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A Cancer Journal for Clinicians

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CA Cancer J Clin 2009;59:285-289; originally published online Aug 14, 2009;

DOI: 10.3322/caac.20030

This information is current as of September 10, 2009

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Taking Action to Ease Suffering

Advancing Cancer Pain Control as a Health Care Priority

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“We don’t beat the Reaper by living longer. We beat the Reaper by living well.” Professor Randy Pausch made this declaration in his May 2008 address to graduates at Carnegie Mellon University just months before his death last September. His cancer battle and his personal priorities, as he described in his Carnegie “Last Lecture,” resonated with the public in a remarkable way and captured the heart and soul of what most patients believe and want.

There is no doubt that persons diagnosed with cancer want to be cured or, at least, achieve a long remission from disease. But setting aside prognosis, most patients and their loved ones also want to be able to live well with their cancer—whether that life lasts weeks, months, or years. They also want to have comfort, dignity, and relief from pain as they face the end of life.

Pain remains one of the most feared and burdensome symptoms for cancer patients and survivors. Nearly all cancer pain can be relieved, yet the prevalence of pain and its undertreatment has remained consistently high and largely unchanged for more than 4 decades.¹ Still more troubling, significant pain treatment and access disparities in medically underserved and socioeconomically disadvantaged populations continue to be documented.^{2–5}

Many effective pain medicines and nondrug therapies are available to bring pain relief to cancer patients so that they can complete scheduled treatments, continue to work, and enjoy the company of family and friends.^{6,7} But significant pain assessment and management deficiencies are consistently reported in the clinical settings where cancer patients are seen.^{8–10} Open communication with health-care

professionals about pain, the medications for it, and other methods available to treat it is essential to relieve symptoms and improve quality of life.

Opioid analgesics, generally recognized as a mainstay of treatment for moderate to severe cancer pain, pose particular policy challenges for practitioners. These controlled substances tend to trigger a dueling policy debate among physicians, who must consider the interface between providing pain relief and curbing diversion and misuse.^{11,12} Health care professionals are increasingly being recruited to fight on both fronts, but they are armed with very little clear and practical prescribing guidance from the Drug Enforcement Administration (DEA) or state medical boards.¹³

Adding to the challenge, the growing misuse of prescription pain medications appears to be receiving more frequent attention, including in the popular press. *USA Today*, and several other media outlets, covered the White House Director of National Drug Control Policy’s release of the DEA’s *National Prescription Drug Threat Assessment* this May and reported that unintentional deaths involving prescription opioids increased 114% from 2001 to 2005 (8,500 deaths nationwide), with pain relievers identified as the most widely abused and diverted, particularly among teens. According to this DEA report, 1 in 5 new drug abusers indicated that they began their illicit drug use with potent opioids such as oxycodone, hydrocodone, and methadone.¹⁴

The Food and Drug Administration (FDA) also has had its scope expanded and chose to carve out a role in drug control through its ongoing Risk Evaluation and Mitigation Strategy deliberations for cer-

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The authors are very grateful and wish to acknowledge the efforts of Angelina Esparza, RN; Terri Ades, DNP, FNP-BC; Katherine Sharpe, MTS; Beverly Shaw, MS; Ian MacLeod; Christine Rodgers; and the Society’s Cancer Information Specialists for helping develop and conduct the call center pain project described in this editorial, as well as Aaron Gilson, MS, MSSW, PhD, Director of the US Program of the Pain & Policy Studies Group, for analyzing and helping interpret the project data.

DISCLOSURES: The authors reported no conflicts of interest.

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tain opioid analgesics to “ensure the benefits of these drugs continue to outweigh certain risks.”¹⁵ Earlier this year, the FDA issued warning letters to 9 companies to stop manufacturing and distributing certain prescription opioids because the products had never received FDA approval. Responding to concerns from patients and health care professionals in the palliative care community, the FDA amended its action to allow the continued marketing and distribution of a morphine sulfate oral solution on an interim basis.¹⁶

Although the dangers of prescription pain medications and their misuse often hit the headlines, we hear far less often about the other side of the story—the individual patients who are suffering and need these medications to ease their cancer pain. But these stories are poignant and often unforgettable. Presenting scientifically sound evidence is always critically important to the establishment of the source of a problem and to the development of potential policy solutions to address it. Personalizing those statistics with related stories, however, is the essential ingredient in achieving effective advocacy that gets policymakers to take notice and take action.

