



Team Customizes, Pilots End-of-Life Curriculum for African-American Health Care Professionals

The EPEC2 Project: End-of-life care education for African-American health care professionals

SUMMARY

From 2002 to 2004, a project team headed by [Richard Payne, MD](#), created a new curriculum that teaches essential clinical competencies and practical skills needed to provide culturally appropriate palliative and end-of-life care to African Americans.

The project was part of the Robert Wood Johnson Foundation's (RWJF) national program *Targeted End-of-Life Projects Initiative*.

APPEAL (A Progressive Palliative Care Educational Curriculum for Care of African Americans at Life's End; previously called EPEC2) was adapted from Education in Palliative and End-of-Life Care (EPEC), an end-of-life-care curriculum for practicing physicians, developed with primary support from the Robert Wood Johnson Foundation (RWJF). (See the [Program Results Report](#) on ID# 040507.)

Key Results

- Small teams of faculty piloted the curriculum at seven sites across the country, including at historically black medical schools and at the 2003 annual meeting of the [National Medical Association](#). Some 400 professionals involved in the end-of-life care of African Americans attended a training session.
- Based on the pilot trainings, the project team is revising the curriculum and raising funds for a wider dissemination of the program.

Funding

RWJF provided \$444,115 for this *solicited* project. North General Hospital (New York City) served as the disburser of funds.

THE PROBLEM

Most practicing physicians receive little training in the care of dying patients as part of their medical education. To address this gap, RWJF in 1997 funded the creation of EPEC (Education in Palliative and End-of-Life Care; see the [Program Results Report](#) on ID# 040507, a curriculum designed to educate practicing physicians on the essential clinical competencies for providing quality end-of-life care.

In 2000, RWJF also funded the Excellence in End-of-Life Nursing Education Consortium (ELNEC), a program to educate nursing school faculty on end-of-life care and integrate the learning into their schools' curricula (see the [Program Results Report](#) on ID# 048733.)

By 2001, EPEC and ELNEC training sessions were reaching significant numbers of physicians, nurses and other health professionals, but a very small percentage were African American. At the August 2001 annual conference of the National Medical Association, representatives from Tuskegee's National Center for Bioethics as well as Howard University College of Medicine surveyed some 150 African-American health care professionals about their perceptions of the EPEC program.

Some 76 percent said they were unaware of EPEC, and 93 percent did not know an African-American physician who had taken the EPEC training ("African American Physicians' Interest in End of Life Training" survey, 2001.)

Focus groups involving 34 African-American physicians in four regions of the country conducted in 2002 noted that EPEC did not adequately address the following areas important in the care of African Americans at the end of life:

- The role of extended family networks.
- The role of spirituality and faith in healing.
- The challenges minority patients encounter when making end-of-life decisions in a setting of incomplete access to full medical care.

These physicians said African-American health care providers needed more education in several areas, including pain and symptom management, knowledge of available local community resources and when and how to discuss advanced directives (Crawley L. "Focus Group Study with African American Physicians in Four U.S. Regions;" funded by the Nathan Cummings Foundation, 2002, Stanford University).

Context

This project fell under RWJF's *Targeted End-of-Life Projects Initiative*, which supports solicited and unsolicited projects that advance RWJF's objective to improve care at the end of life.

RWJF has pursued three strategies in its effort to improve care at the end of life:

- To improve the knowledge and capacity of health care professionals and others to care for the dying.
- To improve the institutional environment in health care institutions and in public policies and regulatory apparatus to enable better care of the dying.
- To engage the public and professionals in efforts to improve end-of-life care.

This project fit within the first of these strategies.

THE PROJECT

The APPEAL curriculum was designed to educate health care professionals (doctors, medical students, nurses, social workers, divinity students, spiritual leaders, professional caregivers and community advocates involved in end-of-life care) about essential clinical competencies and practical skills needed to provide culturally appropriate palliative and end-of-life care to African Americans.

APPEAL aimed primarily at African-American clinicians, who historically have provided a significant portion of health care services to African-American patients. To establish an independent identity for the new curriculum, the name was changed from EPEC2 to APPEAL.

