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# Success of the State Pain Initiatives

## *Moving Pain Management Forward*

**PURPOSE:** The purpose of this article is to describe the history of the State Cancer Pain Initiative (CPI) movement and current initiative activities that are directed at improving the management of cancer pain.

**OVERVIEW:** The undertreatment of pain is a major public health problem in the United States. State CPIs strive to remove the barriers to effective cancer pain management through the provision of innovative professional, patient, and public educational programs, through institutional change projects, and through public advocacy. Collaboration with organizations that share common goals is important in sustaining and maximizing the impact of the movement.

**CLINICAL IMPLICATIONS:** Professionals, patients, and families benefit from the work of the State Initiatives. By enhancing the knowledge and skills of clinicians, supporting institutional change, and teaching patients and families the importance of effective pain control, the Initiatives help to improve the quality of life for all cancer survivors. Models of intervention that respond to local needs are discussed, and legislative and advocacy efforts that affect care also are noted.

**KEY TERMS:** Cancer pain; Pain initiatives; Pain management; Patient advocacy; Patient education; Professional education; Quality of life

Despite major medical and scientific advances, the undertreatment of pain remains a major public health problem in this country. The documentation of the inadequacy of cancer pain management began with the pioneering work of Charles Cleeland and his colleagues<sup>1</sup> in the early 1980s and persists to this day.<sup>2-6</sup> It should therefore come as no surprise that respondents to a survey commissioned by *Modern Maturity* magazine in 2000 said that they feared dying in pain more than they feared death itself.<sup>7</sup> The reasons for undertreatment also have been well documented, and they include inadequate knowledge and inappropriate attitudes of healthcare professionals, patient and family fears and misconceptions, barriers in the drug regu-

latory system, problems within the system of the delivery of care, as well as inadequate reimbursement for drugs and other therapies.<sup>8-10</sup> Over the past 15 years, State Cancer Pain Initiatives (CPIs) have been working to confront these barriers. CPIs are volunteer grassroots interdisciplinary programs involving physicians, nurses, pharmacists, social workers, psychologists, educators, regulators, clergy, and others. These CPIs disseminate accurate pain management information, educate healthcare professionals, raise public and patient awareness of the cancer pain problem and of the benefits of effective pain control, promote clinical and institutional change, and advocate for the removal of regulatory and legislative barriers to effective pain management.<sup>11-13</sup>

The first state CPI was organized in Wisconsin in 1986 as a project of the World Health Organization.<sup>14</sup> The programs and philosophies of the Wisconsin Cancer Pain Initiative (WCPI) stimulated interest by individuals in other states who were similarly concerned about the inadequacy of cancer pain management. The action plan of the WCPI was based on the following:

- The focus should be on cancer pain at all stages of the disease and not limited to pain in the terminally ill.
- The problem of undertreatment is not due to a lack of effective analgesics and other therapies; the problem is that they are not being used appropriately.
- Pain management educational efforts have not changed practice.
- Any program to improve pain management must address the need to change the attitudes and behaviors of healthcare professionals.

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Until the 1990s, there were no organized national efforts to improve cancer pain management, and CPIs filled that void. Other important reasons for the formation of state-based programs relate to the enormous size and geographic and demographic diversity of this nation, and to the fact that regulatory policies and programs are developed and healthcare professionals are trained and licensed at the state level. CPIs can design programs to take advantage of their state's unique strengths and challenges. For example, there are significant differences in the state laws and regulations that govern the prescribing and dispensing of controlled substances. Therefore, in some states, the laws and regulations will be strengths, while in others, regulatory barriers need to be confronted.

National meetings for state CPIs have been held annually since 1989. These meetings provide the opportunity to network, to share expertise and resources, and to build valuable collaborative relationships. Perhaps the only national forums of their kind, these meetings focus specifically on the organizational, educational, ethical, cultural, and policy challenges surrounding the treatment of cancer pain.

In 1996, the leaders of the 44 established CPIs supported the creation of the American Alliance of Cancer Pain Initiatives (AACPI) to provide the state organizations with the following: 1) a communications network; 2) resources and consultation for organizational development; 3) programs and resources to improve pain management; and 4) a national identity.<sup>15</sup> The quarterly newsletter of the AACPI keeps members informed of important clinical issues related to pain management and provides a forum for CPIs to share resources. The AACPI maintains a list serve and a web site ([www.aacpi.org](http://www.aacpi.org)) that allows CPI members to easily access information on conferences, events, and pain management resources and provides links to state CPI web sites.

