



CHAPTER 14

# PAIN MANAGEMENT

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# PAIN MANAGEMENT

Cancer pain can effectively be treated in 85% to 95% of patients using an integrated pain management program consisting of therapies such as medication, nerve blocks, cognitive-behavioral therapy, radiation therapy, and surgery.<sup>1</sup> However, many cancer patients suffer from unrelieved pain from diagnosis throughout their disease trajectory.<sup>2</sup> The World Health Organization estimates that up to 70% of patients with cancer pain do not receive adequate relief.<sup>3</sup> Cancer pain is present in 24% to 62% of adult patients at the time of diagnosis,<sup>4,5</sup> in 35% to 57% of patients receiving active treatment,<sup>6,7</sup> and in 88% to 100% of patients in the terminal phase of disease.<sup>8</sup> Similar statistics are found in children.<sup>9,10,11</sup> Cancer is the second leading cause of death in Maryland, accounting for 24% of all deaths, and currently Maryland

ranks eleventh in the nation for overall cancer mortality.<sup>12</sup> Over 23,000 cases of cancer were diagnosed in Maryland in 1999;<sup>13</sup> the fact that a large number of these patients will experience unrelieved pain constitutes a public health crisis. Additionally, as the population ages and people over the age of 65 become our fastest growing demographic group, cancer pain issues will become even more prevalent.<sup>14</sup>

Cancer pain affects not only pain sufferers, but also their partners, family, and friends. Cancer pain is a family issue. Cancer pain affects the relationships patients have with their significant others and impacts their daily activities, life goals, and quality of life.<sup>15,16</sup>

In a recent *Last Acts* report on pain at the end of life, Maryland earned a grade of B in regard to its state pain policies that allow physicians to treat pain at the end of life.<sup>17</sup> Specifically, the *Last Acts* report found that in 2000 only 59.7% of Maryland hospitals offered pain management programs, 25.8% provided palliative care programs, 19.4% provided hospice programs, and that referrals to hospice and length of stay in hospice are low.<sup>18</sup> Unfortunately, the study did not assess how well pain was managed at the end of life. As a proxy for this measurement, in 1999, approximately

38.5% of Maryland nursing home residents reported persistent pain.<sup>19</sup> Together, these statistics suggest the need for improvement in pain management for the constituents of Maryland.

This chapter addresses the status of cancer pain assessment and management in Maryland. Barriers to effective cancer pain management are described, including limitations in assessment, public awareness, access to services, and provider education and training. Health care disparities, issues related to reimbursement for pain and symptom management, and regulatory barriers are discussed. Rights and responsibilities, diversity considerations, the need for better coordination of pain management services throughout the health care system as well as across the disease trajectory, and the need for additional scientific research are highlighted. Several recommendations are provided that focus on improving access to, and use of, evidence-based assessment and multimodal therapeutic interventions, including complementary and alternative therapies. This assessment and therapy should be available and provided by multiple disciplines across the health care system to effectively manage cancer patients' pain and other symptoms.

## Principles for Cancer Pain Assessment and Management

The following overarching principles are fundamental to the provision of quality cancer pain assessment and management to the citizens of Maryland:

**Rights and Responsibilities:** Patients, their providers, and the health care system as a whole have both rights and responsibilities regarding cancer pain assessment and management. Patients and their caregivers must be educated to understand the importance of cancer pain assessment and management, their role in that process, and to expect that cancer pain is monitored and treated as a routine part of care. The patient and caregivers must be included in health care planning since this increases adherence to prescribed regimens<sup>20</sup> and may improve the management of cancer pain. Health care professionals are responsible for advocating for effective pain relief for cancer patients and working within the health care system to advocate for system changes to provide effective cancer pain control to various patient populations that suffer from pain as a result of their disease process or injury. Health care providers should have access to pain specialists for con-

sultative purposes. Health care institutions and the systems that support them should provide structures that support a comprehensive pain management plan that includes informed consent. Health care providers have the right to adequate reimbursement for providing cancer pain care. Health care providers and systems have the right to information about minimum cancer pain management standards to which they will be held accountable. They also have the right to laws and regulations that support effective cancer pain management and must have access to information about strategies effective in improving cancer pain management. Several states and organizations have developed a Pain Care Bill of Rights (Table 14.1). Maryland has not yet instituted robust legislation to establish a Pain Care Bill of Rights for Marylanders.

**Access and Advocacy:** All cancer patients have the right to effective and affordable pain assessment and management services and therapies. Health care professionals must advocate for effective cancer pain relief. Advocacy is particularly important for populations that are known to be at greatest risk for ineffective cancer pain management (e.g., the uninsured, minorities, women, the elderly, and children) and for those who are unable to self-report or manage their own cancer pain related needs (e.g., due to dementia, age, disability, language barriers).