Co-directors of the project were Marian Gray Secundy, PhD, former director of the Tuskegee University Center for Bioethics in Research and Health and professor emeritus at Howard University College of Medicine (now deceased), and [Richard Payne, MD](#), who at the time of the grant was Chief of Pain & Palliative Care at Memorial Sloan-Kettering Cancer Center in New York and an instructor at North General Hospital. After Secundy's unexpected death in December 2002, Payne oversaw the project, along with [Robert Williams, MD](#), a senior attending physician at Howard University Hospital and a faculty member at Howard University College of Medicine.

Using his contacts in the African-American medical community, Payne (with Secundy's help before her death) recruited advisory committee members, faculty and independent contractors to work on the project (see [Appendices 1, 2 and 3](#) for lists).

A team that included the project co-directors, appointed faculty, and independent editors reviewed the existing instructional modules from EPEC and other end-of-life curricula. They identified gaps and revised and changed the content to be culturally relevant to African Americans. Advisory committee members gave expert advice to the project co-directors.

Faculty members took the basic EPEC training either before or shortly after the grant started to ensure familiarity with the topics covered in the original curriculum. At a one-and-a-half day meeting in December 2002 at Memorial Sloan-Kettering Hospital in New York, Payne and Williams walked the faculty through the proposed APPEAL curriculum, module by module, in order to build a teaching model for the program. See [Results](#) for details about the curriculum components developed.

Independent contractors working on various aspects of the project had the following roles:

- [September Williams](#) and her company, Ninth Month Productions, coordinated the development of the audiovisual segments that accompany the curriculum.
- Sharon R. Latson of Stewart Communications, a public relations firm in Chicago, provided project management services.
- Annette Dula, PhD, a professional editor, writer and expert in ethics and health care for African Americans, helped write the curriculum.
- [Dr. LaVera Crawley](#), a researcher and lecturer at Stanford Center for Biomedical Ethics, Stanford Medical School, helped write the curriculum.

Project staff announced the APPEAL curriculum at the National Medical Association Annual Convention in August 2003 in Honolulu, and presented abbreviated content in post-conference sessions to generate interest among physicians and health care professionals. To recruit participants for the APPEAL trainings held in conjunction with national conferences, project staff got help from the local and regional partners sponsoring the conferences. To recruit for the trainings held at universities, project staff put notices in campus and alumni newsletters and advertised through local electronic and print media.

Project staff and advisory board members made 35 presentations about the APPEAL program to professional organizations across the country. Among these were the NAACP (2002 and 2003), the Association of Black Cardiologists (2002), the American Alliance of Cancer Pain Initiatives (2002 and 2003) and the Black Nurses Association (2002 and 2003).

The project also launched a website (no longer in existence) for the APPEAL curriculum, which links to 13 related websites. See the [Bibliography](#) for details.

RESULTS

The project generated the following results:

- **The project team created APPEAL, a seven-module curriculum on end-of-life care for African Americans.** The curriculum covers these topics:
 - *Comprehensive Patient Evaluation:* the characteristics of a patient's condition and experience, disease history, physical symptoms, psychological symptoms, decision-making capacity, information sharing, social circumstances, spiritual, psychosocial, cultural needs, and practical needs.
 - *Culturally Appropriate Communication:* helps participants build upon their own knowledge and use skills gained to improve communication.
 - *Quality End-of-Life Care:* reviews barriers to quality care and solutions to addressing these barriers.
 - *Pain Treatment and Racial Disparities:* focuses on the principles of pain assessment and management with data documenting disparities grounded in racial, ethnic and gender factors.
 - *Patient-Centered Decision Making—Advanced Care Planning:* delineates the components of advance care planning for African-American patients.
 - *Fundamentals of Hospice Care:* discusses indications for referral and the levels of service; examines barriers to hospice and looks at the relatively low percentage of hospice use.
 - *Spirituality in End-of-Life Care:* explores the important relationship between spirituality and medicine in end-of-life care for African Americans and historical implications.
- **The curriculum package includes a participant's manual and these teaching tools:**
 - A 90-minute DVD, "When We Are Asked," includes interviews with doctors, nurses and other health care providers as well as role-playing segments.
 - PowerPoint presentations for each module topic.
 - Pre- and post-training questionnaires and evaluation forms for participants.
- **In 2003 and 2004, APPEAL faculty teams piloted the curriculum in seven free training sessions attended by 400 health care professionals.** The training sessions were held at historically black medical schools and at national conferences:
 - Charles Drew University of Medicine and Science (Los Angeles, September 2003, 77 participants).

