

Community & Global Initiative: Faith-Based Palliative Care Initiative

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Purpose

- The purpose of the two-phase initiative was to test the feasibility of an interdisciplinary university-community participatory service learning project.
- The project was designed to enhance undergraduate and graduate education with service learning opportunities unavailable in the classroom.
- The project provided service that contributes to the quality of life for individuals and groups in the community by increasing the capacity of selected faith organizations to address unmet palliative care and end-of-life education and support needs in their faith communities.

The Project

- Faculty and students from Nursing, Theology, Medicine and Pharmacy in collaboration with community partners, led the project.
- Lay health advisors, recruited from faith organizations in the Atlanta area, were trained to participate in all phases of the initiative, and contributed significantly to the sustainability of the project.

Phase I

- Activities in Phase I included
 - (1) assessing congregational interest in the project,
 - (2) identifying partners to participate in training to become lay health advisors, and
 - (3) assessing learning needs of congregations.

Phase II

- Phase II included
 - (1) preparation of training modules and other training materials,
 - (2) orienting and training students and community lay advisors,
 - (3) implementing training modules, and
 - (4) program evaluation.

Training Modules:

- Project investigators provided a series of training modules to equip lay members of congregations to offer palliative care (comfort care) and end-of-life care for members of their congregations.
- *Introduction to Palliative care (Overview of Project)*
- *Ethical Issues at the End of Life*
- *Cultural Considerations / Spiritual Care*
- *Communicating with Patients & Families about End-of-Life Care*
- *Loss, Grief and Bereavement*
- *Care during the Final Hours of Life.*

The classes met at participants' churches at times designed by the participants. Classes met for approximately for 1 ½ hours.

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Overview of Mercer University Palliative Care Initiative



- *What is Palliative Care?*
- *What is The Mercer Palliative Care Initiative?*
- *Why is it important?*
- *What is the purpose?*

How can this project help my congregation?

What are the training topics?

What is Palliative Care?

- Palliative care is an approach to care for individuals and their caregivers who are facing problems associated with serious or life-threatening illness, grief and bereavement. This care addresses physical, spiritual, psychological, and social needs.
- The focus of Palliative Care is Comfort, Supportive Treatments, and Bereavement Support. It is *not* intended to hasten nor postpone death but to improve quality of life.

What is the Mercer University Palliative Care Initiative?

- The Mercer University Palliative care Initiative was developed by a group of faculty members from Mercer University (Nursing, Medicine, Pharmacy and Theology) and community partners.
- The project is designed to equip congregational lay health advisors (Mercer Care Partners) to provide end-of-life and palliative care education and support for members of their congregation – and to enhance the congregation's ongoing *Circle of Care*.

Enhancing Congregational Circles of Care

The Continuing Circle of Care

- Caring for babies at the beginning of life
- Caring for children through adulthood
- Caring for new church members

Preventing a Break in the Circle of Care

- Reaching out to members facing illness, end of life, and grief to prepare them for the challenges they face and anticipate and provide the support they need
- Provide support consistently over time

Importance of Lay Health Workers in Congregational Ministry and in the Community

- Many reports in the literature document the effectiveness of lay health workers in *congregations*.
- Many reports in the literature document the effectiveness of lay health workers in the *community*.

The Purpose of the Mercer University Palliative Care Initiative

To provide a series of training sessions in palliative and end-of-life care and support to outreach volunteers in churches. These lay health advisors will be known as *Mercer Care Partners*.

How Can Mercer Care Partners Be Helpful To Our Congregation ?

- Care Partners will assist their pastors and church leaders to enhance the church's ongoing compassionate and skilled care ministry for those who are facing serious life limiting illness, end-of-life or grief experiences.
- Care Partners will have access to a variety of spiritually and culturally appropriate resources to help members who need palliative and end-of-life care.

Care Partners can help address psychological and Spiritual Concerns of the Dying

Those concerns include:

- The process of dying
- Spiritual issues
- Reconciling differences with others
- Being forgotten after death
- Fear of being abandoned
- Fear of the unknown

Other Concerns: Patient and Family Perspectives about their place of death

- PREFERENCE: Patient and family research indicates that most people prefer to
 - die at home, surrounded by loved ones.
 - have spiritual support
 - be as comfortable as possible.
- REALITY: Most people die in hospitals or other institutions.

Egan & Labayak, 2006; Field & Cassel, 1997

Role of Care Partners

We will explore opportunities to provide education and support to assist members of the congregation who are facing these issues of death, grief, loss and spiritual concerns.

Topics of Study to be Provided by the Mercer Palliative Care Project

- Ethics
- Cultural Considerations
- Communication with individuals with life threatening illness of those near the end of life (and their families)
- Loss, Grief, Bereavement, Spiritual Care
- Providing Care During the Final Hours of Life

Examples of Discussion Points for *Ethics Training Session*

- What are Advance Directives?
- How do I make my last wishes known?
- Where should I keep my Advance Directive?
- Who gets a copy?
- What questions should I ask my physician if I become seriously ill?
- What forms are recommended in Georgia? In other states?

Examples of Discussion Points for *Cultural Considerations Training Session*

- What are the components of ‘culture’?
- How do cultural differences impact palliative and end-of-life care?
- How can I become ‘culturally competent’ to provide care?

