



Online Journal Identifies Ways to Implement Innovations in End-of-Life Care

Support for Innovations in End-of-Life Care, an international journal and on-line forum

SUMMARY

The Center for Applied Ethics and Professional Practice at the [Education Development Center](#) in Newton, Mass., published *Innovations in End-of-Life Care*, an online journal, bimonthly from January 1999 through June 2003.

Unlike traditional peer-reviewed journals, *Innovations* had a particular focus on the process of innovation, rather than primarily on results.

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

Key Results

- Project staff published 26 issues of *Innovations*. Each focused on a different theme or practice in end-of-life care.
- The center contracted with publisher Mary Ann Liebert in March 2000 to include a 20-page section of highlighted feature articles and an editorial from *Innovations* in each issue of *Journal of Palliative Medicine*, the official journal of the American Academy of Hospice and Palliative Medicine.
- Under another contract with Mary Ann Liebert, the grantee produced three annual book-length compendia of material from *Innovations*, beginning in 2000.
- As of late April 2003, more than 12,000 people had registered to use the project's [website](#).

Funding

RWJF provided four grants for this project, totaling \$1,809,854 from April 1999 to June 2003.

THE PROBLEM

According to the project director, rigorous scientific and academic journals focus almost exclusively on research findings and on the results of interventions, rather than on the obstacles that arise in the course of developing an intervention and how people overcome them.

In the late 1990s, palliative medicine was beginning to expand as a discipline and innovations in end-of-life care were being made throughout the world, initially in Europe and later in the United States. However, there were few journals on the subject, and none with a particular focus on the process of making changes in end-of-life care.

RWJF provided start-up funding (ID# 030973) to allow Stewart Communications to work with the *Last Acts* Institutional Innovation Task Force, part of a national initiative focused on end-of-life issues, to plan and begin development of *Innovations in End-of-Life Care*, a peer-reviewed online journal designed to emphasize process.

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 project fit within the second and third strategies.

THE PROJECT

Innovations in End-of-Life Care was published by the Center for Applied Ethics and Professional Practice at the Education Development Center, a nonprofit organization in Newton, Mass., dedicated to enhancing learning, promoting health and fostering a deeper understanding of the world.

The first issue of *Innovations* went online on January 12, 1999, and the journal ceased publication in June 2003 after 26 issues. The interdisciplinary journal addressed critical topics in end-of-life care and focused on the process of innovation, as well as on results.

It was guided by a prestigious editorial board with a strong international presence (see the [Appendix](#) for members).

Each issue included tools and resources for those who might wish to replicate all or part of an innovation. Starting in December 2000 and continuing for the next two years, project staff conducted annual readership surveys that indicated the journal was highly valued and had often prompted readers to take action in a new way. An online forum for discussion had initially been proposed for the project, but there was not sufficient interest from readers of *Innovations*, according to the project director.

From the journal's inception, project staff sought to generate revenues or other support to make *Innovations* sustainable within three years of its launch without RWJF funding. As part of RWJF grant ID# 041961, the center hired Marks Paneth Strategy Group, a consulting firm based in New York that works with nonprofit organizations and foundations, to prepare a business plan.

As part of RWJF grant ID# 044641, Marks Paneth was expected to make substantial progress in helping to generate revenue for the project, but by the end of that grant in June 2003, virtually no revenue had materialized. RWJF did not renew the grant for a fifth year, and with no substantial sources of revenue in sight, the project ceased publication.

RESULTS

The project generated the following results:

- **Project staff published 26 issues of *Innovations* under the four RWJF grants; each focused on a different theme or practice in end-of-life care** (see the [Bibliography](#) and [website](#) for issue themes).
- **The center contracted with publisher Mary Ann Liebert in March 2000 to include a 20-page section of highlighted feature articles and an editorial from *Innovations* in each issue of *Journal of Palliative Medicine*, the official journal of the American Academy of Hospice and Palliative Medicine.** The *Journal of Palliative Medicine* continued to publish articles from the online journal through April 2004.
- **Under another contract with Mary Ann Liebert, the grantee produced three annual book-length compendia of material from *Innovations*, beginning in 2000.**
- **As of late April 2003, more than 12,000 people had registered to use the project's [website](#).** Eliminating the registration requirement in October 2002 led to a spike in readership; using the Web Trends tool to track usage, project staff estimated the site received approximately 8,000 unique visitors a month (and an average of more than 17,000 visits per month) in February and March 2003.

