# PAIN Clinical Updates

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## Pain Relief as a Human Right

We must all die. But that I can save him from days of torture, that is what I feel as my great and ever new privilege. Pain is a more terrible lord of mankind than even death itself. Albert Schweitzer.<sup>1</sup>

The time has come. The problem is clear. Pain is a major public health issue throughout the world. The gap between an increasingly sophisticated knowledge of pain and its treatment and the effective application of that knowledge is large and widening. Both acute and chronic pain is often poorly managed for a wide variety of cultural, attitudinal, educational, political, and logistical reasons. Frustrated by the slow pace of change, pain clinicians and national and international pain associations have responded in various ways. This issue of *Pain: Clinical Updates* focuses upon the promotion of pain relief as a fundamental human right, in addition, of course, to being good clinical and ethical practice. A companion issue<sup>2</sup> describes the long-term collaboration of the International Association for the Study of Pain (IASP) with the World Health Organization (WHO) as it enters a new, dynamic phase.

#### What is Driving this Rights-Based Advocacy?

The term "right" is a convenient way of both promoting an ideal and enforcing a duty. Two key factors underlie the emergence of the right to adequate pain treatment. The first is the accumulation of evidence from many sources that pain is inadequately treated and so an "ethic of undertreatment" must be overcome. The second is the widespread language of "rights" since the advent of international human rights laws, the rise of the consumer movement, the culture of rights for minority groups, and the promotion of individualism, especially in Western liberal societies.

However, it is difficult to articulate a right whose nature is not precisely specified. Is the statement that patients have a right to pain relief an exercise in clinical recommendation or moral persuasion, or a statement of law? If it has any pretenses to the latter, the difficulties are clear in affirming such a right that has neither legal precedent nor enforceability. Below, we review the diverse sources of patients' rights to pain relief. Although they all articulate and promote good practice, they lie along a spectrum of legal enforceability. Some are based on a solid legal foundation, while others, such as guidelines by pain associations, are assertions of patient rights without intrinsic legal status.

#### Human Rights Law

One response to the undertreatment of pain has been to promote the concept of pain relief as a public health issue of such critical importance that it constitutes a universal human right.<sup>3–7</sup> International human rights are articulated in the foundation covenants of the United Nations: the Universal Declaration of Human Rights (1948), the International Covenant on Civil and Political Rights (1966), and the International Covenant on Economic, Social and Cultural Rights (ICESCR, 1966). ICESCR articulates the right "of everyone to the enjoyment of the highest attainable standard of physical and mental health." The covenant obliges its signatories to provide, to the maximum of their available resources,

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the rights it guarantees, but contains no express right to pain relief. Nevertheless, a strong argument could be made that a right to pain relief may be implied from the expressed right to health. The concept of health has been defined by various international organizations. In 1949, the Constitution of the WHO defined health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." Provision of adequate pain relief falls comfortably within this definition.

Assuming that pain relief is implied by the universal right "to the highest attainable standards of health," two questions arise. First, could an individual or group, citing ICESCR, complain that this right to pain relief was not met? And second, by what means can the United Nations induce each nation's health service to provide adequate pain relief?

There is no direct compliance mechanism for rights enunciated in ICESCR. The international community assesses compliance with the covenant through reports submitted by every nation to the Committee on Economic, Social and Cultural Rights, documenting how they have implemented the rights. Despite valid questions about this mechanism being the principal means of overseeing compliance with international human rights norms, well-compiled reports do foster implementation of the obligations of ICESCR. Nations are encouraged to identify problems they may be encountering in fulfilling the stipulations of the covenant, including "negative developments, frustrated aspirations and other difficulties."8 Also stressed is the need for appropriate statistical information. For pain relief, the committee would be interested in data on the epidemiology of acute and chronic pain, the provision of pain services to rural and remote communities, and the obstacles, legal or otherwise, to the availability of opioids. Fortunately, such information is now becoming available for the first time.9

Individuals or nongovernmental organizations (NGOs) cannot make a direct complaint that national pain services are inadequate. They may, however, submit specific information about those deficits to the committee. The concept of the progressive realization of rights such as health care includes an obligation for states to take steps to provide for basic needs as the minimum essential level of each right. Inadequate resources and inadequate pain management are clearly linked; in many countries, even the most basic pain relief needs are not being met. The committee, in its General Comment No. 14 (2000), has stated that signatory nations have certain "core obligations" in their provision of health regardless of their resources. They include obligations to ensure access to health facilities, goods, and services on a nondiscriminatory basis, to provide essential drugs, as defined by the WHO,<sup>10</sup> and to adopt and implement a national public health strategy. In the context of pain management, this authoritative interpretation appears to oblige nations to ensure access to analgesics, including opioids (morphine is defined by WHO as an essential drug), to provide pain services on a nondiscriminatory basis, and to include pain management in any public health strategy.

