Launch of End of Life/Palliative Education Resource Center Creates Online National Clearinghouse of Information

Development of the National Resource Center for End-of-Life Physician Education

SUMMARY

From September 1999 through December 2003, project staff at the Medical College of Wisconsin, Milwaukee, developed, launched and expanded a website called the End of Life / Palliative Education Resource Center.

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

Key Results

- In April 2000, the project launched the End of Life / Palliative Education Resource Center, a free, searchable clearinghouse of online education materials on end-of-life care.

  The website provides users with peer-reviewed educational materials, recommended books and articles, training opportunities, funding sources, conferences and links to other resources on the World Wide Web.

  — More than 262 abstracts describe the educational materials available on the site, including syllabi, evaluation tools, videos, case studies and PowerPoint presentations.

  — The site also contains a number of tools specifically for educators:

    - One-page summaries to use as teaching tools.
    - Brief overviews of educational concepts and strategies.
    - Sample exam questions.
    - Standardized patient cases.
— A weekly electronic newsletter announces new materials on the website, answers questions previously submitted and communicates the latest news on end-of-life care.

- By mid-2004, the website had 12,000 registered users from 104 countries and was getting more than 300,000 hits per month.

**Funding**

Two grants from RWJF totaling $1,293,127 funded the project between September 1999 and December 2003.

**THE PROBLEM**

In 1997, RWJF brought together a coalition of 120 national health and consumer groups, called the Last Acts Provider Task Force, to identify critical areas of need to improve end-of-life care. The task force report cited the lack of quality educational materials specifically designed for medical student and postgraduate training and for continuing education training for physicians.

In the late 1990s, several groups launched national education projects to help correct this deficit—the American Board of Internal Medicine end-of-life training requirements and the National Board of Medical Examiners end-of-life project, which increased the content and quality of end-of-life questions on the U.S. medical licensing exam, among others. These programs continue to seek and develop new educational materials. At the same time, academic and community hospitals have been embracing palliative care as a needed component of medical care. As interest in end-of-life care broadens, the field will need wider dissemination of physician education material.

**CONTEXT**

RWJF funded this project under its *Targeted End-of-Life Projects Initiative*, which pursues three strategic objectives 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.

The grants to the Medical College of Wisconsin to develop a website fit within the first strategy.
THE PROJECT

Under grant #036547, project staff at Medical College of Wisconsin pursued four goals:

- To develop an Internet-based resource center to educate medical students, postgraduates and physicians in end-of-life care.
- To provide a peer-review forum for materials evaluated by national experts in palliative care and consistent with standards for faculty recognition and promotion.
- To ensure that the website is fully accessed by educators and serves as a forum for the exchange of ideas and information.
- To provide guidance and suggestions to authors of submitted materials so they can improve the quality and usefulness of the materials.

Under grant #045195, project staff sought to make the website more technologically sophisticated and to broaden its offerings to include additional listings of peer-reviewed educational materials, including methods (i.e., examinations) to assess how effectively students learned and more specialty-specific materials such as those for surgeons, neurologists and oncologists.

The Palliative Care Program and the Office of Educational Services at the Medical College of Wisconsin jointly managed the project, which grants to the Medical College of Wisconsin funded. The project staff subcontracted with Quantum Research Corporation (now QRC Division of Macro International, an opinion research firm with headquarters in Washington) to set up the website. An external advisory committee (see the Appendix) provided project oversight and coordinated project activities with other national end-of-life initiatives.

Project staff also conferred regularly with staff of other professional health care groups, including the American Board of Hospice and Palliative Medicine, the American Geriatrics Society and the Society of Teachers of Family Medicine, as they developed the website.

Project staff envisioned the website as a "one-stop shop" for educators to find quality information on end-of-life care that could be integrated easily into medical education curricula. Because the end-of-life field was in the early stages of developing strong educational materials, initial submissions for the site were limited and varied in quality.

Project staff sought to solicit materials for the site through a variety of means, including personal contact, recommendations of advisory committee members, advertisements in professional journals and outreach at organizational meetings attended by end-of-life educators. Staff also solicited as contributors those who made presentations at various professional meetings, and they made site visits to leading researchers in the field to gather materials.
To insure the quality of the materials, project staff instituted a peer-review process in which experts in end-of-life education evaluated the submitted materials both in terms of end-of-life content and educational quality. Reviewers provided feedback via e-mail to authors about how to revise materials to make them appropriate for inclusion (see Results).

Project staff also held workshops for authors at medical meetings and published an article in the Winter 1999 issue of the *Journal of Palliative Medicine* (Simpson D et al.) on the variables associated with strong versus weak educational materials. (See the Bibliography for details.)

Over the course of the project, staff engaged in a number of activities to market the site to potential users, including dissemination of brochures and materials through mailings, e-mail and at meetings of national medical and health-related organizations; and announcements in numerous electronic newsletters and on listservs (see Communications for specific activities). Marketing efforts waned in the fourth year, however, as resources diminished and were allocated for other purposes.

