide using a train-the-trainer approach. This was to take place as part of the Regional Coordinator's Workshop conducted at the point of statewide launching of the project. We quickly learned that we had not allocated sufficient time to this part of the day's schedule. When disseminating a similar program in the future emphasis must be placed on the selection of statewide trainer based on specific criteria. Once the trainers have been identified, adequate time must be devoted to familiarization with the content of the curriculum they are being asked to deliver. In addition, it is imperative that the trainers be equipped to convey the full intent of the program in a culturally sensitive manner.

Community Outreach and Program Implementation. The Health Council of South Florida devoted significant time and effort to the development of a marketing approach and accompanying materials that were distributed to the regional organizations charged with implementation. This aspect of the project was well designed and can serve as a template for future projects that use this dissemination model.

The Health Council of South Florida, as a sub-contractor, was responsible for guiding the outreach efforts and implementation process on a statewide basis. There are two specific skills sets needed to conduct effective community outreach and to manage the implementation of local education offerings: one is the ability to engage people, talk to groups, approach individuals to solicit support and the like; the other is good organizational, management and statistical skills. These are very different skills and are seldom embodied in one individual. It is important, therefore, to select local organizations that have staff members who can fulfill both functions.

The *Clergy End-of-Life Education Project* was conducted, from start to finish, within a one-year period. That fact precluded sufficient time to publicize and promote the program with enough advance notice. The local health councils did extraordinary work in compiling lists and contacts through which the sessions were made known. However, cooperation with statewide and regional religious councils and associations was hampered by the timeline. Future programs should find a way to start the promotion campaign well in advance of the event.

Project Evaluation

Cross Tabulation of Data. The Advisory Committee alerted project managers that collection of data from clergy might be difficult. However a lot of data was collected, and a more refined analysis of it could offer even greater insights. For example, did clergy respond to the questions differently than non-clergy participants? Were people of color more likely to express concerns over the cultural considerations module? How did the results differ by age, gender or faith community? These are but a few of the potential

areas for further analysis. Such results would be invaluable in ascertaining the best methods for replication, further development, refinement and dissemination of this highly successful program.

B. Recommendations for the Future

The Advisory Committee convened at the conclusion of the project for a one-day session in which the project was reviewed, the evaluation results were presented and recommendations brainstormed for future efforts to improve and disseminate the program. The following suggestions were offered:

1. While participation by members of the clergy was significant, the program also attracted lay members of faith communities who assist in pastoral care tasks. Participation included large congregations as well as small, rural as well as urban. The Committee recommended that future efforts focus on the composition of the audience and gear the program accordingly to include the learning needs of both clergy and lay leadership. In planning future meetings, consideration should be given to setting aside some part of a day's activities for clergy members to meet in a separate session to allow for discussion that might be suppressed in a mixed clergy/lay group.
2. Clergy are clearly interested in increasing their knowledge. One suggestion brought forth was the possibility of developing the curriculum into a certificate program in conjunction with an accredited university or end-of-life center. Such a program would be especially efficacious as a distance learning offering.
3. It was suggested that a clergy education program be offered to local hospitals as a means of adding credibility to the program. This would reinforce the notion within the medical community that clergy are an essential part of the hospital care team.
4. The Committee members noted that the program attracted a preponderance of older people and that it is important to bring end-of-life knowledge to clergy members at the outset of their ministries. It was suggested that conveners of end-of-life curriculum such as HFA partner with seminaries and/or institutions of higher learning that prepare faith leaders at the Masters and post-graduate level in order to reach a young audience and influence their careers from the beginning.
5. In addition to the partnerships mentioned above, the Committee recommended building natural relationships with other organizations that share common concerns such as AIDS organizations. They recommended that relationships with hospice and palliative care groups, particularly the Partnership for Caring, be continued and reinforced. Through their local contacts, these organizations possess a unique networking capability that is invaluable in outreach and marketing efforts. Their influences may not be readily seen or measured, but they will be clearly felt. A partnership with the Area Agencies on Aging is a natural collaboration that should be pursued.

6. In keeping with the project management's recognition that a strong train-the-trainer effort must be included, the Committee recommended that a minimum of a full day and a half session be required for anyone who agrees to be a trainer at any local session throughout the state. The training would be devoted exclusively to familiarization with the materials, practice presentations and reinforcement of presentation skills.
7. Future advisory committees could include representatives from a seminary, a chaplaincy organization, someone who could represent issues relevant to Hispanic groups, area agencies on aging, and other organizations that interface with faith communities.
8. With respect to the curriculum, the Committee had a number of recommendations:
 - € Given the large and growing Spanish-speaking population throughout the State of Florida, the program should be translated into Spanish. At a minimum, the consumer materials, handouts and PowerPoint presentation should be available in Spanish.
 - € They urged HFA to convert as much of the curriculum as possible to the EPEC (Education for Physicians in End-of-Life Care) model as much as possible. The EPEC materials are available for anyone to use and are applicable to a non-physician audience as well. Some topics, essential to this audience, are not included in the EPEC program such as self care, spiritual care, cultural issues, and the grief process. These are modules that would benefit from further refinement. The project was urged to standardize the curriculum and create PowerPoint presentations that would guide program content and permit standardized training.
 - € The development of qualification criteria for those who will be conducting the local education sessions should be a priority. (The material is only as good as the person presenting it.) There are a significant number of certified EPEC trainers throughout the state who could be called upon as qualified trainers to present portions of the program. In addition, ELNEC (End-of-Life Nursing Education Consortium) now has a cadre of nurse educators who could form part of an expert trainer team throughout the state. Hospice staff continue to be another valuable source of trainers with in-depth knowledge..
 - € The Committee grappled with the complexity of how to appropriately incorporate the cultural component into the curriculum materials. The recommendation was to incorporate local input and expertise to address issues distinctive to their ethnic or cultural group. Discussion questions that will increase participants' awareness and sensitivity about historical beliefs, taboos, rituals, and customs could be developed.
 - € Due to the high incidence of grief involving children, it was recommended that a module on children's grief be included. This would cover instances of

children with terminal illnesses or diseases and children experiencing significant loss.

- € In addition to the topic areas included in the curriculum, the Committee recommended the inclusion of a module, or the incorporation throughout the modules, of material that addresses ethical issues at the end of life. Such topics as self-determination, autonomy and informed consent are appropriate issues for discussion in clergy education in end-of-life issues.

ATTACHMENTS