Another possible source of an international right to pain relief is contained in Article 5 of the Universal Declaration of Human Rights, which states that "No one shall be subject ... to inhuman or degrading treatment." Although primarily aimed at the treatment of prisoners, the concept reinforces patients' rights to effective pain management and condemns the worst cases of neglectful pain treatment that have come before the courts. In summary, while there is no explicit international human right to pain relief, there is a right to the "highest attainable standard of health," which comfortably implies a right to pain relief.

Several possible strategies might strengthen the explicit recognition of a universal right to pain relief. The first is through an amendment to the covenants that expressly declares such a right. Such an amendment is unlikely, given that the foundation documents that make up the International Bill of Rights have never been amended. The second strategy is for international associations for pain and palliative care to make submissions to the committee highlighting the central role of pain relief in the attainment of universal health, thereby placing moral pressure on countries to fulfil the basic pain relief needs of their populations.

Such a strategy could build upon the significant recent efforts of WHO and IASP, as surveyed in the companion issue of *Pain: Clinical Updates*.<sup>2</sup> In addition to its seminal work in the promotion of better analgesic practices throughout the world, WHO has already collaborated with other international bodies, including IASP and the International Narcotics Control Board, to lower the cost of opioids and change domestic regulations that limit medical opioid availability . Equally, the European Federation of IASP Chapters (EFIC) has initiated an annual "European Week Against Pain" and, commencing this year, the 30th anniversary of IASP's 1st World Congress on Pain, IASP will sponsor an annual "Global Day Against Pain."<sup>2</sup> The combination of moral persuasion and active assistance may yield greater results than either approach alone.

#### **Constitutional Rights to Pain Relief**

Besides a probable basis in international law, the provision of adequate pain relief has some foundation in domestic law through the vehicles of national constitutions, domestic legislation, and the law of negligence. Many of the world's nations have written constitutions that enumerate the right of their citizens to receive adequate health care. None expressly articulate a right to pain relief.

The U.S. Supreme Court, in two 1997 cases (Washington v. Glucksburg and Vacco v. Quill), expressed support for a constitutional right to adequate palliative care and suggested that individual states should not obstruct its provision. The practical ramifications of these judgments are threefold. First, they have placed pressure on individual states to reform laws and policies restricting the availability of opioids for the management of pain.<sup>11</sup> Second, these judgments have armed doctors caring for the terminally ill against regulatory medical boards that are "ignorant or dismissive of the evidence that high-dosage prescriptions of opioids for treating pain and other distressing symptoms are safe, effective and appropriate."<sup>11</sup> And third, they have compelled states not only to properly fund good end-oflife care but also to remove all mechanisms that may impair it. Justice Souter stated that if states refused to address these issues they may be guilty of "legislative foot-dragging," and Justice Brever stated that such states would "infringe directly upon ... the core of the interest in dying with dignity," which involves "medical assistance, and the avoidance of unnecessary and severe physical suffering."

Whether the U.S. Supreme Court will one day extend these findings to include a constitutional right to pain relief in other contexts such as chronic noncancer pain, is a matter of conjecture. Interestingly, EFIC has submitted a declaration to the European Parliament proposing that chronic noncancer pain is a "disease in its own right" warranting increased attention.<sup>2,4</sup> Whether such a declaration culminates in the articulation in the European Constitution of an express right to pain relief in that context also remains to be seen.

#### **Statutory Rights to Pain Relief**

The best source of a right to pain relief that is both unambiguous and legally enforceable is statutory law. Several models are possible. The first, included in the 1994 *Medical Treatment Act* of the Australian Capital Territory, is an explicit statutory statement of the right to pain relief: "[A] patient under the care of a health professional has a right to receive relief from pain and suffering to the maximum extent that is reasonable in the circumstances." A second model is statutory protection for doctors. An example is contained in the 1995 *Consent to Medical Treatment and Palliative Care Act* of South Australia, where medical practitioners caring for terminally ill patients are protected from any criminal or civil liability if they administer treatment with the intention of relieving pain, providing such treatment is given with consent, in good faith, without negligence, and in accordance with "proper professional standards of palliative care." Similarly, several U.S. states offer protection from disciplinary action by their respective state medical boards when controlled substances are given to treat intractable pain.<sup>12</sup>

