

State Initiatives in End-of-Life Care

Issue 21, November 2003

Focus: Pain Management—Part III

Barriers in Medicaid Reimbursement

Dr. Sean Morrison treats a large number of patients with serious and chronic illness, many of whom suffer from severe pain. One is a 78-year-old woman with advanced heart disease, osteoarthritis, and osteoporosis. Her pain significantly impairs her quality of life and her function, has led to symptoms of depression, and may increase her risk of death, says Morrison, Hermann Merkin Professor of Palliative Care and vice chairman of the Department of Geriatrics at Mt. Sinai Hospital, New York City.

Her only insurance is Medicare, which does not pay for prescription drugs, so she must pay for her own medicine. If cost were not a consideration, Morrison would prescribe a long-acting pain medicine that would last eight to 12 hours or more, with a short-acting “rescue” medicine for breakthrough pain. But at more than \$500 per month, it’s too expensive.

Morrison considered the alternatives, none of which he says were ideal. Methadone, for example, is one of the least expensive pain relievers available, and it is longer-acting than other generic drugs, but its use in addiction treatment lends it a stigma that makes pain patients reluctant to accept it. Methadone also has a very long duration of action and can build up in the body—dangerously so in the elderly—without close monitoring. “Methadone,” Morrison says, “should only be used by clinicians with specialized training in pain management.”



A physician at Balm of Gilead Hospice in Birmingham, Ala., helps a patient with his medications. “Reimbursement rules and regulations should encourage effective treatment of pain,” says Ira Byock, MD, executive director of Promoting Excellence in End-of-Life Care, and a longtime hospice physician. “Instead, they currently act as barriers and contribute to needless suffering.”

Morrison ultimately put his patient on short-acting generic morphine, which is more expensive than methadone but still less expensive than the long-acting drugs. However, its immediate-release formulation, which lasts only three to four hours, still makes it less than ideal. So this frail, elderly woman has to set her alarm clock and wake up in the middle of each night to take her medicine; otherwise, Morrison says, she would wake up in the morning “in agony.”

Morrison sees many such patients. “Some of them give up other needed medications to pay for their pain med-

INSIDE

- **Medicaid’s Limitations for Patients with Pain at the End of Life**

PAGE 2

- **Suggested Policy Revisions and Areas of Proposed Research**

PAGE 4

- **“Concurrent Care” May Improve Pain Care While Reducing Costs**

PAGE 5

ications,” he says. “Others put up with the tremendous inconvenience of inexpensive generic opioids. And some decide that they will continue to live with their pain because of the burden associated with treatment—burdens that are an artifact of our health care system and ones that could be easily remedied with appropriate prescription drug coverage.”

Continues on page 2

Introduction

Continued from page 1

Inadequate reimbursement, or a complete lack of it, presents significant barriers to better pain management for people at the end of life. “The lack of clarity and inconsistencies in Medicaid reimbursement for pain management complicate care through the end of life,” says Ira Byock, MD, executive director of Promoting Excellence in End-of-Life Care, a national program office of The Robert Wood Johnson Foundation. Many reimbursement programs either fail to acknowledge the necessity of pain management for patients at the end of life or force patients to pay for much or all of the treatment out-of-pocket. Prejudice may accentuate these problems. Morrison’s patient is, for example, down on three counts: she is not only poor, but she’s also elderly and a woman. Studies show that women and the poor usually receive lower-quality pain care than men and those with means. Many can’t find a physician as sensitive as Morrison is to the barriers and prejudices patients face.

Evidence suggests that outmoded and inadequate reimbursement policies for pain management erect a barrier to the relief of both acute and chronic pain, including pain from cancer and other life-limiting illnesses. David Joranson, MSSW, director of the Pain and Policy Studies Group at the University of Wisconsin–Madison, notes that the United States is one of the few countries in the world where access to pain medicine and treatment is based on the ability of a person to pay for them, either through personal means or third-party private or government insurance. The reimbursement systems have failed to keep up with technologically advanced, often more expensive, ways to manage pain.