State CPIs clearly recognize that to have maximal impact and sustain the movement, they and the AACPI need to form strong partnerships with other organizations that share common goals. While the state CPI movement was evolving in the last decade, other organizations made pain management a priority in their programs, greatly facilitating the work of the CPIs. In 1991, the Oncology Nursing Society published a position paper that guides the education of nurses and presents a core curriculum on pain.<sup>16</sup> Many members of the Oncology Nursing Society pain special interest group are leaders of their state CPIs. An ad hoc committee of the American Society of Clinical Oncology published a curricular guideline for cancer pain management in 1992.<sup>17</sup> Collaborations with the American Pain Society, the University of Wisconsin Pain & Policy Studies Group, the Cancer Information Service, the American Cancer Society (ACS), Community-State Partnerships to Improve End-of-Life Care, Last Acts, the Association of Oncology Social Workers, the American Society of Pain Management Nurses, the American Pain Foundation, state hospice organizations, and the Intercultural Cancer Council have been important to the CPI movement. Clinical practice guidelines developed by a number of professional organizations are of particular importance to the professional education activities of CPIs, because they bring the authority of national experts to the message of CPIs. The release of the *Cancer Pain*

*Guideline* from the Agency for Health Care Policy and Research (now the Agency for Healthcare Research and Quality) in 1994<sup>18</sup> was of particular importance because it provided national validation of the programs of CPIs. Furthermore, the active involvement of the CPIs in the distribution and media coverage of these guidelines was a great stimulus to individual states and to the movement as a whole.

The multiple programs of the Robert Wood Johnson Foundation to improve end-of-life care also have been of great assistance to the CPI movement.<sup>19</sup> Their emphasis on the importance of effective pain management at the end of life and on broad media coverage of the issue has had a great impact on CPI efforts to improve pain management along the continuum of the disease.

## **Collaboration with the American Cancer Society**

The American Cancer Society (ACS) has a long history of collaborative efforts with state CPIs. Indeed, some CPIs are organized within divisions of the ACS and partner with the ACS on projects. The ACS volunteers and leadership staff have long been eager to address the problems of cancer pain and some have played important roles; yet the institutional emphasis of the ACS has been directed at reducing the incidence of and mortality from cancer as well as at providing patient support in areas other than pain management. Fortunately, the ACS now has broadened its goals to include quality of life, with pain management being a key component. The AACPI and the ACS quickly acknowledged the commonality in their goals and objectives, and the multiple opportunities and models for collaboration. In February 2001, through the generous support of the Robert Wood Johnson Foundation, the AACPI convened a meeting with the ACS and CPI representatives to discuss current exemplary models of ACS-AACPI collaboration and to set the stage for future mutually beneficial collaborations between the two organizations. At that meeting, representatives recognized the special synergy between the ACS and the AACPI, and affirmed their commitment to working together to maximize the unique strengths of each organization. Within 3 months of that meeting, the ACS developed a resource book for their divisions, a component of which is the *Division Guide to Collaboration with State Cancer Pain Initiatives*.<sup>20</sup> This comprehensive document provides background information on the magnitude and impact of unrelieved pain in persons with cancer. It also makes specific recommendations on how ACS divisions can collaborate with state CPIs to improve the treatment of cancer pain.

## **Current Status of the Cancer Pain Initiatives**

There are now 46 CPIs in 44 states, with two in both California and Texas. Ten CPIs have expanded the scope of their efforts to include all pain. More than half of CPI participants are nurses, about 13% are pharmacists, 12% are

physicians, and a smaller percentage are social workers, psychologists, healthcare administrators, and others. Some CPIs have a small number of highly dedicated volunteers who serve as state contacts, while others are well-established organizations and networks that function as driving forces for pain management improvement efforts in their states. The term “small, but mighty” often has been used to describe CPIs, because they are rich in expertise and commitment but typically work with limited resources. Many state CPI leaders report that the most valuable asset of their CPI is its “network” of passionate experts. Many CPIs have formal affiliations with the ACS, state hospice organizations, and Community-State Partnerships to Improve End-of-Life Care; and some are affiliated with academic institutions, hospitals, and other state-based healthcare organizations. These organizations provide the CPIs with a number of resources, including office space, phone lines, email, administrative support, program staff, fax lines, and financial support.

CPIs have, in many different ways, contributed significantly to the improvement of pain management in this country. It is not possible to describe all the accomplishments that each CPI has made. Instead, this article chronicles a few of the many successes of the CPI movement and the critical importance of collaboration with those who share the common goal of promoting pain relief nationwide.

### **Professional Education**

In 1989, the WCPI developed the Cancer Pain Role Model Program,<sup>21</sup> and over the next 10 years conducted 31 role model conferences in 24 states that trained teams of healthcare professionals. These programs often provided the stimulus for the formation of a state CPI. Professional education continues to be one of the top three priorities for state CPIs and is the centerpiece of many of the efforts of CPIs. CPIs produce and distribute a variety of educational materials that are designed to improve healthcare professionals' knowledge of pain management, including handbooks, dosage conversion cards, tabletop displays, and slide kits for educational conferences. CPIs frequently sponsor state or regional conferences, workshops, and seminars on pain management issues for healthcare professionals.