Examples of Discussion Points for *Communication Training Session*

- How do I practice the five steps of open, honest, compassionate communication with someone near the end of life? (Stop, Look, Listen, Respond, Maintain Confidentiality)
- How do I practice therapeutic presence (or mindful presence)?

Examples of Discussion Points for *Grief, Loss, Bereavement and Spiritual Care Training Session*

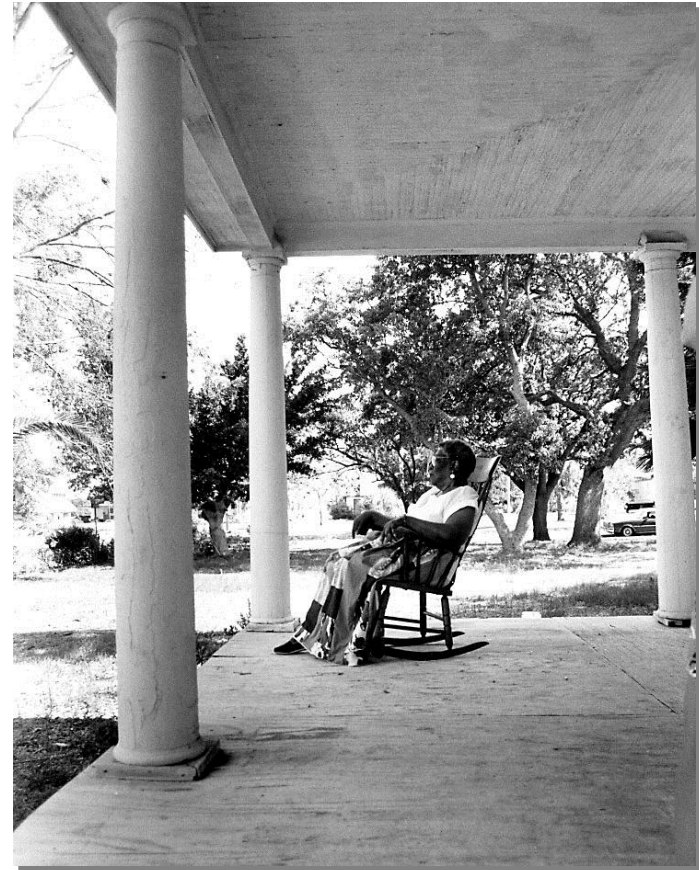
- How do I recognize stages of grief?
- What are the five tasks of mourning?
- What is a ‘timetable for grief work’?
- How can I help someone who is grieving (with psychological and with practical help)?
- What is “spiritual care” and how can I be a spiritual caregiver?

Examples of Discussion Points for *Providing Care at the Time of Death* Training Session

- How will I recognize that someone is dying?
- What should my response be (to the family and to the person who is dying)?
- How can I be most helpful?

Opportunities for Growth

- The last phase of life provides continued opportunities for positive growth in the face of suffering



Completion of Forms at Information Session

- Form to determine your interest in becoming Care Partner
- Form to determine your interest in having a Care Partner assist you in the future
- Your time requests for educational sessions to be provided.
- List of topics and signatures of members who plan to attend.

Other Required Forms

- At the first training session, Care Partner trainees will be asked to complete anonymous questionnaires to help faculty better understand your thoughts, perceptions, or concerns related to palliative / end-of-life care.

Other Required Forms (cont'd)

- Consent forms will also be completed by members of congregation who receive care or training from Mercer Care Partners. These forms will be completed at the time of the first visit.

Confidentiality Issues

- Confidentiality is respected on all forms. Each participant was identified as a code number on forms - known only to the Mercer faculty. All responses were anonymous.
- Confidentiality was respected in every interaction between faculty, Mercer Care Partners, and those we serve.

Benefits for Faculty, Students, and Community Partners

FACULTY and STUDENTS:

- Enhanced teaching, research and outreach activities
- Greater faculty and student engagement in community issues

COMMUNITIES

- Opportunities for communities to build relationships with universities and contribute to the educational process.

- STUDENTS

Students were provided real world experiences that enable learning possibilities precluded in more traditional pedagogies

Resulted in enhanced ability to positively impact the well-being of communities and encourage their sense of personal and professional responsibility to others.

Results

- *Mercer Care Partners*, the participants who complete the training, were provided with information and support to strengthen their skills to provide their congregations palliative care (comfort care) training .
- *Mercer Care Partners* are prepared to provide care and support for members of the congregation who are facing serious illness, end of life issues, grief and bereavement.
- All information collected during the project was used to evaluate the effectiveness of the project and provided information for faculty and church congregations to guide future projects.

- Mercer will use the information to plan and improve additional projects that are designed to assist *Mercer Care Partners* to provide congregational care and support in palliative care and end-of-life care and to evaluate the training to determine if this type of training effectively meets needs of congregations and how the training might be improved. Feedback from community partners guides all aspects of the initiative.

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- The goals of the initiative continue Mercer's tradition of service learning and are consistent with Mercer University and GBCN goals to further enhance the learning environment to engage in students in holistic and transformational learning.