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## **Defining Chronic Pain Ethics**

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## Brief Research Report

# Defining Chronic Pain Ethics

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### Abstract

**Objective.** To identify current issues in the diagnosis and treatment of chronic pain.

**Design.** Focus groups were convened to discuss the current issues in chronic pain care.

**Commentary was analyzed across focus groups using an interpretivist method of qualitative data analysis.**

**Setting.** Focus groups were held in five major US cities throughout the United States.

**Participants.** Key stakeholders working and thinking about the issues surrounding chronic pain, including people with pain, providers, insurance and pharmaceutical industry representatives, law enforcement agents, and advocacy groups.

**Outcome Measures.** Qualitative data was analyzed to determine if consensus regarding the current issues in the diagnosis and treatment of chronic pain exist.

**Results.** Six major themes emerged regarding chronic pain, all of which contained an ethical com-

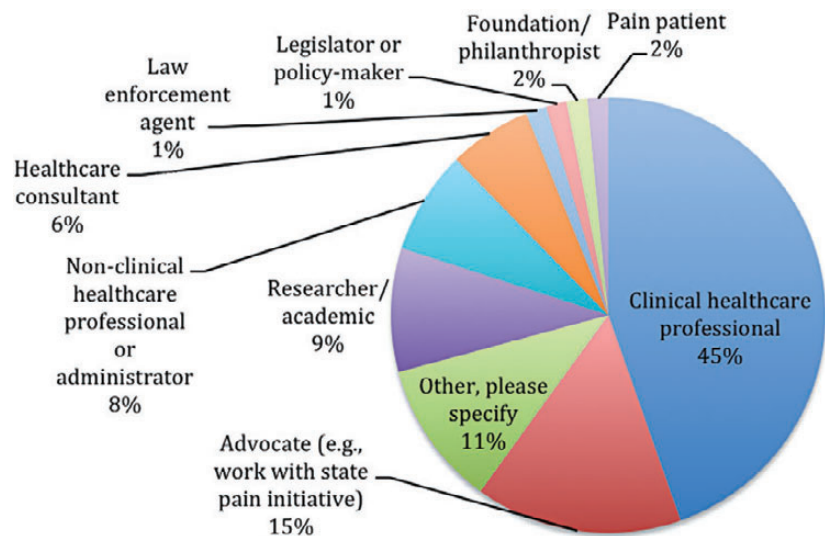
ponent: 1) reducing disparities in access to pain care among the young, elderly, and lower socioeconomic groups, 2) defining quality of care in pain management, 3) the need to train qualified providers and training programs in pain medicine, 4) the need for evidence-based public policy regarding opioid use and diversion, 5) the need to raise awareness about chronic pain as a disease to prevent stigmatization and discrimination, and 6) promotion of multimodal therapies for pain care as a way of diverting attention from opioid abuse problem.

**Conclusions.** There is nationwide consensus among those holding a stake in the diagnosis and treatment of chronic pain regarding the ethical issues that must be addressed. Raising awareness about chronic pain, improving access and outcomes to quality pain care, and resolving public policy debates about the use of opioids in chronic pain populations are the first steps to ensuring a morally justifiable approach to chronic pain management in the 21st century.

**Key Words.** Bioethics; Chronic Pain; Alternative Therapies; Ethics; Sociocultural; Pain Management; Race Disparities

### Introduction

The phenomenon of chronic pain presents profound challenges to medical professionals and our system of medical care, as a whole. While more people suffer from chronic or persistent pain issues than heart disease, diabetes, and cancer combined [1], many living with pain suffer needlessly even though in many situations medical knowledge and treatments exist to manage such pain. Research suggests that pain affects 75–150 million Americans of whom only 3 million seek care from a pain specialist [2]. Recent survey data highlight the prevalent public misconceptions about pain, including beliefs about the inadequacy of medical management, and fears relating to iatrogenic addiction or the side effects of prescription pain medications [3]. Intersecting with these concerns is the public health issue of the abuse of prescription pain medications [4]. This has created significant tension for medical professionals and legal and regulatory officials who desire to control the growing trend of misuse and abuse [5]. However, we are concerned that this locus of concern for clinicians shifts the care focus from the person in pain to the provider as the moral imperative to care has been overshadowed by fear of regulatory or law enforcement intervention.



**Figure 1** Self-reported primary professional affiliations of regional PAINS meeting participants. PAINS = Pain Action Initiative: A National Strategy.

Due to complex sociocultural, economic, political, and legal factors, people in pain continue to suffer. While there have been many efforts toward addressing these issues, we believe that the undertreatment of pain in society is essentially a moral issue and that any effort to address the problem must be reframed based on the premise that treating pain is an ethical obligation embedded in the relationship between the provider and person, and between the healing professions and society at large.