This report examines these barriers in depth, offering policy solutions that could help bring more comfort to dying Americans. ■

Medicaid’s Limitations for Patients with Pain at the End of Life

Medicaid is one of the five primary payment mechanisms in the United States (the others are Medicare; Medicare Hospice; health management organizations [HMOs]; and private insurance). This section examines Medicaid and the limitations it puts upon patients with high levels of pain at the end of life.

One of the biggest overall reimbursement barriers is that insurers—including Medicaid—have no clear-cut policies regarding reimbursement for pain management services. Physicians may file a claim for reimbursement for pain management only in connection with a specific illness—cancer, for example—but claims solely for pain management are often denied. As a result, doctors are overly hesitant when treating pain because either they don’t know which therapies and medications are covered or they don’t want to challenge the system by prescribing a pain reliever or dosage that is strong, expensive, or perhaps not on a formulary. Recent studies show that payment systems—including Medicaid—often discourage and in many instances actually *prevent* access to pain relief.

Medicaid is the primary national health care reimbursement program, funded by federal and state governments, for low-income, elderly, or disabled individuals. Aside from Medicare Hospice (see below), a program that many working in end-of-life care believe is underutilized, Medicaid provides the only government-sponsored prescription drug reimbursement program for Americans. In most industrialized nations, Joranson observes, governments cover most if not all prescription drug costs, but for Americans only about 12 percent of these costs are paid for by government, primarily through the Medicaid program. Among the elderly who are not poor enough to qualify for Medicaid, the bulk of prescription drug costs—including those for pain management—must be paid for out-of-pocket.

Medicaid’s “Silo Mentality”

Each state’s Medicaid program fashions many of its own rules. State governments have continually decreased their support for Medicaid, and, in the current economy, seem unlikely to change course. In restricting Medicaid budgets, states usually decide they must cut a certain amount from the



“Some Medicaid programs only provide 30 pills per month. A limit such as that is outrageous.”

Joanne Lynn, MD,
director, The Washington Home Center
for Palliative Care Studies, in collaboration with RAND Health

prescription drugs budget, beginning with the highest-cost drugs. “They limit the formularies based on cost only, not on what drug is best, often approving only the least expensive generic drugs,” says Pamela Bennett, RN, senior director of advocacy at PurduePharma and past president of the American Society of Pain Management Nurses. In this “silo mentality,” the expensive drugs are thought of as being in a silo of their own.

“Cutting a certain drug or ‘silo’ of drugs out of a formulary can result in more costs to the system—doctors’ visits, ER visits, lost productivity, and other charges,” Bennett says. “The states have to stop this silo mentality that looks only at a certain drug, method, or ‘episode of therapy,’ and begin to look at the overall costs of pain management.”

Silo cuts “put doctors in a real bind,” Bennett adds. Physicians who want to prescribe a drug not on a state’s formulary must complete onerous paperwork each time they prescribe that drug.

Bennett tells the story of a Medicaid patient in New Hampshire who for several years successfully controlled her cancer pain with a certain long-acting opioid. “Then the state put a system in place that said you had to fail [to control pain] on certain drugs—including methadone and some others—before you could be placed on this medication,” Bennett says. “In fact, her physician had taken her through that process several years before—but she had to go through all of that all over again in order to get back to the treatment that had been working for several years. This Medicaid requirement was interfering with her physician’s best clinical judgment.”

“Cutting a certain drug or ‘silo’ of drugs out of a formulary can result in more costs to the system—doctors’ visits, ER visits, lost productivity, and other charges. The states have to stop this silo mentality that looks only at a certain drug, method, or ‘episode of therapy,’ and begin to look at the overall costs of pain management.”

Pamela Bennett, RN, senior director of advocacy at PurduePharma and past president of the American Society of Pain Management Nurses

Bennett adds, “We have medications that have been developed to meet clinical need. With them, patients’ pain is managed, they are able to go to work and to fulfill their family responsibilities. When you take them away from patients, they are unable to go to work, they wind up on disability, they have more frequent doctor and hospital visits. The overall cost is greater.” She suggests states are making decisions out of immediate cost concerns, without paying consideration to the longer-term, total cost to patients and society, including the government.