The Arizona Cancer Pain Initiative has trained more than 500 healthcare professionals in cancer pain management since its establishment in 1993. Recently, this CPI held a “Train the Trainers” workshop, which was modeled after the AACPI Institutional Change Projects and the City of Hope Pain Resource Nurse training<sup>22</sup> to improve clinical competence in pain management practices. Pain team leaders were recruited from healthcare facilities throughout the state to lead pain management efforts in their respective organizations.

The bimonthly newsletter of the Alaska Pain Network, “Pain News,” provides healthcare professionals with diverse insights into pain management issues from a broad range of perspectives. Pharmacists, nurse practitioners, long-term care facility workers, hospital personnel, military

hospital personnel, and representatives from native clinics all have contributed to the newsletter. More than 600 Alaskan healthcare professionals received “Pain News” within the last 3 years, and hundreds more receive electronic versions of the informational newsletter.

The Southern California Cancer Pain Initiative (SCCPI) has been a leader in establishing a viable and effective organization, and it has become a role model for other CPIs. Since its establishment in 1993, the SCCPI has sponsored a multitude of educational programs, including an annual conference on cancer pain management, palliative care, or both, and an American Medical Association Education for Physicians on End-of-Life Care (EPEC) program. It also hosts an annual event to recognize pain champions throughout southern California. The SCCPI has revised its pocket card devoted to “Principles of Cancer Pain Management” and is distributing it to healthcare professionals throughout southern California. Future efforts include the convening of representatives of all California medical schools to explore expanded curricula devoted to cancer pain management, increasing medical involvement in SCCPI courses, developing a formal liaison with each medical school, and the strengthening of the relationship of the CPI with the California Medical Association and county medical societies.

The New Jersey Pain Initiative, a project of the ACS, administers a “Best Practices in Pain Management Program” to improve pain management in healthcare facilities across New Jersey. From November 1999 through December 2000, 23 seminars for 1500 healthcare professionals at 31 partnering organizations were completed. Future endeavors include collaborations with long-term care facilities, physicians, and community pharmacists. A statewide conference was organized for participating organizations with the opportunity for continuing education and the sharing of resources.

### **Practice and Institutional Change**

Initiative leaders recognize that professional education alone does not change practice. Therefore, many CPIs are involved in programs to effect positive changes in pain management practices, policies, and procedures within healthcare organizations. With the support of the Robert Wood Johnson Foundation, the AACPI provided grants to six CPIs (Connecticut, Delaware, Michigan, North Carolina, New Mexico, and Virginia) to implement “Institutional Change Projects.” These projects are designed to help small healthcare organizations (eg, long-term care facilities, home health agencies, small community-based hospitals, or a combination) to improve pain management practices. They also are designed to strengthen or revitalize CPIs. The programs educate teams from committed organizations on pain assessment and management, self-assessment of the organization, implementation of an individual organizational change plan, and evaluation of selected patient outcomes. It is estimated that each day more than 20,000 patients are cared for by the healthcare organizations that participated in these programs.

### **Patient and Public Education**

Educating patients and the public about the importance of controlling pain effectively is a major focus of the AACPI and CPIs. In early 2001, the AACPI coordinated a national multimedia campaign surrounding the implementation of new pain standards from the Joint Commission on Accreditation of Health Care Organizations.<sup>23,24</sup> The campaign resulted in prominent coverage on the importance of pain management by most of the national news organizations and in approximately 500 daily newspapers nationwide. A local television news component of the campaign placed 250 news stories about pain management in more than 100 television markets nationwide. It is estimated that more than 10 million viewers watched these news stories. In addition, CPIs have actively participated in national medical outreach campaigns, such as the Fall 2000 PBS series "On Our Own Terms: Moyers on Dying in America."<sup>25</sup>

Cancer Pain Relief-Utah engaged in a successful public awareness campaign to inform Utah citizens that cancer pain can be relieved. Part of the campaign included a radio public service announcement that imparted to listeners the following three important messages: 1) pain can be relieved; 2) telling your caregivers about your pain is important; and 3) addiction is not something to fear when using pain medications appropriately for cancer pain. The 60-second public service announcements were aired nearly 4000 times on 35 radio stations throughout Utah, including rural areas that were in desperate need of pain management information. Through the Utah Broadcasters Association, Cancer Pain Relief-Utah was able to obtain more than \$275,000 worth of air time for an investment of only \$8000.

