What Do We Owe Patients with Chronic Pain?

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Introduction

Patients with chronic pain suffer. They also wonder what is wrong with them. They seek relief and answers. This leads clinicians to ask: What do we owe patients with chronic pain? If we examine this question systematically, it becomes clear that the answer is more complicated than it initially appears. There are a number of possible goals for chronic pain care.

A Diagnosis, a Cure

Patients with chronic pain very often present initially with the question “What is causing my pain?” and the request “Please fix the problem.” These are reasonable expectations of modern health care. Pain specialists do have an obligation to pursue a diagnosis, to the extent that this is possible and appropriate. Patients with chronic pain are often frustrated when their requests for a diagnosis and a cure are turned aside by clinicians who can find no broken part or malfunctioning organ on physical exam or imaging tests. They are easily seduced by clinicians who focus on bulging or degenerated discs on imaging tests as easily reversible causes of back pain, despite the fact that many patients with no back pain have these findings [1,2]. The popular press still commonly includes advertisements promising rapid and easy diagnosis and cure of chronic pain. But the scientific literature supports the assertion that diagnosis and cure will not be possible for many of the most common forms of chronic pain, such as back pain, neck pain, fibromyalgia, and chronic headache. One of the biggest challenges of pain specialty care is instilling reasonable expectations concerning diagnosis and cure in the patients who come to us for care. This is often the first step in framing chronic pain as a chronic disease that must be managed rather than cured.

Pain Relief: No Pain, Less Pain?

Once the patient has relinquished the search for a cure, the patient’s attention usually shifts to pain relief. If pain cannot be ended once and for all by removing its cause, can it be eliminated or reduced through medical treatment? Clinicians often caution patients with chronic pain that it is not possible to remove all their pain with current treatments. They try to get patients to accept “less pain” rather than “no pain” as their treatment goal. This is an important first step, but it is inadequate. Patients want enduring and comprehensive pain relief. But this is difficult for pain specialists to deliver. Too often providers offer temporary pain relief in the form of injections or medications that leave patients no better, or even worse in the long term. Patients are often desperate enough to accept these temporary benefits, so providers must be careful not to mislead patients about the duration of pain relief to be expected.

Another problem is that patients’ request for pain relief is often framed within some very specific assessment and treatment strategies. First, it is generally assumed that pain relief is provided through pain reduction. This pain reduction is typically assessed and quantified using the 0–10 numeric rating scale for pain intensity that is universally deployed throughout contemporary health care. Pain relief is commonly defined as a significant reduction in pain intensity, either as a percent reduction (e.g., 30%) or reduction below a crucial threshold (e.g., below 4 on a 10-point scale [2]). This approach to assess pain relief may be useful for acute pain in some circumstances, but its widespread use in chronic pain to assess need for treatment and response to treatment is flawed for multiple reasons. First, pain may be relieved through a change in its meaning rather than a change in intensity. For example, patients with cancer are often relieved when they learn their pain is due to treatment or

concurrent illness, or anything other than progression of their cancer [3]. Second, it is now clear that what had been called the pain neuromatrix in the brain encodes pain salience and other multisensory input in addition to pain intensity [4]. The relevance of pain to the survival of the organism is the most important and valuable thing for the brain to monitor and encode. This relevance is shaped by other threats and rewards for the organism and is not a direct product of the severity of injury or strength of nociception. If pain salience rather than pain intensity is the focus of our pain therapies, these therapies will be very different [5].

Pain Management: What Tools, What Goals?

The International Association for the Study of Pain Declaration of Montreal mentions the “right of all people to have access to pain management without discrimination” [6]. Earlier versions of this declaration mentioned a right to pain relief, but this was changed as it is not possible to guarantee all patients pain relief [7]. A right of access to pain management is meant to be more flexible and accommodating of different types of pain problems and health care systems. However, it is not clear what “access to pain management” means and whether it captures what is most important to patients with chronic pain who are seeking care. At the most basic level, it is not clear what tools are included in this effort at pain management and what goals this effort aims at. Some stakeholders have interpreted this right to pain management as a right to immediate pain relief through opioids. While this access to opioids may be necessary for acute pain care and palliative care, a right of access to opioids for chronic pain care lacks both scientific and ethical justification [8].

