National Cancer Pain Initiative Resource Center Supports State-Level Initiatives as They Implement Pain Management Practices

Supporting state cancer pain initiatives

SUMMARY

From November 1992 through May 1996, faculty and staff at the University of Wisconsin School of Medicine and Public Health established the Resource Center, to support the growth and development of State Pain Initiatives. The initiatives formed a national organization, the American Alliance of Cancer Pain Initiatives (now called the Alliance of State Pain Initiatives), in 1996.

From February 2000 through June 2005, project staff continued to strengthen individual initiatives by providing resources, programs, training and consultation and an enhanced network of communication, as well as by cultivating collaborative relationships with other organizations with similar missions.

Key Results

The First Grant: ID# 020623

- The Resource Center for State Pain Initiatives was established to provide information, guidance and technical assistance to health care professionals interested in establishing and/or strengthening Cancer Pain Initiatives in their states.

- Almost all states established a State Pain Initiative during this period. Their primary mission was to improve the practice of pain management.

- The Resource Center coordinated a program to increase awareness of the Cancer Pain Guideline released by the federal Agency for Health Care Policy and Research (AHCPR) in 1994. As a result, 3.6 million copies of the guideline were disseminated.

- A Communications Toolbox enabled State Pain Initiatives to generate media interest in cancer pain.

- The Resource Center organized and obtained funding for annual national meetings for State Pain Initiatives.
• State Pain Initiatives formed the American Alliance of Cancer Pain Initiatives (AACPI). The AACPI's mission is to promote pain relief nationwide by working to overcome the barriers responsible for the under-treatment of pain. It is now called the Alliance of State Pain Initiatives.

**The Second Grant: ID# 037589**

Project staff:

• Updated the website and created two listservs for alliance members.
• Conducted 90 site visits to 44 states and convened 12 stakeholder meetings.
• Implemented six Practice Change Programs to help small health care organizations (hospitals, long-term care facilities, home health agencies) employ better pain management policies and practices. (Three more Practice Change Programs were conducted with other grant funds.)
• Publicized new pain standards released by the Joint Commission on the Accreditation of Health Care Organizations. The standards integrate pain assessment and pain management into the criteria used to accredit the nation's health care facilities.

**Funding**

The Robert Wood Johnson Foundation (RWJF) provided an unsolicited $444,546 grant (ID# 020623) and a second unsolicited $1,408,628 grant (ID# 037589) for this project.

**THE PROBLEM**

According to the American Cancer Society, cancer is the second leading cause of death in the United States, exceeded only by heart disease. More than 10 million Americans are cancer survivors, and one in four deaths is from cancer.

A third of patients have pain when their disease is diagnosed, and upwards of 75 percent of persons with advanced cancer have pain. Often that pain is severe. Pain is often inadequately treated in spite of the fact that there are drugs and other therapies that can control almost all of the pain associated with cancer.

In 1996, the World Health Organization (WHO) published Cancer Pain Relief to focus attention on the under-treatment of cancer pain in the United States and worldwide. That same year, an interdisciplinary group formed the Wisconsin Cancer Pain Initiative (WCPI) to address the barriers to effective pain control in that state and was named a demonstration project of WHO.

Leaders of the WCPI were invited to discuss their program at the first International Congress on Cancer Pain held in July 1987 in Rye, N.Y. In response to the interest in the
initiative, the WCPI hosted a national meeting for those interested in forming state pain initiatives in Madison, Wis., in July 1989.

By 1992, 27 states had formed Cancer Pain Initiatives: volunteer, interdisciplinary organizations dedicated to improving the management of cancer pain. Cancer Pain Initiatives:

- Disseminate information about pain and palliative care.
- Educate health care professionals.
- Promote media attention to pain treatment.
- Work with drug regulatory authorities on pain treatment issues.
- Provide educational materials to patients and families.

Opioid analgesics are the drugs of choice for the management of moderate to severe pain associated with cancer. In spite of their documented effectiveness, these medicines are often underutilized because of fears about their side effects, in particular concerns about addiction. Health care professionals, patients and the public fear addiction and are also concerned that opioids may be diverted to illicit use.