A third model is a wider package of statutory requirements for pain management and education. An example is a recently enacted California statute that imposed three statutory obligations: doctors who refuse to prescribe opioids must refer patients to an expert pain physician, all doctors must complete continuing education in pain management and end-of-life care, and the Medical Board of California must develop a protocol to follow up complaints of undertreatment of pain and report annually to the state legislature its actions relating to that protocol. Russell Portenoy, a past president of the American Pain Society, stated that the law was "a very extraordinary step ... to address what is clearly an enormous problem," and Kathryn Tucker, director of Legal Affairs for the Compassion in Dying Federation, termed it "a model for the other states to follow."<sup>13</sup>

The above statutory innovations in Australia and California provide sound models for any future legislative activity that would empower any professional or lay group to lobby for reform. Essential aspects of such legislation include an explicit statement that adequate analgesia is a right, that doctors have a duty to listen to and reasonably respond to a patient's report of pain, that provision of necessary pain relief is immune from potential legal liability, that doctors who are neither able nor willing to ensure adequate analgesia must refer patients to a colleague who has the necessary expertise, and that continuing medical education in pain management must be compulsory.

#### **Pain and Negligence**

In common law, the law of negligence provides a further possible legal foundation to pain relief. Margaret Somerville, Professor of Law and Medicine at McGill University, has long argued that the unreasonable failure to provide adequate pain relief constitutes negligence. The law of medical negligence emphasizes taking reasonable care in all aspects of patient management. With respect to pain control, doctors may breach their standard of care by failing to take an adequate pain history from the patient; by treating the pain inadequately; and, in the context of uncontrolled pain, by failing to consult an expert in pain management. A few such cases of pain-related negligence have already appeared. With time, more cases will emerge to better outline the boundaries of reasonable action by doctors, nurses, and pharmacists in pain management.

#### **Statements by Professional Associations**

In recent years many professional bodies, overseeing tens of thousands of clinicians, have issued statements, guidelines, or recommendations on pain management. Leading pain, medical (e.g., anesthesiology), and nursing organizations have published major statements on pain. These organizations include, in North America, IASP, the American Academy of Pain Medicine (AAPM), the American Pain Society, the American Geriatrics Society, and the Joint Commission on Accreditation of Healthcare Organizations; in Europe, EFIC; and in Australasia, the Australian and New Zealand College of Anaesthetists (ANZCA), the Faculty of Pain Medicine, the Joint Faculty of Intensive Care Medicine, and the National Health and Medical Research Council. All such statements make it clear that pain relief requires the highest professional standards. Many express this as a patient right. The best not only state that patients have a right to pain relief, but also provide the context for that right. Such content includes rights to be believed in one's expression of pain, to receive appropriate assessment and management of pain, to have the results of assessment regularly recorded, to be cared for by health professionals with training and experience in assessment and management of pain, and to receive effective pain management strategies. See, for example, ANZCA's Statement on Patients' Rights to Pain Management (Table I).

#### Table I

The Australian and New Zealand College of Anaesthetists and Faculty of Pain Medicine and Joint Faculty of Intensive Care Medicine's Statement on Patients' Rights to Pain Management

ANZCA recognizes that severe unrelieved pain can have severe adverse physical and psychological effects on patients, with associated emotional, social and spiritual effects causing suffering in patients, their families and those close to them. At times severe pain can be extremely difficult to treat and management must be subject to the availability in each health care setting of appropriate, safe and effective methods. However, ANZCA recognizes the following rights of patients to management of acute pain, cancer pain and persistent noncancer pain:

- 1. The right to be believed, recognizing that pain is a personal experience and that there is a great variability among people in their response to different situations causing pain.
- 2. The right to appropriate assessment and management of pain; patients and their families have a key role in working with the health care team to develop realistic goals for pain management.
- 3. The right to have the results of assessment regularly recorded in a way that assists in adjusting treatment to achieve effective and ongoing pain relief.
- 4. The right to be cared for by health professionals with training and experience in assessment and management of pain, and who maintain such competencies by all necessary means. Where such competencies are unavailable, the patients should be referred appropriately.
- 5. The right to appropriate effective pain management strategies. These must be supported by policies and procedures and must be appropriate for use by the health professionals employing them.
- 6. The right to education about effective pain management options for their particular problem; families should also be included in such education.
- 7. The right to appropriate planning for pain management after discharge from immediate care.