The Pain Action Initiative: A National Strategy (PAINS) is a program that seeks to address the undertreatment of chronic pain through a coordinated and strategic effort to assure that those in pain receive the treatment they need and to which they are morally entitled. The PAINS Project, a research and social advocacy project funded by the Lance Armstrong Foundation, the Rx Action Alliance, and Purdue Pharmaceuticals, is driven by the hypothesis that increased understanding of these complex issues might be the first step toward removing the barriers between those who suffer from pain and the possibility of treating it. Phase one of the PAINS project is an effort to assess the capacity and readiness of individual leaders, organizations, and consumers working on these issues to collaborate for the purpose of developing a national strategic plan to improve the treatment of chronic and persistent pain in the United States. Our stated goals were to 1) gain a sense of current work being done by stakeholders regarding chronic or persistent pain, 2) learn about barriers encountered that limit or hinder these efforts, and 3) assess whether a national effort and strategic plan would be beneficial to stakeholders whose work and/or lives deal with chronic pain and their work.

## Methods

Beginning in late summer 2010, stakeholder meetings took place in five US cities: Seattle, Tampa, Boston, Chicago, and San Diego. A total of 110 individuals repre-

senting 25 states participated. Participants included a wide range of professionals who deal with issues related to pain management and care including clinicians, academic researchers, people living with pain, legislators, advocates, and others. Figure 1 indicates how these participants at the regional meetings self-identified according to profession.

During each half-day regional meeting, the author (BDK) took notes containing the commentary of meeting participants. The authors (MJC and BDK) identified themes for each meeting. Qualitative data from each site were aggregated, and common themes, words, and phrases were identified using an interpretivist method of qualitative data analysis.

## Results

From the 110 participants who took part in five discrete focus groups at sites across the United States, six primary themes emerged as areas that were under- or unaddressed and/or mishandled in regard to the diagnosis and treatment of chronic pain. It should be noted that these participants in the regional meetings were highly aware as to what was not sufficiently addressed by these regional meetings and would require further exploration. A list of these topics is included in Table 1. Therefore, the results of this exploratory study are not meant to be exhaustive or comprehensive, but instead focus upon those themes regarding chronic pain care around which consensus emerged.

### *Theme 1: Barriers of Access to Pain Care*

Our discussions revealed that multiple reasons exist why patients seeking pain care often cannot access the providers and treatments they need. These included the lack of trained pain specialists, insurance and cost issues, and health disparities in pain care among children, the elderly, and minority groups.

**Table 1** Participants' self-reported topics inadequately addressed by PAINS regional meetings

Issue or Topic	Frequency
Insurance companies, managed care, third-party payers	18
Legislators and law makers	8
Increased roles for medical specialties (family practice, pediatrics, psychology/psychiatry, orthopedics)	6
Ethnic, racial, cultural, and economic diversity	5
Role of government and regulatory agencies (e.g., Health Resources and Services Administration, Centers for Disease Control and Prevention, Food and Drug Administration, Drug Enforcement Administration)	4
Academic medicine and medical education	3
Law enforcement	3
Role and responsibility of policy makers	3
Role and responsibility of the media	2
Addiction	1
Use of alternative care providers	1
Role of health economists	1

PAINS = Pain Action Initiative: A National Strategy.

At each of the meetings, the theme of reimbursement as a barrier to accessing pain care was discussed. The nature of payment for pain care was perceived to limit access to appropriate pain management specialists and certain treatment modalities, including physical rehabilitation, complimentary and alternative medicine practitioners, and psychological counseling. Compounding this problem is the current system of pain management clinics and providers that require multiple visits to multiple practitioners over long periods of time. The cost of time spent traveling to and from the clinic and to multiple medical appointments means lost wages, time away from family, child-care costs, and other expenses in addition to co-pays, pharmaceuticals, and other direct medical costs. Stakeholders acknowledged that these costs are inordinate to those already experiencing functional deficiencies due to pain, who are of low socioeconomic status, who live in rural areas, and/or who already experience the effects of pain on their ability to work and live their lives.

Meeting participants agreed that incentives must be created for providers to receive specialized training in pain management generally. When specialist care is needed, patients and providers find that insufficient numbers of generalists and specialists are trained in the management of pain and related issues, and because those trained are not equally distributed geographically around the nation, access to qualified, well-trained providers of pain care is often difficult. Unfortunately, these stakeholders understand that it is children, the elderly, and the poor who most acutely bear the burden of barriers to access created by geography, inadequate reimbursement by insurers, and practice patterns of providers within the current disorganized system of care.

*Theme 2: Quality Pain Care*

When assessing the quality of pain care in the United States, participants at our regional meetings agreed that significant barriers exist toward the provision of quality

pain care. This includes both the unique nature of the diagnosis and treatment of pain itself and the practice environments in which pain is treated. The consequences are that interventional therapies are overused, multimodal therapies are underused, and physicians with inadequate training are misused within the health care system.