**Cultural Sensitivity:** Health care professionals and the systems in which they function must be sensitive to the pain perceptions and the expression of patients' needs as they are influenced by race, culture, religious and spiritual practice, sexual orientation, and economic status. Numerous health care studies demonstrate that the uninsured, minorities, women, the elderly, and children are at greater risk for under-treatment of pain. Details of these disparities are discussed later in this chapter. Specific attention to populations disparately affected by cancer pain is required in order to more effectively manage pain.

## Barriers to Cancer Pain Assessment and Management

There are multiple reasons for the lack of effective cancer pain and symptom control. Cancer pain has been a neglected subject during professional training among physicians,<sup>21</sup> oncologists,<sup>22,23</sup> oncology nurses,<sup>24</sup> and other health care practitioners.<sup>25,26,27</sup> This lack of training impacts routine systematic assessment and effective

**Table 14.1**  
**Pain Care Bill of Rights**

**As a person with pain, you have:**

- the right to have your report of pain taken seriously and to be treated with dignity and respect by doctors, nurses, pharmacists, and other health care professionals.
- the right to have your pain thoroughly assessed and promptly treated.
- the right to be informed by your doctor about what may be causing your pain, possible treatments, and the benefits, risks, and costs of each.
- the right to participate actively in decisions about how to manage your pain.
- the right to have your pain reassessed regularly and your treatment adjusted if your pain has not been eased.
- the right to be referred to a pain specialist if your pain persists.
- the right to get clear and prompt answers to your questions, take time to make decisions, and refuse a particular type of treatment if you choose.

Although not always required by law, these are the rights one should expect, and if necessary, demand, for pain care.

Source: American Pain Foundation, 2003.

cancer pain treatment. There are multiple types of pain (e.g., somatic nociceptive pain, visceral nociceptive pain, bone pain, and peripheral neuropathic pain) that require that medications and non-pharmacologic therapy be directed at the specific type and etiology of the pain in order to be effective. Preferred drug lists and review processes, patient and clinician attitudes towards pain and pain therapies, providers' inexperience, insufficient referrals to pain specialists, lack of reimbursement for pain treatment, lack of access to appropriate health care and pain specialists, and cultural factors are all barriers which often impede effective cancer pain management.

**Patient and Clinician Attitudes About Cancer Pain**

A significant barrier to effective cancer pain management is patients' and clinicians' attitudes about pain and pain medication. Attitudes of patients and family members often result in reluctance to report symptoms to health care providers. Patients may fear that an increase in pain means their cancer has worsened, that it will distract the health care provider from cancer treatment, that pain is to be expected, or that they will be labeled a "bad patient." Cancer patients and their families may lack knowledge about options for effective

pain management or may not be aware that they have the right to have their pain assessed and appropriately managed. Cancer patients and their families may have misconceptions: pain is inevitable, pain builds character, and complaints about pain distract the health care professional. Cancer patients may also fear the side effects of pain therapies. In addition, cancer patients may fear being perceived as weak for acknowledging their pain. In a survey conducted by the American Pain Foundation, 61% of Maryland respondents indicated that they did not seek help for their pain because they were embarrassed or didn't want to be seen as complaining.<sup>28</sup> These perceptions prevent them from seeking treatment.

The stigma associated with opioids and other powerful painkillers presents another barrier. Some patients cite fear of addiction<sup>29,30,31,32</sup> as a reason for rejecting or reduced use of painkillers, but research has found that opioids decrease pain, increase function, and improve mood without causing addiction. Taking opioid medications for pain relief as prescribed, under the direction of a health care provider, is safe and effective and only in rare cases leads to addiction.<sup>33</sup>

## Provider Education and Training

Most physicians and other health care professionals receive limited training in pain management. Knowledge gaps, negative attitudes toward opioids, and inadequate assessment skills are all barriers to effective cancer pain management. The low priority given to pain treatment in professional training<sup>34,35,36,37,38</sup> (including medical schools and residency programs) and educational texts<sup>39</sup> contributes to the problem. Senior medical students were found, in one study, to be reluctant to prescribe opioid therapy for pain.<sup>40</sup> Another study found them to be deficient in their understanding of multiple available options for relieving suffering in cancer patients.<sup>41</sup> In addition, a recent study found pain management to be lacking among pharmacy school curricula.<sup>42</sup> The training of doctors, nurses, pharmacists, and therapists in general is suboptimal regarding the thorough assessment and treatment of pain and other associated symptoms in patients with cancer.