Recommendations alone, even historic statements, do not change behavior. Guidelines per se have no force in law. Nevertheless, collectively they provide their specific professional audiences and indeed the entire medical community with the clarity, structure, and rationale for pain management so lacking in previous decades. Doctors can no longer practice in a microcosm bereft of knowledge about pain.

#### **Dangers in Promoting Pain Relief as a Right**

Revolutions often have unintended consequences. Although the goal is to dismantle the "ethic of underprescribing," the danger is that the language employed by statutes, courts, professional bodies, and medical boards may be misinterpreted by the public and by health professionals.

The public may interpret a "right to pain relief" as a legal right to demand any analgesic treatment they see fit. This interpretation potentially disrupts the nuances of clinical assessment and care by doctors and other clinicians. For instance, not all pains require or indeed respond to opioids.<sup>14</sup> Similarly, for neuropathic pain, an opioid may not be the drug of choice for all patients, and some may benefit from tapering opioid medication.

Another possible sequel of the promotion of pain relief as a right "is the implied message that all pain can be treated satisfactorily."15 Not all pain can be relieved, however, and the right to pain relief is not the right to a pain-free life. For patients, or their advocates, to interpret the right to analgesia to mean a guarantee of perfection distorts the intended content of that right. Such a misinterpretation could lead to an erroneous "notion of total analgesia"<sup>15</sup> that may lead to patient dissatisfaction or worse, litigation. Thus, it is important that whenever the right to pain relief is articulated, it should be made clear that the content of that right requires simply that the professional response be both reasonable and proportionate to the level and character of the pain experienced.

Within the health care profession, the promotion of pain relief as a right may have deleterious consequences. Doctors may see the declaration of such a right as potentially threatening their autonomy and clinical judgment. They may see guidelines, court rulings, or statutory prescriptions as onerous, lawyerdriven, and unrealistic. The attitudes of doctors to pain management may not alter. Indeed, attitudes to analgesia, especially opioids, may become more rigid and defensive.

The above unintended consequences of a "rights" discourse in pain relief and palliative care signal caution that the promotion of these goals depends upon their acceptance by health care professionals. For courts, legislatures, medical boards, and professional bodies, including specialist colleges, to assert these rights in isolation from the broad community of health professionals is potentially counterproductive. Clearly, education is necessary. Commencing with postgraduates is too late. Pain management, like the management of angina or asthma, must be taught early, before final-year medical students, junior doctors, and other health care professionals are socialized into a culture of underprescribing or worse, opiophobia. The content of that education should include medical, legal, and ethical dimensions of pain management. An encouraging start has been made by IASP's development of curricula for undergraduate health care professionals. In the United States, a practical boost has come from the launch in 2003 of an AAPM teaching initiative on pain in medical schools. The initiative, called TOPMED, is overseen by an advisory board that includes the former Secretary of U.S. Health and Human Services, Dr. Louis Sullivan, and former U.S. Surgeon General Dr. David Satcher. Similar initiatives are also underway in several European countries.

Societal attitudes to pain and pain relief are potent factors in determining how rapidly patients' rights to pain relief develop.<sup>16,17</sup> Such attitudes are a complex and interesting topic that is beyond the scope of this article. The ideal of universal and meticulous pain management will likewise remain utopian until we can lower fundamental systemic and regulatory barriers that limit opioid availability in many countries and inflate the cost of analgesic medications.

#### Conclusion

The impulse to characterize pain relief as a "right" emerges from two main lines of reasoning. First, we know that pain is undertreated, that barriers to effective pain management still exist, and that there is an urgent need for a global response. Second, the culture of rights in society concentrates on what individuals may reasonably expect. There is no single "right" to pain relief. Instead, there is a constellation of "rights" to pain relief, each with a variable degree of legal enforceability. The articulation of a right to pain relief is but one strategy in the pursuit of universal and meticulous pain management. Reform will depend on a combination of approaches by which to address the problem at all the levels in which it exists-education for health undergraduates; the adoption of universal pain management standards by professional bodies; the promotion of legislative reform; the liberalization of national policies on opioid availability; the reduction in cost of analgesics; the promotion in all nations, irrespective of resources, of the development and maintenance of domestic pain treatment programs; and the continuing activism of the supreme world forum on health, WHO, in collaboration with IASP and leading national and international bodies on pain.<sup>18</sup> The transition from the current pursuit of pain relief as an aspiration and a right to be asserted, to a future where pain relief is a universal reality, will require much effort, commitment, and vigilance.

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