The growing economic pressures on provider practice, including fee-for-service reimbursement paradigms that incentivize number of patients seen over quality of time spent, were discussed as a significant barrier that affects the quality of pain care that people in pain experience. This is especially true in the primary care setting. The complexity of chronic and persistent pain requires time to understand the unique biopsychosocial aspects that constitute a person and their unique pain-related issues. Time, however, has become a precious resource that many providers said they have less and less to devote to proper diagnosis and determining appropriate treatments. While the number of people presenting to providers with pain-related issues is understood to be increasing, many meeting participants discussed that there remains cultural and spiritual beliefs in our society that affect people's willingness to talk about their pain and/or seek treatment. These beliefs can create a barrier to accepting persistent pain as a problem that warrants medical intervention or that can be addressed by medical care. The many non-physical aspects of pain, such as spiritual or existential suffering, are unique to each person and require in-depth discussion about the coping mechanisms and beliefs that frame the experience of pain. There was expressed understanding and general consensus that providers are largely ignorant about these aspects of pain management or view it outside their purview.

More and more people with pain find themselves leaving provider offices with a prescription for opioids, an attempt to deal with the symptoms of pain rather than addressing the foundations of that pain. Many participants stated that emergency rooms and acute care settings now find them-

selves overburdened with people who need relief from pain because the current structure of care and its providers have been unable to handle such chronic issues. Given the repeated visits required and time intensive nature of physical and psychological modalities, these modalities are frequently underutilized, leaving patients without the right treatment at the right time nor in the right way.

Discussion at a number of meetings focused on the disproportionate utilization of interventional modalities in our system of pain care. Specialized pain care is viewed as overly biased toward interventional treatments due to the predominance of pain providers emerging from subspecialty anesthesiology fellowships, in addition to the reimbursement structures that incentivize such treatment modalities. As a result, meeting participants note a steady decline in the number of practitioners that incorporate multimodal therapy as a practice paradigm. They primarily provide treatments that are less time-intensive and provide increased compensation. In addition, the programs and institutions attempting to support interdisciplinary models of care have had trouble in selling collective billing practices to insurance companies. Such programs end up losing money and support, leading to many providers witnessing the number multidisciplinary pain clinics decrease over the course of the last generation.

Across focus groups, stakeholders called for the embrace of an interdisciplinary model of care, one that recognizes chronic pain as a multifactorial disease and incorporates the necessary practice structures that support such care, is universally recognized as essential to ensuring quality health care for all those who experience chronic or persistent pain. Additionally, meeting participants agreed that the capacity to offer quality pain care must be supported by our health care system's reimbursement structure, and that the provider-patient relationship in the treatment of pain should never be compromised by financial or other structural limitations.

### *Theme 3: Need for Medical Education and Research on Pain*

At each of our regional meetings, the lack of education for providers at all levels was discussed as a significant barrier to the proper treatment of people living with chronic or persistent pain. This deficit begins early in medical education and continues throughout health professionals' careers. Many of the pain medicine specialists at our meetings stated that not only do primary providers have limited education on the proper diagnosis and treatment of pain, but specialists themselves were never trained as comprehensive interdisciplinary providers. Without standardized training and certification, patients and primary providers are unable to discern what constitutes a quality/qualified pain specialist when needed. This problem compounds the access and quality issues that people in pain face.

Providers participating in the regional meetings agreed that there were few lectures explicitly on pain or chronic pain, as a disease entity, during their primary medical education, leaving them without a strong foundation in the biological, psychosocial, and spiritual aspects of pain. Consequently, providers are left struggling, not only to educate and communicate with patients about pain, but also to offer reassurance that chronic pain can be managed. Additionally, primary providers are neither able to inform patients about possible options and available resources nor to manage the coordination of multiple treatment modalities. Additionally, as providers move through their respective careers, the education gap is compounded, when little or no quality continuing education exists.

While a consensus existed among stakeholders that pain management specialists must be trained as interdisciplinary providers, they were quick to note that there has been no concurrent evolution in the medical education system that incorporates the requisite broad interdisciplinary perspective. Educators stated that at present, there remains limited impetus or incentive for curricular reform for pain medicine at all levels despite concerted efforts, including advocacy for designating pain medicine as its own recognized specialty.

Discrepancy between the prevalence of undertreated pain and the amount of funding and focus on pain-related research troubled all stakeholder groups at our meetings. Given the number of people with chronic pain and the need to form educational standards and practice guidelines using sound evidence-based data, such discrepancies are appreciated by stakeholders as unjustifiable. The absence of useful and sound research data has resulted in the overutilization of interventional modalities and pharmacotherapy, continued ignorance about alternative options, and diminished ability to correct conceptual limitations in provider practice. Participants agreed that funding priorities should be put in place at the federal level, and advocacy groups must support study of the diagnosis and treatment of pain.