It is the power of science, coupled with compelling personal stories, that the American Cancer Society Cancer Action Network (ACS CAN), the advocacy affiliate of the American Cancer Society (the Society), uses as the foundation for its cancer advocacy work to advance policies in Washington, DC, and in statehouses across the country. ACS CAN is an important vehicle that empowers practitioners and their patients to make their statistics—and their stories—heard, so they can be part of the driving force behind new or improved cancer policies.

Nearly 1.5 million new cancer cases and 560,000 cancer deaths are expected in 2009 alone.¹⁷ Cancer pain will be a problem in up to 60% or more of patients who are undergoing active treatment, more than 60% of patients with advanced disease, and at least 30% after treatment concludes, and possibly more.^{1,18,19} This pain may be caused by direct tumor involvement, diagnostic or therapeutic procedures, side effects, or toxicities of cancer treatment.¹⁸ No matter its source, uncontrolled pain can affect every aspect of a patient’s quality of life—causing suffering, interference with sleep, and reduced physical and social activity and appetite.²⁰ Integrating pain and symptom management earlier and more often in

treatment will help patients feel and live better with their cancer, even if they don’t get better.

The evidence demonstrating continuing gaps in cancer pain control is now very well established.^{9,10,21,22} To put faces on published statistics, ACS CAN partnered with the Society to develop and launch a cancer pain patient information and education project through its cancer information call center, at (800) ACS-2345, earlier this year. The Society’s call center receives more than 1 million calls annually from patients, survivors, caregivers, health-care professionals, and others. All calls are answered by trained Cancer Information Specialists (CISs) who are available every day, around the clock, to provide cancer-related information and referrals to useful resources and services.

Building on findings from earlier pain pilot studies that the Society conducted through its call center, this project was intended to get a snapshot of how many callers experienced pain with their cancer, whether they told their health care team about it, and what was done in response. This project also included a component designed for CISs to help patients understand the importance of pain management as an element of their care and to help these patients develop skills to describe and record their cancer-related pain to facilitate pain assessment and treatment that could provide them adequate relief. Although the project design followed a research-based format, the goal was not to undertake a comprehensive research study. Rather, in order to bolster cancer pain advocacy efforts, the objective was to tally the number of callers who were experiencing cancer-related pain and who were not receiving adequate relief. Once identified, CISs could provide cancer pain information, identify gaps in the Society’s current range of pain-management materials and services, and consider future enhancements to existing offerings for callers.

The project took place from November 2008 through January 2009 and was conducted by 15 experienced call specialists who were trained on basic cancer pain information and the specifics of the project. The call specialists selected callers to include in the project from among those calls they received each day. Callers included patients in active treatment, those who had concluded treatment, or their caregivers who were calling our 800 number from across the country between 7 AM and 11 PM Central

Time (CST). The project had 3 components: (1) a series of 8 survey questions the call specialists used to capture the relevant data points in an online survey tool using their desktop computer; (2) an intervention conversation to explain the importance of pain management and, if relevant, how to use a daily pain diary tool; and (3) selected call backs after 2 or 3 weeks with a limited number of callers to collect follow-up data on 4 questions.

All call specialists used the same guidance script and data collection tool that provided consistent language for data collection and their telephone conversations with callers. The call specialists also had available a range of cancer-information tools that could be sent to callers, including a pain-diary tool with accompanying instructions for its use. After the call specialists addressed the caller's primary reason for contacting the Society, they determined whether the caller was an appropriate candidate to include in the project by using predetermined eligibility criteria, and requested permission from the caller to ask a few questions about cancer pain.

In all, the project used a data-collection tool to capture data from nearly 360 callers to the Society's cancer line from 38 states. Although these callers typically had another reason for their call, all were eager to discuss their pain when prompted. Callers who said they were experiencing cancer-related pain were asked to rate their pain intensity on a 0-10 numerical scale at 2 points—on the day of the call and 3 days before, with "0 being no pain and 10 being the worst pain you have ever had." Callers were also asked whether they told someone on their health care team about their pain. Following these and other questions, callers were divided into 2 groups for the intervention conversation based on their pain intensity rating (Group 1 callers reported 0-3 on the pain scale, and Group 2 callers reported 4-10 on the pain scale), which included introduction of the pain-diary tool for callers in Group 2.