Additional pain and symptom management content has recently been integrated into the curriculum at the University of Maryland School of Medicine and internal residency programs. Pain courses are also available as electives at the University of Maryland School of Nursing and School of Pharmacy. A palliative care pharmacy residency is also available. In addition, both Johns Hopkins University and the University of Maryland have pain fellowship programs. While Maryland professional schools may be on the forefront of training health care students in pain and symptom assessment and management, most clinicians practicing in Maryland have not completed their training in the state within the last few years. So most clinicians in Maryland were not exposed to adequate pain management training during their basic or advanced training. Postgraduate training for practicing health care providers may increase the use of effective methods of pain assessment and treatment,<sup>43,44</sup> but often requires intensive mentoring, specialty programs, or the use of additional change strategies.<sup>45,46,47,48,49</sup>

A two-pronged approach is required to facilitate pain management education for Maryland's health care professionals. Professional schools in Maryland should be required to have significant curriculum hours devoted to pain and symptom assessment and management, as should all residency programs. In addition, currently practicing health care providers should be required to complete additional training in this area through continuing education programs.

## Preferred Drug Lists and Review Processes

Preferred drug lists and pre-approval processes are barriers to cancer pain management. Recent genetic evidence has confirmed long-standing clinical observations that medication is not “one size fits all.” Genetic variations are responsible for the individual differences in pain medication response.<sup>50</sup> Some individuals may be incapable of metabolizing some analgesics into active compounds and thus may never obtain pain relief from certain medications. Other individuals are fast or slow metabolizers, causing varying analgesic response as well as impacting side effect profiles and severity. Testing for the genetic polymorphisms responsible for these individual differences is not currently available except in a research environment. This means that cancer pain treatment, including drug selection, must be individualized for each patient based on clinical response. Preferred drug lists and pre-approval processes hinder the health care practitioner's ability to tailor therapy and to provide timely, effective analgesia with manageable side effects.

## Cultural, Ethnic, and Religious Factors

Cultural, ethnic, and religious factors are an important part of health care services, and their influence on cancer pain cannot be underestimated. A patient's culturally patterned understanding of the cause and interpretation of cancer pain will affect the course of the pain management plan. Religious or spiritual coping strategies may have an effect on the cancer patient's perception of pain. It is important to provide culturally competent care and to respect and maintain sensitivity to issues related to an individual's culture, race, sex, social class, economic status, and religious or spiritual coping strategies.

## Comprehensive Pain Assessment Barriers

A comprehensive pain assessment is critical to provide health care providers with information for cancer pain management. Providers cite the lack of systematic assessment,<sup>51</sup> subjectivity of the pain experience, and lack of time as the biggest obstacles to providing effective pain management. Routine screening using pain measurement tools can help health care providers determine when a patient is experiencing pain and thus respond to changes in pain, but simple pain screenings do not assess how pain affects that patient's life, the quality of the pain, when it occurs, or how much or what kind of medication(s) or other therapies will help reduce a particular patient's pain.

### Pharmacy Barriers

Pharmacy issues can present barriers to pain management for people with cancer. Handling controlled substances that are used for cancer pain treatment poses several difficulties for pharmacies and pharmacists that are passed on to consumers as access issues, delays in therapy, or price increases. Specifically, staffing is required for security and record keeping of Schedule II pain medications. Governmental programs such as Medicaid often require overwhelming amounts of paperwork to dispense some controlled substances. The numbers of different medications, dosage size, form, and amounts needed may be difficult to estimate. Few discounts are available to pharmacies purchasing small quantities, resulting in little profit to small independent community pharmacies that may purchase opioids on an individual patient basis.<sup>52</sup> While pharmacies must pay for medications up front, Medicaid may not reimburse pharmacies for several months. These issues show that there is little incentive for small pharmacies to stock some controlled substances, and this may adversely affect those individuals that depend on them, increasing disparities in the care of people in pain who are elderly, live in rural areas, or are in a low-income bracket.

### Legal and Legislative Barriers

Pain management is also affected by legal and legislative barriers developed in response to concerns about drug abuse. Laws concerning controlled substances vary. In states with pain coalitions, efforts are being made to revise legislation to remove barriers to the use of opioids, such as removing dosage restrictions. A balanced approach to the dispensation of pain medication is needed so the effort to prevent drug abuse does not impede access of controlled substances to pain sufferers.<sup>53,54</sup>

It is believed that careful attention to the assessment and effective treatment of pain and other symptoms of cancer patients is found more frequently among hospice patients than patients who have not been referred to a hospice program.<sup>55,56</sup> Nationally and in Maryland, the average and median hospice lengths of stay are low.<sup>57</sup> This suggests late referrals to hospice, delaying access to effective pain and symptom management at the end of life that should have been available throughout the disease trajectory.

### Disparities

Certain groups of patients face higher risks of unrelieved pain. Rural patients may not have access to pain specialists or pain clinics within a reasonable distance. Older people may view pain as an inevitable part of aging; some may have medical or cognitive conditions that may prevent them from describing their pain or following a pain management plan. Minorities, females, children, the elderly, and the underserved face significant risk for under-treatment of pain. Many of these patient populations have lower rates of insurance coverage and less access to health care. Minority cancer patients are at two to three times the risk of inadequate pain management than other cancer patients.<sup>58</sup> Factors that may be responsible for this disparity include cultural differences between providers and patients, language barriers, and length of time spent with providers. Physiologic mechanisms including drug metabolism may compound disparities in some populations. In addition, there is compelling evidence that health care professionals may unknowingly treat pain differently in these populations, resulting in under-treatment<sup>59,60,61,62,63,64,65,66</sup> and increasing the previously mentioned disparities in care.