Communications

The publisher reported total sales of 1,560 for the three compendium volumes through 2003. Project staff gave formal presentations or discussed *Innovations* with colleagues at a variety of conferences (see the [Bibliography](#)) and distributed several thousand Web bookmarks at conferences, and to contributors and other colleagues as part of the marketing effort. Editorial staff regularly marketed issues to targeted websites and estimated that more than 500 sites had links to the journal.

LESSONS LEARNED

1. **Creating intellectual capital is labor-intensive.** *Innovations* received fewer-than-expected finished manuscripts because the innovators in end-of-life care were often inexperienced writers or too busy to develop articles on their own. Editorial staff had to work closely with many contributors to develop articles, increasing the time and skill required to produce the journal. (Project Director)
2. **A new field such as palliative care can benefit from the opportunity to exchange ideas and reflect on innovative practice.** The online journal created an opportunity to focus on the process of change in a rigorous way and generated a positive response from people across disciplines and around the world. (Project Director)
3. **Marketing and fund-raising for mission-driven work that is not inherently profitable is extremely difficult.** Project staff had less time than anticipated to make the transition to self-sufficiency and ultimately found it impossible to generate sufficient income to sustain the journal. (Project Director)

AFTERWARD

The Educational Development Center has continued to fund the website and all issues of *Innovations* remain available online. The website continues to draw readers, counting more than 13,000 visits (not visitors) in September 2004, more than a year after the last issue.

Prepared by: Nanci Healy

Reviewed by: Karyn Feiden and Molly McKaughan

Program Officer: Victoria D. Weisfeld

Grant ID# 36037, 38962, 41961, 44641

Program area: Quality/Equality

APPENDIX

Editorial Board of Innovations in End-of-Life Care

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

For biographies of the board members, see <http://www2.edc.org/lastacts/edboard.asp>.

Susan D. Block, MD

Dana Farber Cancer Institute
Boston, Mass.

Eduardo Bruera, MD

University of Texas
Houston, Texas

Ira Byock, MD

Palliative Care Service
Missoula, Mont.

Thomas Delbanco, MD

Beth Israel Deaconess Medical Center
Boston, Mass.

Alan Fleischman, MD

New York Academy of Medicine
New York, N.Y.

Betty Ferrell, RN, PhD

City of Hope National Medical Center
Duarte, Calif.

Irene Higginson, PhD

King's College and St. Christopher's Hospice
London, England

Stein Kaasa, MD PhD

Trondheim Regional Hospital
Trondheim, Norway

Linda Kristjanson, PhD

Edith Cowan University
Western Australia, Australia

Neil MacDonald, MD

Clinical Research Institute of Montreal
Montreal, Canada

Juan. M. Nuñez Olarte, MD, PhD

Hospital General Universitario Gregorio
Marañón
Madrid, Spain

Laurence O'Connell, PhD

Park Ridge Center for the Study of Health,
Faith and Ethics
Chicago, Ill.

Carla Ripamonti, MD

National Cancer Institute
Milan, Italy

Robert Ubell

Stevens Institute of Technology
Hoboken, N.J.

Michael Zenz, MD

BG University Clinic
Bergmannsheil, Germany

Zbigniew Zylicz, MD, PhD

Hospice Rozenheuvel
Rozendaal, Netherlands

BIBLIOGRAPHY

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

Books

Solomon MZ, Romer AL and Heller KS (eds.). *Innovations in End of Life Care: Practical Strategies and International Perspectives, Volume 1*. New York: Mary Ann Liebert Publishing Company, 2000.