Overall findings were consistent with the literature on pain prevalence^{1,20} and also yielded some unexpected results concerning the number of patients who said they had reported pain to their health care team and the pain-intensity ratings of those callers:

- 65% were experiencing cancer-related pain at the time of their call, with nearly two-thirds rating their pain intensity on the 0-10 scale as moderate (27% rated pain 4-6) or severe (36% rated pain 7-10).

- Of the individuals who reported moderate or severe pain scores, 53% had either the same or higher levels of pain currently, as compared to 3 days earlier.
- 76% of callers said they had told their health care team about their pain, but nearly two-thirds of those callers still rated their current pain intensity as moderate (29% rated pain 4-6) or severe (35% rated pain 7-10).
- 58% of callers who reported pain said they were regularly asked about their pain during clinic visits, and only 55% had ever been asked to describe or rate pain intensity using any type of scale.

Why are we continuing to see a large number of cancer patients suffering pain, particularly at higher intensities, when treatments are available to control it and the majority of patients are saying that they are raising pain as an issue with their health care team in clinical visits? Numerous studies have documented a variety of barriers that contribute to these problems.

Chief among barriers are the words associated with pain management itself—"narcotics," "addiction," "painkillers." These words are strong, scary, and stigmatizing, thus discouraging patients from taking the medicines they need.²³ In addition, patients, families, and even health care professionals often have misconceptions and confusion about addiction, physical dependence, and tolerance, which contribute to patient and family fears about using pain medications and to practitioners' reluctance to prescribe them.^{22,24-28} In fact, 16 states' controlled-substance or professional-practice laws would still incorrectly define any patient who is physically dependent on an opioid medication as an "addict."²⁹

Delivery of quality cancer care includes providing pain and symptom management alongside disease-directed treatment, which requires frequent and comprehensive pain assessment. As improvements continue in cancer management that extend life expectancy for patients, it will be increasingly important to also control cancer-related pain during the active treatment course to reduce the likelihood that cancer survivors will have to endure chronic pain later on.³⁰ But the Society's call-center project findings add to mounting evidence that inadequate assessment and treatment of cancer pain continues to be a significant public health problem that requires immediate and concerted action.^{7,22,26}

The National Pain Care Policy Act (HR 756/S 660) is a useful policy tool to help move pain control

forward. This bipartisan federal legislation is geared to help people better understand the importance of pain management and dispel some of the myths. As of July 28, 2009, it has already passed the full House of Representatives and has been introduced in the Senate, where it has been accepted for inclusion as an amendment to health care reform legislation before the Health, Education, Labor, and Pensions Committee. This bill has not yet been scored by the Congressional Budget Office and, as is often customary, does not specify funding amounts, instead authorizing “such sums as necessary.” Funding levels would be determined through the appropriations process after the bill is passed. It has 4 major provisions:

1. Convene an Institute of Medicine conference on pain care, with a report summarizing findings and recommendations.
2. Expand, through the Pain Consortium at the National Institutes of Health, an aggressive program for basic and clinical research on causes and potential treatments of pain.
3. Create an education and training grant program to improve health professionals’ understanding and ability to assess and appropriately treat pain.
4. Develop and implement a national pain-management public outreach and awareness campaign.

More than 100 organizations, including medical, nursing, pharmacy, and social work professional societies, patient-advocacy organizations, the Alliance of State Pain Initiatives, and the Pain & Policy Studies Group, have signed the consensus statement supporting this bill. ACS CAN, the American Pain Foundation, and many other partner health groups and professional organizations plan to use our collective grassroots forces strategically to get this legislation passed in the Senate and signed into law this year.

Now is the time for the health care community and all its disciplines to collectively help ensure that pain is discussed, assessed, and treated to provide relief to every patient as part of every clinical visit. September has been designated by Congress as National Pain Awareness Month. Now is a particularly opportune time for the cancer clinical community to join the Society, ACS CAN, and the many organizations who support the National Pain Care Policy Act by taking action through www.acscan.org to urge this bill’s Senate passage, so it can be signed into law by the president. Working together with a sense of

urgency, we can all help motivate the policy and practice change necessary to harmonize health care’s focus on the fundamental tenet of curing when we can and providing comfort always. ■

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