### Health Insurance Policies and Reimbursement for Cancer Pain Care

Major contributors to inadequate cancer pain control include insufficient health insurance coverage, insufficient reimbursement rates,<sup>67</sup> inconsistency in health care benefits for pain control therapies provided by various health insurers<sup>68</sup> and increasing numbers of uninsured individuals.<sup>69</sup> Lack of health insurance coverage and uneven reimbursement policies for prescription drugs, medical equipment, and professional services inhibit access to cancer pain management.<sup>70</sup> Recent evidence suggests that effective cancer pain management may reduce cost of care, improve quality of life, and lengthen the lives of cancer patients.<sup>71,72</sup>

Information on insurance coverage for pain management is sparse.<sup>73</sup> A recent study of 35 BlueCross BlueShield (BCBS) plan senior medical directors (SMDs) showed that most BCBS plans deal with pain coverage on a case-by-case basis and do not have uniform pain treatment or coverage guidelines.<sup>74</sup> Plan coverage for various pain treatments for the 35 BCBS SMDs is reported in Table 14.2. Although most plans

**Table 14.2**  
**Percentage of BCBS Plans Not Providing Various Pain Management Therapies**

Pain management strategy	Percentage of plans not providing coverage (n=35)
Behavioral interventions	46%
Biofeedback	63%
Acupuncture	80%
Implanted pumps	17%
TENS (transcutaneous electrical nerve stimulation)	29%
Nerve Blocks	0

Source: Hoffman DE. Pain management and palliative care in the era of managed care: issues for health insurers. *Journal of Law, Medicine, and Ethics* 1998;26:(4)267-89.

have an in-house or out-of-house expert pain consultant, only a few plans indicated that their expert held board certification in pain management. Only 13 plans reported that they had addressed pain management in the terminally ill.

Data regarding pain management reimbursement by commercial payors and HMOs primarily consists of anecdotal reports by health care providers.<sup>75</sup> These providers report repeated submission and substantiation of pain management treatment plans prior to reimbursement or preauthorization by payors.<sup>76</sup> Critical components of the pain management treatment plan may be denied<sup>77,78</sup> or inconsistently approved.<sup>79</sup> This indicates the comprehensive, multidisciplinary approach that is required to effectively manage many cancer pain problems is not understood by payors or their experts.

Little information exists about the impact of Medicaid policies on pain control for cancer patients. Medicaid reimbursement for end-of-life care is known to be inadequate in providing advanced types of pain relief such as chemotherapy, radiation treatments,<sup>80</sup> and specialized analgesic therapy. Pain treatments available for Medicaid reimbursement vary based on setting (e.g., home, nursing home, or hospital) and services provided (e.g., hospice or acute care) and, to a degree, are state regulated.<sup>81</sup>

Medicaid cancer patients may receive more pain medications and more effective pain medication than patients covered by some other insurers because Medicaid provides pharmaceutical benefits.<sup>82</sup> A recent initiative in Maryland to restrict the Medicaid formulary has the

potential to deny patients access to certain pain medications and impede effective cancer pain management. Preferred drug lists and review processes are system barriers<sup>83</sup> that hamper effective cancer pain treatment. Preferred drug lists and pre-approval processes are believed to increase the reluctance of health care providers to prescribe effective pain therapy and is therefore likely to impede the provision of timely, effective pain management.

Similar to Medicaid, few studies have used Medicare data to assess reimbursement for pain management strategies. Several issues may affect access to, and payment of, cancer pain management therapies by Medicare. The lag time between the introduction of new drugs and adjustments to Diagnosis Related Groups (DRG) and Resource Utilization Groups (RUG) used in acute care settings and nursing homes can be two years or greater,<sup>84</sup> reducing access to new treatments. Medicare coverage is also subject to a reasonable and necessary test based on the patient's clinical condition, which can result in significant variability in coverage decisions across the United States.<sup>85</sup> Medicare limits its payment for physician's services for pain management, and this is believed to deter adequate treatment.<sup>86</sup> Under Medicare, injections cannot be billed separately unless no other physician services are billed at the same time.<sup>87</sup> Bundling of pain management in post-operative services<sup>88</sup> also deters the use of specialists in the provision of effective pain management<sup>89,90,91</sup> and may be partially responsible for continual problems of uncontrolled post-operative pain, premature discontinuance from specialized analgesic therapy, and untoward effects from specialized analgesic therapies.<sup>92</sup>