State Pain Initiatives have worked in collaboration with regulatory authorities and others to present accurate information about the risks and benefits of using opioid analgesics for pain control.

**CONTEXT**

In January 2001, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) released pain standards. These standards were the outgrowth of a two-year collaboration between faculty and staff at the University of Wisconsin Medical School and JCAHO.

The goal of the collaboration funded by RWJF (ID# 032037; see Program Results Report on ID# 040809), was to integrate pain assessment and management into the standards used to accredit the nation's health care organizations.

Staff at RWJF believed that these standards could raise the visibility and importance of pain management among health professionals, policy-makers and the public. Staff also believed that this project would advance RWJF's End-of-Life initiatives, which supported projects that advanced three strategic objectives to improve care at the end of life:

1. To improve the knowledge and capacity of health care professionals and others to care for the dying.
2. To improve the institutional environment in health care institutions and in public policies and regulatory apparatus to enable better care of the dying.

3. To engage the public and professionals in efforts to improve end-of-life care.

The grants described in this report supported the second objective.

THE PROJECT

ID# 020623

The objective of this grant was to establish the Resource Center for State Pain Initiatives to:

- Provide information, guidance and technical assistance to help volunteers create and publicize Pain Initiatives in their states.
- Acquire funding for annual meetings of State Pain Initiatives.
- Provide information and guidance about cancer pain treatment to health professionals, cancer patients and the public at large.

During this grant period, project staff published two books, a book chapter and 36 articles. See the Bibliography for details about the publications. The principal investigator participated in a task force of the Federation of State Medical Boards (the national association of state medical licensing authorities) to create the Model Guideline on the Use of Controlled Substances for the Treatment of Pain.

It was published in 1998 and also participated in a series of workshops to educate members of state medical boards about the prevalence and impact of pain and the role of opioid analgesics in providing pain control.

ID# 037589

The objectives of this project were to:

- Stabilize and institutionalize State Pain Initiatives by:
  - Improving the way they shared information with each other and
  - Helping them develop programs to address the barriers to effective pain control pain and to formulate strategic plans to ensure their long-term viability.
- Strengthen the American Alliance of Cancer Initiatives (AACPI) established by the State Pain Initiatives at the end of the period of funding provided by the first grant.
  The mission of the AACPI is to promote cancer pain relief nationwide by working to overcome the documented barriers to effective pain control.
The principal investigator participated in a task force of the Federation of State Medical Boards to revise the Federation's *Model Guideline on the Use of Controlled Substances for the Treatment of Pain*. The resultant model policy was published in May 2004.

The principal investigator and AACPI staff also participated in an initiative of the federal Drug Enforcement Administration to develop and issue a statement calling for a balance between addressing abuse and diversion of prescription pain medicines and maintaining access for patients. That statement was released in September 2001.

The AACPI entered into a joint venture with the American Cancer Society to help it ensure that pain management becomes a core component of its mission and work. These activities continued with ongoing grants from RWJF. For details, see *Afterward*.

During this grant period, project staff published 20 articles, two book chapters and seven reports. See the *Bibliography* for details about publications for both grants.

During this grant period, staff secured $544,850 in additional funding from 18 other sources to cover expenses related to the annual conference. For a complete list of other funders, see *Appendix 1*.

## RESULTS

Project staff reported the following results from the two projects:

**ID# 020623**

- **Project staff established the Resource Center to support the growth and development of State Cancer Pain Initiatives.**

- **The Resource Center guided health care professionals in almost all states to form Cancer Pain Initiatives.** Some of these initiatives involved just a small number of committed individuals, others engaged several hundred professionals in a range of activities.
  
  — Several State Pain Initiatives obtained independent funding to hire staff to assist their membership and provide general information to the public.

  — State initiatives have used or adapted information from the Resource Center to create specific projects that reflect their unique cultures and laws.