Patient-Level Restrictions

More than half of states are trying to cut Medicaid budgets by putting restrictions on patients that include copayments for prescription medications, caps on numbers of refills, caps on quantities dispensed per prescription, and limits on the number of prescriptions filled per month. A 1991 study by Soumerai et al. showed such patient-level limitations increase older Americans’ likelihood of entering nursing homes just to obtain payment for the medications they need. The limitations also were associated with Medicaid cost increases: paying for long-term care costs states far more than the savings generated by limiting access to medications.

Pharmacists’ Concerns About Medicaid Reimbursement

The pharmacy profession has become increasingly concerned about the lengthy lags in Medicaid reimbursement for prescription drugs. Pharmacists routinely order, stock, and dispense pain medications for Medicaid patients and cover the costs of the medications until reimbursement is paid. This can be quite some time: in Illinois, for example, the lag in Medicaid reimbursement has at times exceeded 100 days. In such a situation, a pharmacy is extending credit to the government and carrying accounts receivable. Add to that the additional requirements placed upon pharmacists when dealing with strong pain medication, and “you get to a point where you have perverse incentives—you’re spending more time and bringing in less money,” says Susan Winckler, JD, RPh, vice president for policy and communications and staff counsel, American Pharmacists Association (APhA). “There is a cost to all the record-keeping. Especially when it comes to Medicaid patients, whose reimbursements are so low, it’s getting to be with pharmacists the way it’s been with doctors—if you’re not going to make any money when that patient walks in the door, you’re going to be hesitant to see them.” ■

Suggested Policy Revisions and Areas of Proposed Research

So, what to do about patients like Sean Morrison's, who can afford neither the medications that might be most appropriate for their conditions nor the insurance coverage that would pay for them?

"It is the right sentiment that Sean feels bad about the situation his patient is in," says Joanne Lynn, MD, director of The Washington Home Center for Palliative Care Studies. "Doctors should feel bad if they have to make compromises for their patients.

"The question for the community is, is it reasonable for this person to take pills every four hours and save that money?" she asks. "It is part of good policy to be attentive to costs. It is sometimes legitimate for a public benefit to insist upon a preference for a less costly alternative. There has to be substantial benefit to justify prescribing a drug that is, for example, one hundred times the cost of another medication that may be quite effective."

Neither the most expensive nor the least expensive pain medications are appropriate for all patients, and clinicians must educate themselves not only about the benefits and risks but also about the cost of potential therapies. The goal in pain management, experts say, is for clinicians to match the appropriate pain management therapies—which can include low-cost options that are often overlooked, such as volunteer clergy in hospice to alleviate existential pain that can manifest as physical pain—with each individual patient, ideally

achieving the best outcome at the lowest cost. And by the same token, the goal in pain policy is to achieve cost-effectiveness while also supporting clinicians' process of pain assessment and treatment.

To that end, Lynn says, some deeply problematic policies must be changed. "There are some outrageous policies out there—for example, some [Medicaid] programs provide only 30 pills per month," she notes. "If the person has to take 30 pills a day, then they have to pay for the other 29 days out-of-pocket. And, yes, if you have a person with severe neuropathy [nerve pain] who is opioid-tolerant, they could quite easily need 30 pills a day to control their pain. A limit such as 30 pills a month is outrageous."



"Our basic argument was: If the doctor writes a prescription for more than 60 tablets, in my opinion, this is medically necessary. To put additional burdens in the doctor's way just puts a chilling effect on the use of this medication."