Medicare does not provide coverage for self-administered outpatient medications other than for patients electing the Hospice Medicare Benefit. Although there is some limited coverage for home infusion of medications,<sup>93</sup> the lack of an outpatient drug benefit may mean that more expensive invasive pain treatments may be substituted for simple, more cost-effective oral regimens. Regardless of the route of analgesic therapy, lack of prescription coverage may negatively impact the control of analgesic side effects and detrimentally affect pain control. In addition, side effects, which are most often treated with other oral medications, have been shown to decrease patient adherence to prescribed pain medication regimens and are believed to be partially responsible for the continued problem of inadequate pain control.<sup>94</sup>

Some analysis of the Medicare hospice benefit has been performed. While Medicare's hospice benefit provides outpatient medications, a recent survey of hospice programs suggests that low payment rates make it difficult to provide expensive treatments such as palliative radiation and chemotherapy, effective modalities to provide pain control in the cancer patient.<sup>95</sup> Fixed per diem rates may also limit hospice patient access to newer, more costly medications<sup>96</sup> and may require a change in therapy when a patient switches to the Medicare Hospice benefit. Anecdotal evidence also suggests hospice formularies and specialty analgesic therapies are restricted in an effort to reduce costs.

Many people in pain never see a pain specialist. Primary care providers may not refer patients to specialists or to other members of the multidisciplinary pain team.<sup>97,98</sup> Last but not least, a separate rider may be required for beneficiaries to obtain coverage for medications. For those with prescription drug benefits, any limitations on prescriptions, network pharmacy restrictions, and caps on prescription drugs also limit access to effective pain management.

With new knowledge and rapidly changing technologies, consideration must be given to ensuring that cancer patients have access to pain management specialists and effective therapies. Since a full range of pain management modalities is cost effective,<sup>99</sup> they should be available to individuals regardless of the illness trajectory, health insurance, setting, or election of special services (e.g., acute care or hospice). Access to a wide variety of pain control options and medications is necessary because of the highly individual nature of pain, wide variety of clinical conditions, and varied responses to pain related treatments.

## Pain Management Standards

The Institute of Medicine report, "Priority Areas for National Action: Transforming Health Care Quality,"<sup>100</sup> targeted pain control in advanced cancer as a priority area. The authors concluded that improving pain care would allow all stakeholders to improve the quality of health care and reduce disparities. Although several guidelines, such as the World Health Organization's analgesic ladder, have been validated, cancer pain continues to be under-treated due to inconsistencies among various health care systems. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) implemented pain management standards in 2000 and added them to all their organizational manuals. The essential components addressed by the JCAHO standards are:<sup>101</sup>

- Individuals have the right to appropriate assessment and management of pain.
- Assess the existence of and, if present, the nature and intensity of pain in all patients, residents, or clients.
- Establish policies and procedures that support the appropriate prescribing or ordering of effective pain medications.
- Educate patients, residents, and clients and their families about effective pain control.
- Address the individual's needs for symptom management in the discharge planning process.
- Incorporate pain management into the organization's performance measurement and improvement program.

Facilities within the health care system involved in assessing or treating patients in pain should be held to consistent standards of quality pain management regardless of their accreditation. Unfortunately, many licensed health care facilities that care for cancer patients are not accredited by the JCAHO, including extended care facilities, nursing homes, freestanding radiation oncology centers, hospices, home health agencies, pain clinics, and physician offices. These facilities should have pain assessment and management standards similar to JCAHO standards enforced by the applicable licensing or accrediting agency. The Wisconsin Cancer Pain Initiative has developed guidelines to assist organizations in their efforts to institutionalize pain management. The eight steps essential in implementing this approach are:<sup>102</sup>

- Develop an interdisciplinary workgroup.
- Analyze current pain management practices in your care setting.
- Articulate and implement a standard of practice.
- Establish accountability for pain management.
- Provide information about pharmacologic and nonpharmacologic interventions to clinicians to facilitate order writing and interpretation and implementation of orders.
- Promise individuals a quick response to their reports of pain.
- Provide education for staff.
- Continually evaluate and work to improve the quality of pain management.

In Maryland, there is inconsistency among licensing boards in the development of statements outlining each profession's role in the assessment and management of pain, subsequent monitoring and interventions regarding adherence to standards, and dissemination of related information to professionals.

When all health care professionals and facilities are held to similar pain management standards, the quality of pain management can be sustained as patients transition between health care settings. Moreover, accountability for pain management will then be clearly defined throughout the health care system.