- **State Pain Initiatives formed a national organization, the American Alliance of Cancer Pain Initiatives (now called the Alliance of State Pain Initiatives).**
**Enhanced Communication with State Pain Initiatives**

- **Updated the website.** Requests to the website increased from 354 per month in 2000 to 775 per month in 2005. The website provides links to Cancer Pain Initiatives and other organizations, newsletters and resources.

- **Created two listservs:** One listserv includes 100 key people involved with Cancer Pain Initiatives and the other distributes a monthly e-newsletter to approximately 1,300 subscribers.

**Technical Assistance to State Pain Initiatives**

- **Conducted 90 site visits to State Pain Initiatives in 44 states.** During the visits project staff moderated meetings to build or revitalize Initiatives, assisted in strategic planning sessions and participated in state conferences.

- **Convened 12 state and regional stakeholder meetings to engage new volunteers and improve involvement by other organizations.**

- **Created position statements, toolkits and templates to help Cancer Pain Initiatives influence cancer prevention and treatment policies in their state.** These resources also help staff and volunteers prepare and publicize information about pain management.

- **Developed and implemented Practice Change Programs in collaboration with State Pain Initiatives: six in 2001; two in 2002 and two in 2003.** The Initiatives and the AACPI collaborated to direct the efforts of 10 small health care organizations (hospitals, long-term care facilities and home health agencies) to improve the way they manage pain. For details on the Practice Change Programs, see Appendix 2.

**Raised the Visibility of the American Alliance of Cancer Pain Initiatives (Now Called the Alliance of State Pain Initiatives)**

- **Designed and launched a media strategy related to the new pain standards released by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO).**

  The strategy featured:

  — Media resources to assist State Pain Initiative staff to communicate with the media about the new pain standards.

  — Joint news releases with JCAHO.
LESSONS LEARNED

1. **Be prepared for numerous challenges when trying to sustain volunteer grassroots organizations.** As Cancer Pain Initiatives evolved, the most effective ones hired paid staff or affiliated with other organizations. The busy schedules of many volunteers limited their ability to carry out tasks required to sustain the Initiatives. (Project Director)

2. **Be prepared not only to create resources for volunteers, but also to show them how to use those resources.** Project staff drafted template news releases for use by volunteers. Staff had to provide additional guidance to help volunteers adapt the templates for local media. (Project Director)

3. **Adjust assistance to the learning styles and changing needs of different organizations to help these organizations develop their own capacities.** Early efforts by the AACPI were prescriptive in dictating how Cancer Pain Initiatives should operate. Project staff moved away from this approach to one that helped initiatives create their own fund-raising strategies and operations plans. (Project Director)

AFTERWARD

The University of Wisconsin School of Medicine and Public Health received the following grants to further the mission of the American Alliance of Cancer Pain Initiatives.

**Grants from Funders Other Than RWJF**

- The United States Cancer Pain Relief Committee provided support for the AACPI to implement model regulatory programs.

- The Medtronic Foundation provided funds to revise patient education materials.

- The Open Society Institute—Project on Death in America (funded by the Soros Foundation) provided $105,362 to support Practice Change Programs.

- Beginning in 2005, the AACPI used a $300,000 grant from Purdue Pharma—a Stamford, Conn., pharmaceutical company—to provide 11 State Pain Initiatives (see Appendix 3 for details) with grants of up to $10,000 for projects that were designed to:
  - Remove one or more of the barriers to effective care for pain and
  - Build the capacity of Cancer Pain Initiatives to become self-sustaining by: designing fund-raising initiatives, creating comprehensive strategic plans or creating newsletters, websites or promotional brochures.
• The Medtronic Foundation provided funding to support a project to improve pain management for Hmong immigrants.

• In 2005, with funds from the Lance Armstrong Foundation, the AACPI provided funds to State Pain Initiatives for projects directed at overcoming barriers to pain management at the state level. Projects included fund-raising planning, educational material and media strategies.

• Multiple organizations provided support for the annual meeting of the AACPI.