Solomon MZ, Romer AL and Heller KS (eds.). *Innovations in End of Life Care: Practical Strategies and International Perspectives, Volume 2*. New York: Mary Ann Liebert Publishing Company, 2001.

Solomon MZ, Romer AL and Heller KS (eds.). *Innovations in End of Life Care: Practical Strategies and International Perspectives, Volume 3*. New York: Mary Ann Liebert Publishing Company, 2002.

Book Chapters

Solomon MZ, Romer AL and Heller KS (eds.). "Innovations in End-of-Life Care: Mission and Purpose," in *Innovations in End of Life Care: Practical Strategies and International Perspectives, Volume 1*. New York: Mary Ann Liebert Publishing Company, 2000.

Articles

Innovations in End-of-Life Care, January 1999 through June 2003. The themes of each issue are:

- January–February 1999, Vol. 1, No. 1
Communication, Truth-telling and Advance Care Planning
- March 1999, Vol. 1, No. 2
Moving Toward Family-Centered Care
- April–May 1999, Vol. 1, No. 3
Pain Management Near the End of Life
- June–July 1999, Vol. 1, No. 4
Only Connect: Promoting Meaning in the Lives of Patients with Advanced Dementia
- September–October 1999, Vol. 1, No. 5
March–April 2000, Vol. 2, No. 2

- Pediatric Palliative Care
- May–June 2000, Vol. 2, No. 3
Hospice In Prison
 - September–October 2000, Vol. 2, No. 5
Building Bridges for Better Continuity of Care
(AHA Circle of Life Award Winner 2000)
 - November–December 2000, Vol. 2, No. 6
Quality of Life
 - January–February 2001, Vol. 3, No. 1
Promoting Better Pain Management in Long-Term Care Facilities
 - March–April 2001, Vol. 3, No. 2
Supporting Family Caregivers
 - May–June 2001, Vol. 3, No. 3
On Grief and Bereavement
 - July–August 2001, Vol. 3, No. 4
Institutionalizing Palliative Care
 - September–October 2001, Vol. 3, No. 5
Palliative Care in African American Communities
 - November–December 2001, Vol. 3, No. 6
Coping with Loss
 - January–February 2002, Vol. 4, No. 1
Filling Current Gaps in Care: Hospice Expands its Reach
 - March–April 2002, Vol. 4, No. 2
Palliative Care in Nursing Homes
 - May–June 2002, Vol. 4, No. 3
Palliative Care for People Living with HIV/AIDS
 - July–August 2002, Vol. 4, No. 4
Reinterpreting Comprehensive Cancer Care

- September–October 2002, Vol. 4, No. 5
Designing Postgraduate Training in Palliative Care
- November–December 2002, Vol. 4, No. 6
Enhancing Meaning, Hope, and Dignity Near the End of Life
- January–February 2003, Vol. 5, No. 1
A Model for Improving Access to Opioids: The Latin American Experience
- March–April 2003, Vol. 5, No. 2
Continuing the Conversation about Advance Care Planning: Part 1
- May–June 2003, Vol. 5, No. 3
Continuing the Conversation about Advance Care Planning: Part 2
- July–August 2003, Vol. 5, No. 4
Widening the Circle for Palliative Care

Solomon MZ. "Innovations in End-of-Life Care: Improving Quality by Focusing on the Process of Change." *Journal of Palliative Medicine*, 3(1): 111–114, 2000.

Journal of Palliative Medicine, June 2000 through April 2004. Although each issue of this journal during the dates noted contains a special section from Innovations, the website no longer identifies it as a special section; it has instead been folded into the general text.

Grantee Websites

www2.edc.org/lastacts. *Innovations in End-of-Life Care*, peer-reviewed journal, contains all issues of the journal, information about the annual compendia and the standing print section in *Journal of Palliative Medicine*. Newton, MA: Education Development Center, January 1999.