## Complementary and Alternative Medicine

Complementary and alternative medicine, as defined by the National Center for Complementary and Alternative Medicine (NCCAM), is a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine.<sup>103</sup> “While some scientific evidence exists regarding some complementary and alternative medicine (CAM) therapies, for most there are key questions that are yet to be answered through well-designed scientific studies—questions such as whether they are safe and whether they work for the diseases or medical conditions for which they are used.”<sup>104</sup>

Therapies used jointly with traditional medicine, such as aromatherapy to lessen a patient's post-surgery discomfort, are considered complementary therapies. In contrast, alternative therapies are used as a substitute

for conventional treatments. For example, the use of a special diet to treat cancer instead of undergoing conventionally recommended surgery, radiation, or chemotherapy is considered an alternative therapy.<sup>105</sup>

Integrative medicine, as defined by NCCAM, combines mainstream medical therapies and CAM therapies for which there is some high-quality scientific evidence of safety and effectiveness.<sup>106</sup> Ongoing research regarding the efficacy and appropriateness of CAM therapies in cancer pain management should be encouraged and supported. The use of scientifically validated complementary and alternative therapies for pain control should be supported as individual measures or in conjunction with traditional pain management methods. To that end, patients and providers must discuss how CAM therapies may be integrated into their overall pain management. In addition, reimbursement of these therapies by insurance companies is necessary to allow their use in the cancer patient population.

## Research

There is a lack of research and knowledge in the area of cancer pain. In a recent NIH State of the Science Conference—Symptom Management in Cancer: Pain, Depression, and Fatigue, key research findings and future research avenues were identified and included in an evidence-based report.<sup>107</sup> Specifically, epidemiologic characteristics, including details regarding the various types of cancer pain, have not been adequately described. A minimalist approach to assessment of pain and analgesic side effects has been utilized, despite voluminous literature that suggests a more robust approach. Major gaps exist in the knowledge about therapeutics, such as relative efficacy of analgesics, adjuvant therapy, surgical interventions, non-invasive therapies, non-pharmacological treatments, and palliative care regimens. The NIH State of the Science conference also suggested pain be assessed in conjunction with other symptoms such as depression and fatigue as symptom clusters.

Many pain treatment guidelines have not been validated by research. Little information exists on procedural pain and its management in a population that undergoes a multitude of painful procedures. There are insufficient studies available to guide appropriate assessment and treatment of pain in special populations, such as children, the elderly, or the cognitively impaired.

Additional topics and specific considerations for con-

ducting cancer pain research are identified in the NIH State of the Conference evidence-based report,<sup>108</sup> as well as recent Agency for Healthcare Research and Quality evidence reports.<sup>109,110</sup> It is vitally important that funding for future cancer pain research and study be identified and promoted. For example, pharmaceutical companies should be encouraged to continue research and development of new treatments for the management of cancer pain. Insurers should be solicited to fund and provide data for epidemiological studies regarding the prevalence of cancer pain among patients in Maryland. Funding should be allocated to assist in the assessment of new or existing statewide policies regarding their impact on cancer pain control.



## Pain Management Goals, Objectives, and Strategies

### Goal:

To increase awareness of, and access to, comprehensive pain assessment and management services for all cancer patients in Maryland in light of the current public health crisis of inadequate pain control.

### Target for Change

By 2008, develop a system to monitor the availability and quality of pain assessment and management services for cancer patients in Maryland, with specific attention to the needs of special populations, including pediatrics and minorities.

### Objective 1:

Increase provider awareness and training regarding appropriate cancer pain assessment, management, and relevant regulatory issues.

### Strategies:

1. Provide cancer pain management education to all target audiences, which include, but are not limited to, health care systems, licensing boards (including investigators), professional organizations, ethics committees, Ombudsmen, state surveyors, regulators and reviewers, the Inspector General, the Insurance Commission, the Attorney General, criminal justice officials, medical examiners, and insurers.
2. Require all cancer health care providers (including, but not limited to, physicians, nurses, and pharmacists) to earn continuing education credits in the area of cancer pain assessment and management before license renewal.
3. Health care students in all disciplines should receive both didactic and clinical training in cancer pain assessment and management standards before receiving licensure. This training includes, but is not limited to, disparity issues in cancer pain management and topics related to licensure and cancer pain control as well as drug utilization and surveillance utilization review. The educational curriculum should be assessed by pain management experts, use multiple educational formats, and be accompanied by an assessment of knowledge and competency on an ongoing basis.
4. Each licensing board should develop a statement about their discipline's role in cancer pain assessment and management, including minimum competencies and education requirements. Such documents should be developed with the input of pain specialists and address issues of pain management and licensure. Providers should be required to view the statement prior to licensing or reciprocity. The



statement should be broadly available including via electronic media and accompanied by practitioner educational efforts.

5. Professional licensing boards should be encouraged to treat transgressions of untreated or under-treated cancer pain aggressively. Appropriate remedial education should be made mandatory prior to actions against a practitioner's professional license.
  - Evidence-based guidelines (e.g., Federation of State Medical Boards guidelines)<sup>111</sup> and pain experts should be used by licensing boards and the state drug enforcement agency to investigate cancer pain or analgesic-related issues.
6. New policy and legislation relevant to cancer pain assessment and management should be accompanied by educational initiatives targeting appropriate audiences.
7. Increase provider awareness of scientifically validated complementary and alternative cancer pain therapies, and encourage providers to discuss these therapies with their patients.