**Grants from RWJF**

The University of Wisconsin School of Medicine and Public Health helped carry out the work of the American Alliance of Cancer Pain Initiatives to develop collaborative projects with the American Cancer Society (ID# 043940). See Program Results Report.

Researchers at the University of Wisconsin-Madison Medical School conducted an assessment of state laws, regulations and guidelines for treating pain with controlled substances and disseminated their findings (ID# 043412, 036509 and 035950). See Program Results Report.

Prepared by: Robert Crum
Reviewed by: Mary Nakashian and Marian Bass
Program Officers: Amy Mone Heaps and Rosemary Gibson
Grant ID# 20623, 37589
Program area: Quality/Equality
APPENDIX 1

Other Funders

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

The American Alliance of Cancer Pain Initiatives received an aggregate $544,850 from the following sources to cover expenses involved with the organization’s annual conference.

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APPENDIX 2

Findings from the Assessment of Practice Change Programs

The American Alliance of Cancer Pain Initiatives (AACPI) (now the Alliance of State Pain Initiatives (ASPI) used RWJF funds to provide six state Initiatives (Connecticut, Delaware, Michigan, New Mexico, North Carolina and Virginia) with contracts of $16,497 each to support Practice Change Programs. Funds from the Project on Death in
America supported a seventh program in Arizona, and the ACS New England Division supported an eighth program in Vermont.

The AACPI directed these State Pain Initiatives in a 10-month quality improvement program involving teams of staff from 20–25 health care organizations in each state. During this time, health care organizations were involved in efforts to:

- Provide staff with education about pain assessment and management.
- Assess their organizations pain management practices and patient outcomes.
- Develop and implement plans to improve and the organizational structures to support pain management practices.
- Evaluate structural changes and patient outcomes.

During 2001–2002, 137 health care organizations participated. On average, these facilities had 220 patients (range 22–2337). Some 65 percent of the facilities served urban areas; 50 percent served rural areas. The AACPI analyzed data from 88 health care facilities that submitted both pre- and post-program data:

- **Organizations significantly improved their ability to assess and manage pain.**
  - 74 percent of organizations had pain assessment standards before participating in the Practice Change Programs and 95 percent had these standards at the program's end.
  - 26 percent had pain management standards in place before participating, while 59 percent had these standards after.
  - 25 percent had pain assessment tools for the cognitively impaired before participating, and 60 percent had these tools after.
  - 42 percent had a practice of giving patients and families pain management material before participating, while 78 percent had this practice after.
  - 48 percent had formal mechanisms to convey the importance of pain relief to patients and families before participating, while 81 percent had these mechanisms after.
  - 62 percent had pain quality improvement teams before participating, and 88 percent had these teams after.

- **Patients in long-term care facilities reported improvements in their experiences of pain.**
  - 47 percent of patients reported moderate to severe pain before the facility participated in the Practice Change Program, while 36 percent said they had moderate or severe pain one year later.
APPENDIX 3

States That Received Grants Supported by the Purdue Pharma Grant

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

Round One Awards

Alabama
$10,000
June 2005 to May 2006

Illinois
$10,000
July 2005 to January 2006

Kansas
$10,000
June 2005 to May 2006

Maine
$9,286
June 2005 to May 2006

Maryland
$9,930
July 2005 to May 2006

Massachusetts
June 2005 to May 2006
$5,000

New Hampshire
$7,500
June 2005 to May 2006

South Carolina
$8,500
July 2005 to June 2006

Virginia
$9,784
June 2005 to May 2006

West Virginia
$10,000
July 2005 to June 2006

Round Two Awards

Arizona
$9,000
March 2006 to March 2007

Missouri
$6,410
March 2006 to November 2006

Nevada
$3,600
April 2006 to March 2007

Virginia
$9,994
July 2006 to June 2007
BIBLIOGRAPHY

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

Books


Book Chapters


Articles


Reports


Audio-Visuals and Computer Software


Survey Instruments


Grantee Websites