- Morehouse School of Medicine (Atlanta, November 2003, 29 participants).
- Miles College (Birmingham, Ala., December 2003, 34 participants).
- Howard University College of Medicine (Washington, March 2004, 44 participants).
- National Medical Association's Annual Meeting (Philadelphia, August 2003, 86 participants).
- National Medical Association 2003 Regional Meeting (Chicago, May 2003, 58 participants).
- "Last Miles of the Way Home: A National Conference to Improve End-of-Life Care for African Americans" (see the [Program Results Report](#) on ID# 047348 Atlanta, February 2004, 79 participants).
- **The sessions attracted a wide variety of professionals, but not as many physicians, training directors of teaching hospitals or other key decision-makers as hoped.** Attendees included 35 percent physicians; 15 percent nurses; 15 percent medical students; and the remainder, other professionals involved with care at the end of life.

LESSONS LEARNED

1. **When renaming a project, do it early in the process, before time and money have gone into building a "brand name."** EPEC2 became APPEAL after considerable time and expense had gone into building the project's original identity. The process had to be repeated to build the new name. (Project Director/Payne)
2. **Recruit teams of professionals, rather than individuals, to foster immediate practical application of the learning in clinical settings.** For future APPEAL training sessions, project staff hope to attract interdisciplinary teams consisting of, for example, a doctor, nurse and social worker or pharmacist. "We think this is the best way to have a more powerful local resource that will also train other health care professionals. We want to emphasize translating the educational experience into real life and best practice." (Project Director/Payne)
3. **Select strong regional and local partners when introducing a new curriculum to the medical community.** It is difficult to get the right people (key decision-makers, hospital training directors) interested unless there is a well-regarded partner with the resources and interest to market the training many weeks in advance. (Project Director/Payne)

AFTERWARD

As of the date this report was written, the project director was seeking funding for an expanded APPEAL program. Priorities included developing modules for bereavement and an expanded module on how to communicate better with the dying and their families. An expanded APPEAL faculty of 26 held a meeting in December 2005 at Duke University, Durham, N.C., to discuss modifying the curriculum and to plan for future teaching sessions.

APPEAL received \$150,000 in funding from the Aetna Foundation for three years beginning in July 2005 and \$50,000 from the United States Cancer Pain Relief Committee, Madison, Wis., for one year beginning in December 2005.

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Grant ID# 43073

Program area: Quality/Equality

APPENDIX 1

Advisory Committee of Progressive Palliative Care Educational Curriculum for the Care of African Americans at Life's End

(Current as of the end date of the program; provided by the program's management; not verified by RWJF.)

Myra Christopher
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APPENDIX 2

Faculty for "A Progressive Palliative Care Educational Curriculum for the Care of African Americans at Life's End"

(Current as of the end date of the program; provided by the program's management; not verified by RWJF.)

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APPENDIX 3

Independent Contractors Working on APPEAL Project

(Current as of the end date of the program; provided by the program's management; not verified by RWJF.)

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BIBLIOGRAPHY

(Current as of date of the report; as provided by the grantee organization; not verified by RWJF; items not available from RWJF.)

Audio-Visuals and Computer Software

When We Are Asked, 90-minute DVD with seven modules on palliative and end-of-life care for African Americans. San Francisco: Ninth Month Productions, 2003.

Grantee Websites

www.appealproject.org, no longer in existence, included brief audio samples of the DVD, *When We Are Asked*, an overview of APPEAL (A Progressive Palliative Care Educational Curriculum for the Care of African Americans at Life's End) program for African-American health care professionals, and links to related websites.