#### **Objective 2:**

Increase provider reimbursement for cancer pain therapies.

#### **Strategies:**

1. Recommend that insurers in Maryland provide a uniform pain assessment and management benefit for all age and income groups that would include, but would not be limited to:
  - inpatient and outpatient referral to a pain specialist for pain assessment and treatment planning, short and long-term multimodal treatments and follow-up, including management of side-effects.
  - Follow-up by licensed health care professionals including non-prescribers (e.g., home health nurses, clinical specialists) to provide education, assess adherence, and work with the patient and his/her caregivers and the prescriber to maximize pain management therapy.
  - Uniform minimal reimbursement for pharmacologic and scientifically based non-pharmacologic pain management therapies regardless of therapeutic medication class, choice of drug or therapy, method of medication delivery (i.e. route), site of service, or disease phase. Therapeutic interventions to manage pain including palliative pain interventions (chemotherapy, radiation therapy, and radioisotope therapy), pharmacologics (long- and short-acting analgesics, adjuvants, and side-effect medications), non-pharmacologics (e.g., physical therapy, acupuncture, and behavioral interventions), interventional procedures (e.g., temporary and permanent nerve blocks) and associated durable medical equipment, should be included in uniform minimal reimbursement standards.



In the development of this mandated benefit, consideration should also be given to:

- minimizing drug premiums and co-pays while keeping the benefit sustainable and attractive.
  - assuring uniformity of coverage across the Medicare and Medicaid programs and coordination of benefits between these programs, including hospice.
  - the components and effect of Medicaid drug utilization review (e.g., the impact of regulations regarding limiting drug quantities, refills, co-payments, the number of allowed prescriptions per month, and pharmacy dispensing fees; provider prescribing practices; referrals to Medicaid Fraud Control Units or Surveillance and Utilization Review programs).
  - facilitating seamless, timely, and adequate reimbursement of claims.
  - rapid assessment of new therapies by a team of pain experts for inclusion in minimum uniform coverage benefit.
2. Extend assistance for pain therapy payments for patients at or below 250% of the federal poverty level.
  3. Encourage insurers to offer a discount on malpractice insurance for providers who have completed continuing education in the area of cancer pain assessment and management and demonstrate competency in this field.
  4. Advocate for reimbursement of scientifically validated complementary and alternative pain therapies by insurance companies.
  5. Insurance contracts should be required to specifically provide current and prospective plan subscribers with information about the pain management services provided by the plan.

### **Objective 3:**

Increase consistency among different health care systems regarding compliance and adherence to standards for cancer pain assessment and management.

### **Strategies:**

1. Develop and test an external source of norms to which all health care facilities assessing or treating cancer patients in pain would be held accountable. Licensed health care facilities not accredited by the JCAHO (e.g., extended care facilities, nursing homes, freestanding radiation oncology centers, hospices, home health agencies, pain clinics) should be held to pain assessment and management standards similar to JCAHO standards by the applicable state licensing agency. Financial reimbursement should be tied to meeting these quality standards.
2. Reduce limitations to prescribing cancer pain medications (e.g., specific dose required instead of a dose range) and medications for side effects (e.g., use of haloperidol for nausea and vomiting) in extended care facilities.
3. Promote institutional scrutiny for disparity-related cancer pain management issues.
4. Information about a patient's cancer pain management regimen should be transferred with any discharge or transfer of care.
5. Develop standardized definitions of service scope for cancer pain specialists and cancer pain treatment centers.
6. Promote the use of population specific, standardized, reliable, valid, cancer pain assessment tools. Special consideration should be given to the effect of cancer pain on patient function and to patients with limited ability to communicate or advocate for themselves (e.g., children, people with language barriers, patients with dementia).

**Objective 4:**

Eliminate barriers due to cultural, age, sex, and income disparities and ensure equal access to cancer pain management therapies within the health care system.

**Strategies:**

1. Convene an independent committee to improve and accelerate the process relative to prior authorization of non-formulary medications and invasive techniques used in cancer pain management. The committee should work to reduce excessive co-payments for non-formulary medication if the non-formulary medication provides the best results for a particular patient.
2. Pharmacies should be required to have pain management medications, particularly opioids, readily available for patients.
3. Ensure that excessive restrictions do not exist on the amount of medication prescribed, prescription renewals, and telephone, fax, or other electronic prescription ordering of analgesics for cancer pain.
4. Encourage the establishment of multidisciplinary cancer pain treatment centers employing pain specialists in multiple health care disciplines.
5. Draft legislation that requires cancer patients with unrelieved pain to be referred to cancer pain specialists in a timely fashion and guarantees that information about cancer pain treatment plans is communicated between providers and institutions at the time of discharge or transfer.

**Objective 5:**

Increase scientific knowledge regarding assessment and treatment of cancer pain.