I believe the intention of the Declaration is to provide more patients access to multidisciplinary pain care, but this is available to only a small fraction of patients with chronic pain coming from the most advanced economies and health systems. It is also not clear what goals this effort at pain management aims for. Is the goal pain reduction, functional improvement, or a better quality of life? Who selects these goals—patients, providers, health systems, governments? The authors of the Declaration of Montreal have emphasized that they are not arguing for universal access to opioid therapy for chronic pain, but what concrete and feasible substitute should be provided is not clear [9].

Improved Function: What Kind, What Goals?

It has now become commonplace in the professional literature on chronic pain and in governmental policy on chronic pain to argue that the appropriate goal in chronic pain care is not reduced pain but improved function [10,11]. This is an improvement over a simple focus on pain reduction but leaves crucial questions unanswered.

First, is improved function always granted priority over pain reduction, or is there some optimal way to combine these goals? Who decides when these have been appropriately optimized? Second, what kind of function is the goal? There are many possible kinds of patient function: physical function (e.g., ability to lift, climb stairs), social function (e.g., ability to relate to others, manage interpersonal conflicts), role function (e.g., ability to meet expectations as a parent, spouse, breadwinner), cognitive function (e.g., ability to decide and remember), and emotional function (e.g., ability to manage emotional distress and remain hopeful [12]. Third, it is not clear that patients consider themselves to have functions [13]. For example, my own kidneys have a function in my body, but I do not consider myself as having a function, except when considered as part of a larger whole like a family or a workplace. Persons have purposes rather than functions. These purposes are chosen by the persons themselves and are infinitely various [14]. Thus we ask: Which patient purposes should be facilitated by pain treatment?

Improved Quality of Life: As Defined by Whom, According to What Standard?

A focus on function in chronic pain care, which usually means physical function, can be criticized as neglecting the aversive pain experience itself. Patients do not like pain at least partly because it feels bad [15]. This aversive experience affects a patient’s quality of life as well as any functional impairment produced by chronic pain. Quality of life is a more comprehensive and patient-centered goal for chronic pain care than functional status because it includes patient experience and patient values. Although it captures more of what is important to patients, it is a more complex and difficult outcome to achieve in clinical practice.

Quality of life, even in those with chronic illness, is determined by many factors other than health and health care. For example, quality of life may be defined by quality of relationships and neighborhood, level of income and education, and employment situation [16]. If function and purpose vary greatly from patient to patient, quality of life and its determinants show even more variability among persons. Not only do the determinants of quality of life vary, but the standards defining an adequate quality of life also vary greatly. What would constitute an adequate quality of life in a low-income country where daily income averages a few dollars a day is very different from what might be considered an adequate quality of life in a high-income country.

Improved Health

A somewhat more modest goal than improving the patient’s overall quality of life is improving the patient’s health. It has been difficult to define health in a positive manner that does not refer to the absence of disease.

But this is especially important in chronic pain care, where the quest to diagnose and treat disease may lead us astray. One possible definition of health is the capacity to pursue personally meaningful activities. This personalizes the improvement in function described above. It includes aversive symptoms such as pain, insofar as these symptoms interfere with valued activities. This goal definition focuses not on providing an adequate quality of life to the patient (because this encompasses much more than clinical efforts can achieve), but on providing the capacity to achieve an adequate quality of life. Clinicians may provide various tools to manage symptoms and improve function, but the patient must participate in achieving that quality of life by defining it and pursuing it [17]. Clinicians cannot do that for patients.

