

Website Aims to Guide Cancer Survivors in Finding Comfort Care

Empowering cancer survivors through information and programs about palliative care

SUMMARY

Starting in 2002, project staff at the National Coalition for Cancer Survivorship, Silver Spring, Md., developed a section of the coalition's website to provide information on palliative care (or comfort care) for people living with cancer, their families and their caregivers and organized a town meeting with recommendations for the field.

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

Key Results

The project accomplished the following:

- Created and launched *Essential Care: Your Comprehensive Guide to Living with Cancer*, a section of the coalition's existing website.
- Planned and hosted a town meeting on April 25, 2003, in Cleveland on palliative care. *Living and Dying Well with Cancer: A Community Conversation* drew a live audience of 140 people, with an additional 100 participating via webcast.
- The meeting, held on the campus of Case Western Reserve University, also highlighted Project Safe Conduct as a model of exemplary care for those with cancer. The meeting offered the following recommendations:
 - Formalize better reimbursement from health insurance carriers for palliative cancer care.
 - Curative cancer care therapy and palliative care should not be mutually exclusive in health care settings.
 - Include palliative care as a component of a comprehensive cancer care center.

Funding

RWJF provided a grant of \$159,630 from September 2002 through November 2003 to support these projects.

THE PROBLEM

"It is difficult, if not impossible, for patients and their families to get basic information explaining the content and availability of palliative care throughout the course of disease...," stated the Institute of Medicine's 2001 report, *Improving Palliative Cancer Care*. The Internet is an excellent tool to provide this information, but according to the project director, cancer-based organizations often fail to utilize it well. In addition, she said, there was a need for discussions at the community level about how to provide consistent quality palliative care to those living with cancer.

CONTEXT

RWJF has supported numerous initiatives to improve care at the end of life. 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 grant fits the third strategy.

THE PROJECT

Founded in 1986, the National Coalition for Cancer Survivorship advocates on behalf of cancer survivors for quality care. To raise awareness about the need for quality palliative care, project staff designed an online resource for cancer survivors and their caregivers and hosted a town hall meeting in Cleveland focusing on palliative care.

Susan Butler, a cancer survivor, author and Web writer, developed the Web content in consultation with a 20-member expert advisory panel. Members of the panel reviewed the content before its launch on the coalition website. For a complete list of panel members, see the Appendix.

RESULTS

The project accomplished the following:

- Created and launched Essential Care: Your Comprehensive Guide to Living with Cancer, a section of the coalition's existing website. More than 250 pages of Web content focus specifically on palliative care and cancer, including such topics as: side effects of cancer, pain, end-of-life issues, issues of heart and mind, nutrition, exercise, caregiving and essential care for children. The site also includes a section, "Questions to Ask Your Doctor." As of December 2003, the site was receiving 1,200–1,500 visits each month.
- Planned and hosted a town meeting on April 25, 2003, in Cleveland on palliative care. Living and Dying Well with Cancer: A Community Conversation drew a live audience of 140 people, with an additional 100 participating via webcast. Andrew von Eschenbach, MD, director of the National Cancer Institute, delivered the keynote address. Ira Byock, MD, moderated a panel discussion. Byock is director of Promoting Excellence in End-of-Life Care, an RWJF national program to foster changes in health care institutions to improve care for dying persons and their families (for more information see the Program Results Report). U.S. Congressman Ralph Regula (R-Ohio, 16th District) and Theresa Coaxum, with the office of Congresswoman Stephanie Tubbs Jones (D-Ohio, 11th District), also spoke. (See the Bibliography for details of the meeting.)

The meeting, held on the campus of Case Western Reserve University, also highlighted Project Safe Conduct as a model of exemplary care for those with cancer. A collaboration of the Ireland Cancer Center at University Hospitals of Cleveland/Case Western Reserve University and Hospice of Western Reserve, Project Safe Conduct has found innovative ways to help patients with a terminal diagnosis to pursue treatment while also receiving palliation and hospice care. Project Safe Conduct began as a demonstration project of *Promoting Excellence in End-of-Life Care*. More information on Project Safe Conduct is available online.

Recommendations

The town hall meeting offered the following recommendations for the field:

- Formalize better reimbursement from health insurance carriers for palliative cancer care.
- Curative cancer care therapy and palliative care should not be mutually exclusive in health care settings. As it stands now, a patient can get "pieces" of palliative care in a hospice setting, but cannot get "full-scale" curative care and palliative care simultaneously.
- Include palliative care as a component of a comprehensive cancer care center.

Communications

As a result of promoting the town hall meeting, the following outlets placed stories: The *Plain Dealer* (Cleveland's daily newspaper), *Oncology Times* and WKYC-Channel 3 (NBC), which aired an interview with von Eschenbach on April 25, 2003.

In June 2003, the coalition received OncoLink's Editor's Choice Award. Sponsored by the Abramson Center of the University of Pennsylvania, OncoLink is a Web-based resource for cancer information. This award, which is given out monthly, recognizes providers of the highest-quality cancer information on the Internet that help patients and families empower themselves.

LESSONS LEARNED

- 1. **Develop your content before deciding how you will distribute the information.**Coalition staff initially planned to develop Web content and then produce brochures based on that content. They modified that plan in favor of concentrating on Web content, which is much more cost-effective and easier to maintain over time. (Project Director)
- 2. When planning an event in another location, conduct a site visit early in the planning stage. Early visits will help improve communication with local partners, as well as help address local concerns and needs. (Project Director)
- 3. If you are unable to have your own staff on-site, engage a local public relations or event planning firm help facilitate events. (Project Director)
- 4. Featuring speakers of national prominence at your public meeting will attract a larger and more diverse audience. (Project Director)
- 5. **Be sure to solicit feedback about the event through an evaluation.** This information is invaluable for planning future events. (Project Director)
- 6. Plan for paid advertising if free media coverage does not materialize as hoped. Media coverage for events can be unreliable, as competing breaking news may take priority. (Project Director)
- 7. To increase the chances of media coverage for an event, begin working with the media as early as possible to engage them in the project. Also, in addition to targeting general news outlets, reach out to industry publications that focus on end-of-life care. (Project Director)
- 8. Consider holding town hall-style meetings at neutral locations, such as libraries or community centers, where a broad spectrum of people naturally gather. Holding the town hall meeting on the campus of Case Western Reserve University inadvertently narrowed the focus of those who attended to those in the academic community. (Project Director)

AFTERWARD

Both components of the project continue. The coalition posted the Spanish version of *Essential Care* to its website on March 3, 2004 and has scheduled two additional town hall meetings—in Richmond, Va., in September 2004 and in Northern California in October 2004. The Lance Armstrong Foundation is funding these meetings.

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Grant ID# 45476

Program area: Quality/Equality

APPENDIX

Advisory Panel Members for Essential Care Website

(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.)

Grantee Websites

www.canceradvocacy.org/toolbox. Provides information to cancer survivors and caregivers about palliative care, including managing pain, emotional support and understanding end-of-life issues. Silver Spring, MD: National Coalition for Cancer Survivorship, 2003. As of December 2003, the site was receiving 1,200–1,500 visits each month.

Sponsored Conferences

"Living and Dying Well with Cancer: A Community Conversation," April 25, 2003, Cleveland. town hall meeting to discuss exemplary models of delivering palliative care to cancer patients. Attended by 140 participants with 100 additional participants via webcast. Organizations represented included the National Cancer Institute, Promoting Excellence in End-of-Life Care, the Ireland Cancer Center and Hospice of Western Reserve. Three presentations, including one keynote, and a moderated question-and-answer session.