**RESULTS**

Project staff reported the following results to RWJF:

- **In April 2000, the project launched the End of Life / Palliative Education Resource Center**, a free, searchable clearinghouse of online education materials on end-of-life care. The website provides users with peer-reviewed educational materials, recommended books and articles, training opportunities, funding sources, conferences and links to other resources on the World Wide Web. A weekly electronic newsletter announces new materials on the website, reminds subscribers to visit the site, answers questions previously submitted and communicates the latest news on end-of-life care.

  - More than 262 abstracts describe the educational materials available through the site. These materials include syllabi, evaluation tools, videos, case studies and PowerPoint presentations. More than 140 reviewers, 70 clinical content experts and 70 education experts participate in the formal peer-review process of the contributed materials.

  - The site also contains a number of tools specifically for educators:
    - "Fast facts and concepts," one-page summaries to use as teaching tools.
    - "Edu-mentals," brief overviews of educational concepts and strategies for teachers, curriculum authors, assessors and evaluators.
    - Sample exam questions and standardized patient cases.
The redesign of the site, under the second grant, added several new features to improve "user friendliness." Users can search for materials according to the six competencies in end-of-life education endorsed by the Accreditation Council for Graduate Medical Education. They can link to books and articles, including the National Library of Medicine's PubMed database. Physicians may also download information from the site onto their PDAs (personal digital assistants, such as a Palm Pilot) to use immediately in clinical settings.

A weekly electronic newsletter announces new materials on the website, answers questions previously submitted and communicates the latest news on end-of-life care.

- **By mid-2004, the website had 12,000 registered users from 104 countries and was getting more than 300,000 hits per month.** Although originally intended for medical educators, the site draws many users from social work, the clergy and nursing as well as medical specialties such as pediatrics, surgery and internal medicine. More than 40 organizations provide a link to the website on their own website, including the American Association for Cancer Education, the American College of Physicians, Americans for Better Care of the Dying and the American Association of Colleges of Nursing.

**Communications**

The project staff's activities to market the site to potential users are described in The Project. Over the course of the grant, project staff made more than 40 presentations about the website to medical groups and distributed 7,400 brochures at 17 regional and national meetings, including those of the American Association of Hospice and Palliative Medicine and the National Hospice and Palliative Care Organization.

In addition to these efforts, project staff published six articles about aspects of the project in the peer-reviewed *Journal of Palliative Medicine*. (See the Bibliography for details.)

**LESSONS LEARNED**

1. **You must be proactive in soliciting material from busy educators.** When submission of quality end-of-life materials was slower than expected, project staff made a site visit to two of the top researchers and educators in the field to personally gather their materials to be included on the website. (Project Director)

2. **Successful websites require ongoing revision and updating.** Through periodic online assessment and questions, the center staff was able to respond to user needs by increasing the number of listings and the number of specialty-specific listings as well as improving the site's user-friendliness. (Project Director)

3. **Allocate enough funds to market a new website aggressively.** Marketing took more time and money than expected to generate results. Although the project increased
funding for this purpose, the growth of the site waned in the fourth year as resources ran out. (Project Director)

4. **Engage a seasoned subcontractor to help design and administer a website.** The project team's selection of Quantum Research Corporation paid off in a high level of support and expertise. (Project Director)

5. **Respond in a timely way to users' recommendations and suggestions.** Among the responses specifically to user requests were a weekly electronic newsletter, a "fast facts" section and two multiple-choice examinations. (Project Director)

6. **A Web project requires a project manager.** The project manager coordinated tasks, identified concerns, ensured quality control, managed crises and ensured timeliness. (Project Director)

7. **Website development is complex.** Engaging experts from various disciplines helps ensure a high-quality product. Throughout the project, experts from the fields of palliative medicine, education, library science and Web design helped conceptualize, design, implement and improve the site. (Project Director)

**AFTERWARD**

The project is seeking funding to continue the website. Support for the site in 2004 came from two pharmaceutical companies and the publisher of the *Journal of Palliative Medicine*, as well as from the sales of two educational CDs ($20,000). As of June 2004, project staff at the Medical College of Wisconsin were discussing with staff at the Association of Hospice and Palliative Medicine the possibility of the association taking over the costs of maintaining the infrastructure of the website.

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**Grant ID#s 36547, 45195**  
**Program area: Quality/Equality**
APPENDIX

Advisory Committee of the National Center for End-of-Life and Palliative Center

(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.)

Articles


Survey Instruments


Grantee Websites

[www.eperc.mcw.edu/EPERC](http://www.eperc.mcw.edu/EPERC). The End of Life Palliative Education Resource Center (EPERC), originating from the Medical College of Wisconsin, provides a centralized, comprehensive resource for end-of-life physician educators. The site's key feature, searchable databases, allows registrants to retrieve abstracts of peer-reviewed educational materials by category, links to end-of-life and medical education resources, funding and training opportunities, upcoming meetings, significant articles and suggested books.