As we have moved through this list of possible goals for chronic pain care, we have moved from the simple to the complex and from the grossly incomplete to the more complete. The simpler goals are easier to operationalize but misdirect care in some important ways. The more complex goals come closer to the comprehensive benefit we want but are difficult to operationalize and achieve through health care.

Pain as Innocent Suffering

Pain is not only a bad experience, but it is a bad experience assumed to have a special moral character. Clinicians tend to privilege pain as a form of physical suffering for which the patient is not responsible. On the model of acute pain and disease, patients usually consider chronic pain to be *innocent* suffering: “I did nothing to bring this on myself.” This stands in contrast to addiction, which may involve voluntary ingestion of licit or illicit drugs. Chronic pain also stands in contrast to depression, which can include the taint of laziness and willful neglect of one’s duties and one’s self. In addition, chronic pain stands in contrast to “stress,” where lack of strength and resilience to overcome stress are seen by some as an indicator of weakness.

We must ask: Why do we speak of a right to pain relief but not a right to depression or anxiety or stress relief? We propose that this is because pain is the most medical of aversive experiences, pointing toward injury or illness that could have befallen anyone. Pain is classically considered more urgent and more essential than nausea, dizziness, fatigue, dyspnea, or weakness. In the philosophy of the Enlightenment, for example, pain was used as a concept to cover all the aversive and unfortunate experiences in life. Jeremy Bentham, the father of the utilitarian approach to social policy, said, “Nature has placed mankind under the governance of two sovereign masters, pain and pleasure. It is for them alone to point out what we ought to do, as well as to determine what we shall do” [18]. According to Bentham and similar political theorists, pain is the essence of misfortune and must be reduced by a just society.

Opioids as Pain-Specific Relief

Parallel and corollary to this view of pain as innocent suffering is a view of opioids as pain-specific relief. Physicians prescribe opioids to “kill” the pain and leave the person alone. As our patients often say to us, “Don’t give me any of your mind-altering drugs. Just take away my pain!” This assumes that we can take away all of a patient’s pain and not alter who they are as a person. Pain is a simple evil and should be removed by opioid therapy.

This might sound like an extreme view, but echoes of this can be found in the medical literature. This occurred first with the treatment of pain at the end of life. As justifications for allowing patients to die in pain were cast aside as invalid, the following argument was made: “The proper dose of pain medication is the dose that is sufficient to relieve pain and suffering. . . . To allow a patient to experience unbearable pain or suffering is unethical medical practice” [19]. This principle was gradually extended from end-of-life care to cancer pain care, and then to chronic noncancer pain care. It is echoed in the pleas of chronic pain patients to their prescribers: “Don’t you believe I am in pain? Don’t you think I deserve relief?” These questions are difficult for clinicians to answer because they are posed within a cultural and clinical context where pain is a simple evil to be reduced whenever possible.

Titrating opioid doses to a pain level may simultaneously reduce pain and make it harder for a patient to live his or her life by producing sedation or confusion or addiction. Pain reduction and quality of life reduction can both occur with opioid therapy. Pain and suffering may be reduced, but life is diminished with less activity, less interaction, and less enthusiasm. There is increasing recognition of this fact. For example, the new standards issued by The Joint Commission (TJC) [20] concerning management of pain within the hospital set a new criterion of adequacy. The new TJC standards state that the adequacy of pain relief should be determined in terms of adequacy of function. Zero pain is not the clinical goal; facilitating hospital discharge and a return to functional life is the clinical goal of inpatient pain management.

Conclusion: What We Owe to Patients with Chronic Pain

Our foremost duty to patients with chronic pain is not to reduce their pain intensity but to improve their health. This consists of increasing the capacity of patients to be agents in their own lives [17]. We seek to provide patients with the capability to move their lives forward again. This means the ability to pursue their passions in work or play. It means the ability to form and sustain relationships. It means the ability to carve one’s own environmental niche in the complex natural and social

environment that is human society. When our most potent analgesic erodes that ability, it is time to rethink what duty to relieve pain actually means.

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