**Strategies:**

1. Encourage and promote research in such areas as:
  - cancer pain assessment tools, particularly for minority populations and populations that are unable to advocate for themselves because of limited communication skills.
  - low-cost medications for cancer pain management (e.g., methadone).
  - outcomes analysis (e.g., long term opioid use; opioid rotation, tolerance, and addiction; cancer pain quality tools for use by surveyors and accrediting organizations; and the financial as well as quality impact of recommendations made herein and associated legislative changes).
  - cognitive, behavioral, complementary, and alternative cancer pain therapies.
  - guidelines for the assessment and management of specific types of cancer pain (e.g., neuropathic pain).
  - when to refer patients to cancer pain specialists and the accompanying credentials for certification of such specialists.
  - pediatric cancer pain management.
  - changing clinical practice and clinicians' fear of regulatory scrutiny.
  - improving patient adherence to cancer pain therapy.
  - occurrence of cancer-related pain by cancer, stage, type of cancer pain, and other factors such as demographics and longitudinal trajectory.
  - use of medical marijuana for cancer pain.



2. Encourage pharmaceutical companies to continue research and development of new treatments for the management of cancer pain.

**Objective 6:**

Increase public knowledge and awareness of cancer pain management practices and referral sources.

**Strategies:**

1. Partner with organizations such as the American Cancer Society, the American Chronic Pain Association, the American Pain Foundation, and the Maryland Pain Initiative to conduct a comprehensive, statewide, and culturally sensitive public health campaign to promote cancer pain assessment and management. This effort should utilize public health strategies and include an educational media campaign. The message should include a focus on patients' rights to adequate cancer pain management and their health care providers' responsibilities in the process as well as their own responsibilities, dispel myths about pain medications, describe options that exist for cancer pain management, and instruct the public to communicate with their health care provider about cancer pain.
2. Provide culturally sensitive and language-appropriate cancer pain control information to all patients and/or their surrogate at the time of diagnosis and throughout their disease process. Consider the use of educational materials already in existence from organizations such as the American Cancer Society and National Cancer Institute. As part of this effort, develop a mechanism to disseminate standard, medically appropriate information on specific cancer pain medications and therapies to patients. Seek to inform patients and/or surrogates of options, alternatives, and potential outcomes and involve them in treatment selection.
3. New policy and legislation relevant to cancer pain assessment and management should be accompanied by educational initiatives targeting the general public.
4. Develop and make available in a variety of media a list of Maryland cancer pain resources including, but not limited to, pain specialists, pain experts, pain clinics, hospices, medical schools, and pain specialty consumer groups.
5. Develop, staff, and publicize a pain management hotline for cancer patients and health care providers.

**Objective 7:**

Enhance existing legislation and create new regulations designed to increase awareness of, and access to, comprehensive cancer pain assessment and management services for all cancer patients in Maryland.

**Strategies:**

1. Revise the advanced directive and living will forms for clarity. Make the power of attorney (POA) form the lead form provided to cancer patients and consider eliminating the living will in favor of a revised advanced directive. Instructions should be written to strongly favor POA, supported with more specific guidance if the declarant wishes.
2. Modify state regulations to facilitate availability and prescribing of cancer pain medications.
3. Modify state regulations to mandate that insurers in Maryland provide a uniform cancer pain assessment and management benefit for all ages, income groups, phases of the disease trajectory and regardless of site of care (see Objective 2).
4. Allocate funding to assist in the assessment of relevant, new, or existing statewide policies regarding their impact on cancer pain control.
5. Develop a Cancer Pain Patient's Bill of Rights based on a similar California bill (1997) CAHLTH & S 124960. This bill should include:



- some mechanism of enforcement.
  - a recommended course of action if an individual is denied cancer pain care.
  - a requirement for regular assessment and charting of cancer pain in physicians' offices, health care clinics, and licensed health care facilities.
  - A provision that licensed health care facilities as well as clinics, treatment centers, home health agencies, hospices, and physicians' offices adhere to an external cancer pain assessment and management standard that defines minimum practice and quality monitoring requirements.
  - a requirement for transfer of cancer pain-related information when care is transferred (e.g., at discharge, between providers, or among institutions).
  - A requirement that patients receive an explanation of cancer pain management options, alternatives, and potential outcomes and are involved in treatment selection.
6. Provide funding for the educational initiatives put forth in this document.
  7. Provide regulatory structure and legislative support for policy initiatives put forth in this document.

**Note:** Under-treatment of pain is a public health problem, regardless of the underlying etiology. Hence, the issues related to cancer pain apply to pain in general. Like all pain, cancer pain can be acute or chronic, assessment and management is often inadequate, and the related cultural and psychological issues and barriers are similar in both malignant and non-malignant pain conditions. Therefore, it is suggested that the recommendations in this chapter be extended to the management of acute and chronic pain and associated symptoms of non-malignant conditions so that all the citizens of Maryland, whether or not they have cancer, may benefit from the goals, objectives, and strategies suggested here.

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