Drew Edmondson, JD, attorney general, State of Oklahoma

Researchers in pain policy suggest five ways policy might be revised to ensure that fewer Americans die in pain as a result of lack of payment for pain management:

1. Relieve patients of onerous limitations and cost burdens, and include medical necessity as a criterion, along with cost effectiveness, in making formulary decisions. Oklahoma's attorney general's office recently advocated for a reversal of a decision by that state's Medicaid program to limit prescriptions for a certain pain medication to no more than 60 tablets—and won. Lynn suggests developing "a short list of very inexpensive drugs of broad utility" that public benefits would fund with little question. "And then if a patient required something off that formulary"—for example, if a patient had failed treatment on the low-cost medications; if a patient suffers a memory deficit and someone can drop in to make sure they take their medications twice a day, but not four times a day; if a person might be better off with a local infusion, such as a patient with pelvic cancer whose needs for intensive pain treatment make oral medications difficult to manage—"an exception could be made. Codifying this in policy would be complicated and difficult, but no more so than it is now."

Continues on page 6

“Concurrent Care” May Improve Pain Care While Reducing Costs

“Because of advances in medical science, there is no longer—if there ever was—a clear distinction between living and dying,” states *Financial Implications of Promoting Excellence in End-of-Life Care*. This report was issued recently by a national program office of The Robert Wood Johnson Foundation that has funded 20 innovative demonstration projects across the country that target care in a variety of challenging settings and hard-to-reach populations.

Several of these demonstration projects studied a new clinical service-delivery model for improving quality of end-of-life care called “concurrent care.” Concurrent care is palliative care given simultaneously with aggressive, cure-oriented treatment for patients with advanced illness that may limit life expectancy.

This is a radical departure from the Medicare Hospice Benefit’s requirements for reimbursement. The MHB requires that patients electing hospice give up curative, potentially life-prolonging care in order to qualify. “The either-or dilemma confronting patients has come to be known as ‘the terrible choice’ and is regarded as the predominant barrier to hospice access currently,” the report states.

For the past five years, the Promoting Excellence program has supported the development of new modes of delivering palliative services, of which concurrent care has emerged as perhaps the most promising.

“Good pain and symptom management is certainly at the heart of good palliative care,” which includes psychosocial and spiritual care, says Jeanne Twohig, deputy director of the Promoting Excellence Program at the University of Montana in Missoula. “We need a change in reimbursement policy that integrates the complete spectrum of palliative care into the care of patients with life-limiting illnesses.”

A keystone of concurrent care is case management. Case managers serve as intermediaries between patients/families and physicians, and between patients and payers. Case managers are available to patients and their families day and night, seven days a week. Case plans devised at the outset of the relationship and cooperation with providers enable case managers to troubleshoot, skirting crises before they happen and averting more costly interventions—emergency department visits, intensive care unit stays, and other services

that become necessary when curative care is the sole focus of treatment, and when no one is dedicated to helping patients and families with more than immediate, crisis-oriented needs.

The Medicaid program in the state of Washington determined, based on a recent analysis of six high-cost patients participating in the Promoting Excellence Program, that it saved an average of more than \$3,600 per month for each client receiving concurrent care. Other sites have generated similar data.

“There’s really promising information about providing palliative care concurrently with curative care,” says Twohig, but in these studies “the numbers of patients were small. We need larger *n*’s to demonstrate impacts—to further test these ways of providing palliative care.” Twohig and others working on this issue suggest that such studies should be sponsored by the Centers for Medicare and Medicaid Services. ■



“Less-than-optimal pain treatment doesn’t only erode quality of life, it also costs Medicaid more money.”

Ira Byock, MD, director,
Promoting Excellence in
End-of-Life Care

Policy Revisions and Areas of Proposed Research

Continued from page 4

2. Bring Medicaid reimbursements for pain therapies up to par with current practice and costs, and develop systems to keep up with technological changes. “There are still five to ten percent—and it may be that with the new treatments, there may be five or ten percent more than that—who need something more elegant than oral morphine,” Lynn asserts. “But it’s still a pretty good bet that at least 75 percent of people could be managed with the good old standbys. Let’s not lose sight of the fact that we can manage most people’s pain with cheap drugs. The idea of reimbursing for a high-cost drug is so much more tolerable if you’re using it on no more than 20 percent or so of the population.”

3. Clarify Medicaid policy to specify which pain therapies are covered, to relieve physicians’ concerns about prescribing.