Through a collaborative effort with Cancer Care Connection, the Delaware Cancer Pain Initiative has helped establish a telephone hotline enabling the public to obtain helpful information on controlling pain. The Delaware Cancer Pain Initiative is promoting the hotline as a primary public information number for pain management information.

Several CPIs have participated in the production of patient education videos, brochures, and other resources as a way to dispel fears and misconceptions about pain control that are commonly held by patients and their families. The North Carolina Pain Initiative, together with state health agencies and the ACS, produced a video ("Living Without Cancer Pain: A North Carolina Success Story") to help the public better understand the treatment of cancer pain. To address the bringing of important health information to rural areas, the Virginia Cancer Pain Initiative produced a video entitled, "Managing Cancer Pain: A Rural Perspective."

### **Regulatory and Legislative Advocacy**

There is increasing interest at the federal and state levels in placing additional restrictions on the prescribing and dispensing of controlled substances. It is the position of CPIs that no additional regulations should be promulgated

unless there is clear evidence of the need for such programs, of their benefit in reducing prescription drug abuse and diversion, and of their impact on patient access to pain-relieving drugs. The financial costs associated with setting up and maintaining the administrative structure to support additional regulations is also of concern. It is particularly noteworthy that the National Association of State Controlled Substances Authorities<sup>26</sup> formally endorsed the CPI movement, recognizing that the underlying principle of regulation is to ensure that patients receive the care that they need. Regulatory barriers to pain management now have been systematically identified in every state. A profile for every state is available on the web site of the Pain & Policy Studies Group ([www.medsch.wisc.edu/painpolicy](http://www.medsch.wisc.edu/painpolicy)).

Progress has been made to remove regulatory barriers in some states, and also to adopt positive pain-related policies as reported in the 2000 Annual Review of State Pain Policies.<sup>27</sup> Eight states have adopted the model guidelines from the Federation of State Medical Boards.<sup>28</sup> Ten additional states have adopted it in part. The Initiative recommends that all state medical boards consider adopting or adapting the model guideline of the Federation of State Medical Boards in cooperation with pharmacy and nursing boards. They then should educate their licensees to clarify that pain management is encouraged, that it is a part of good professional practice, and that there is nothing to fear if opioids are prescribed, dispensed, or administered in accordance with evidence-based guidelines.

To promote balanced state regulations and policies relating to pain management, the SCCPI sponsored a statewide conference that brought together members from regulatory boards and law enforcement. This type of conference provides a forum for healthcare professionals, patients, and others to share their concerns regarding pain management.

The Maine Cancer Pain Initiative, a committee of the Maine Hospice Council, frequently advocates for health policy initiatives that are consistent with its mission of improving pain management. The most recent legislative efforts of the Maine Cancer Pain Initiative/Maine Hospice Council involved defeating a referendum for physician-assisted suicide and passing legislation to improve end-of-life care.

Building on the momentum of a pain summit sponsored by the Commonwealth of Virginia in 1996, the Virginia Cancer Pain Initiative successfully advocated for three legislative proposals to improve state law pertaining to healthcare access. The legislation, which is now law, does the following: 1) provides access to hospice services through health maintenance organizations and insurance companies; 2) requires reimbursement by private insurers for cancer pain medications and access to pain specialists and oncologists without a referral when pain is the primary problem; and 3) establishes a state-sponsored palliative care study. The Virginia Cancer Pain Initiative also partnered with the Virginia Department of Health and 40 other agencies to develop and promote a 5-year Cancer Control Plan for the Commonwealth of Virginia. This partnership has ensured that pain management is incorporated into the foundation of this statewide plan.

## Conclusion

The greatest strengths of the CPIs are the following: 1) the presence of committed leadership with expertise and passion for the mission; 2) their ability to collaborate and network with others who share common goals; and 3) the interdisciplinary nature of their programs. These strengths must be enhanced as the state CPIs enter the next phase of their work. Inspired by the end-of-life care movement and the new pain standards from the Joint Commission on Accreditation of Health Care Organizations, many CPIs have expanded their public and professional education programs, increased public and patient awareness of the importance of pain management, and had a positive impact in the legislative and regulatory arenas. Yet, challenges remain. The recent media attention on the unfortunate abuse of Oxycontin (Purdue Pharma LP, Stamford, CT) is reinforcing myths and misconceptions about opioids that CPIs have worked hard to eliminate.

There appears to be no reduction in the need for these state-based organizations. While CPIs have historically focused on cancer pain, there is increasing recognition of the need to expand the movement to embrace all kinds of pain. The current crisis in healthcare delivery is likely to enhance the need for independent, forceful advocacy groups to promote adequate pain relief for all persons.

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