4. Ensure Medicaid’s timely reimbursement to pharmacies.

5. Simplify reimbursement policies so that patients crossing into different care settings, or with certain illnesses, don’t find coverage of medication curtailed.

Research Agenda Needed

Palliative care experts say neither state nor federal governments have thoroughly studied the nature of the problem of pain and its management. Charles S. Cleeland, PhD, chairman of the Department of Symptom Research at M. D. Anderson Cancer

Center, has estimated that less than 1 percent of the federal health budget is spent on pain research, even though pain crosses almost every institute within the National Institutes of Health. Says Cleeland, “I’d like to know, from pharmacies in major public hospitals, how many patients don’t get their prescriptions filled for pain medication. That’s a simple study, but nobody has yet shown any interest in it.”

In its 2001 report, *Improving Palliative Care for Cancer: Summary and Recommendations*, the Institute of Medicine (IOM) called for the National Cancer Institute to convene a research summit on palliative care and symptom control and to invite other government research agencies to participate. Experts also say that, in order to make responsible decisions about Medicaid program coverage of pain therapies, state governments must study the needs of their constituents and evaluate whether current programs are meeting those needs.

Finally, the IOM and other palliative care experts have strongly recommended that CMS fund concurrent care pilot models that do not force patients to choose between curative care and pain treatment. “What I’ve heard CMS say is that there’s more likelihood that they’ll do something if there’s an ever-louder voice from the public, demanding that these studies be done,” says Promoting Excellence’s Twohig. ■

State Initiatives in End-of-Life Care

Information about the Series

“Pain Management—Part III: Barriers in Medicaid Reimbursement” is the twenty-first in a series of briefs profiling promising policies and practices in end-of-life care, and the third in a miniseries about improving pain management.

Executive Editor:

Myra Christopher

President and CEO, Midwest Bioethics Center

Director, Community–State Partnerships National Program Office

Researcher and Writer:

Jennifer Matesa

Associate, Spann Publications Consulting, LLC, Pittsburgh, PA

Designer:

Rob Henning

Rob Henning Design, for Spann Publications Consulting, LLC

Editorial guidance for the *State Initiatives* series is provided jointly by Midwest Bioethics Center and The Robert Wood Johnson Foundation in cooperation with Last Acts. The Robert Wood Johnson Foundation supplies series funding.

To Order Publications

To order additional copies of this publication, phone, write, or fax Midwest Bioethics Center using the following contact information, and reference **Issue #21** in your request.

Previous issues of this series are available. Midwest Bioethics Center will provide a list of available back issues upon request. They are also available online at www.lastacts.org (go to “Activities” and click on “Publications” for the series in PDF format).

Midwest Bioethics Center

1021–1025 Jefferson Street
Kansas City, MO 64105-1329

Telephone 1 (800) 344-3829
Fax 1 (816) 842-3440
E-mail jhough@midbio.org
Web site www.midbio.org



MBC directed the Community-State Partnerships national program office (1998-2003), a program supported by The Robert Wood Johnson Foundation. MBC continues to provide resources and education about ethical issues in health and health care to advocates, policymakers, professionals, and consumers.

To Order Audio Programs

To order Parts I, II, III, or IV of the new *State Initiatives* audio series, *Heart-to-Heart: Improving Care for the Dying through Public Policy*, visit www.partnershipforcaring.org/statepolicy/audioseries/ or call **1 (800) 989-9455**.



Last acts.

A national coalition to improve care and caring at the end of life

Last Acts is a coalition of more than 1,200 national and local organizations dedicated to improving end-of-life care. For more information about the Last Acts campaign, contact

Partnership for Caring

1620 Eye Street—Suite 202

Washington, DC 20006-4017

Telephone (202) 296-8071
Fax (202) 296-8352
E-mail lastacts@aol.com
Web site <http://www.lastacts.org>

All State Initiatives Audio Programs Now Available

For information about our series of compelling audio programs on key end-of-life care policy issues—pain, policy heroes, children, and cultural diversity—call **1 (800) 989-9455** or visit <http://www.partnershipforcaring.org/statepolicy/audioseries/>.