### *Theme 4: Legal and Regulatory Barriers*

Across the country, stakeholders commented that the increased fear about diversion and abuse of medications for treating chronic pain, particularly opioids, has resulted in a push to create state and federal regulations that will ultimately constrain the provision of proper pain care. There exists the belief that practice guidelines and policies meant to address the growing number of overdose-related deaths from controlled substances will ultimately have the unfortunate consequence of harming people in pain.

Many participants suggested that the laws originating out of concerns about overdose deaths or abuse and diversion are not grounded in well-researched data. To change the status quo, stakeholders believed research on physician prescribing patterns, sources of diversion, and abuse/overdose deaths must be undertaken and expanded. A shift toward evidence-based policy must be

advocated for, both to inform and to evaluate any proposed legislative effort that has the potential of affecting the care of people in pain.

Increased regulations, a bureaucratic environment, and additional documentation practices such as opioid contracts have led to mistreatment of those needing care. While becoming the accepted standard of care when prescribing opioids, providers and people experiencing chronic pain agreed that pain contracts, when wielded as a tool to combat provider liability and regarded as mandatory to even begin care, have the effect of undermining trust and the foundations for a healthy provider–patient relationship. Such contracts also may overshadow a discussion of modalities other than opioids, creating a double standard for behavior and scrutiny for those taking opioid therapy, and even deterring or excluding people with previous substance abuse problems. Some health care professionals suggested that there exists a belief among many providers that patients have a duty to be trustworthy and honest in order to “deserve” treatment, and believe agreements and monitoring are the only recourse to bridge the distrust. However, many argued that continued accommodation because of fear and regulation at the expense of a patient’s dignity is the consequence of mistrust when it takes precedence over caring for people who suffer. A perceived environment where the provider–patient relationship is devolving is of serious concern to those advocating for people in pain. When the differences between legal/regulatory and professional practice issues become confused, the priority of patient care is lost.

#### *Theme 5: Public Awareness About Chronic Pain*

According to organizational leaders and advocates who work in this area, concerted efforts to raise public awareness about chronic pain have experienced difficulty in cultivating interest among key stakeholders. Many participants highlighted the fact that there are numerous organizations and people working on specific focus areas, including public education, professional and political advocacy, and balanced policy and regulation. Nevertheless, a general lack of coherence and collaboration in such efforts is often encountered, with many working in different directions or opposing directions at different levels.

The complexity of the phenomenon has been described in the past as “too broad” to garner any significant support from diverse funders, organizations, and policy makers; many participants agreed that it is easier to advocate for a specific illness that is readily identifiable to the public and stakeholders. Therefore, participants commented that work is done in “silos” and is often focused on particular interest areas.

It was also stated that political barriers among the various academies and organizations sometimes get in the way of establishing common goals and common ideals. However, it is the strong narrative surrounding the abuse of prescription medication that has overshadowed many of these issues and repeatedly emerged across focus

groups. Consequentially, many stakeholders noted that efforts have failed to rise to the complex challenge.

#### *Theme 6: Opioid Therapy: The Good, The Bad, The Ugly*

Participants within each focus group spent time discussing the intense public focus on the abuse of prescription pain medications. All agreed that such focus perpetuates and overshadows the undertreatment of chronic pain and the disparities found within pain management. State and federal regulations, professional practice guidelines, and the fear of perceived or actual legal intervention due to prescribing habits weigh on the minds of many health care providers, inhibiting their willingness to treat people with pain who could benefit from opioid therapy. While opioids have a legitimate place in pain management, a widely accepted fact according to meeting participants, the stigmas and biases associated with them have the unfortunate consequence of accentuating the barriers of access, quality, and education regarding proper pain care and public discussions of possible strategies to cultivate needed change.

While understood as a serious public health issue in its own right, the public has been subjected to media portrayals that overemphasize stories about outliers who abuse prescription pain medications and our system of care. Those at our meetings who live with chronic or persistent pain agreed that the stories and biases perpetuated about people who abuse the system of care and feign pain symptoms to obtain prescription pain medications have caused legitimate people with pain on opioids to be judged as addicts and abusers. All stakeholders agreed that this has created stigma surrounding opioids and their use, people in pain, and the professionals who treat them. Many people with persistent pain issues make the decision to refuse opioid therapy when offered due to worries about becoming addicted based in some small or large part on these media portrayals, misinformation, and biases, not scientific or medical evidence. The stigma that comes with the very diagnosis of having chronic pain, or even possibly being on long-term opioid therapy, has a profound negative connotation in the eyes of the public, serving as a significant barrier for people in pain. The public remains largely uninformed about the scope of proper pain management beyond opioids, of their benefits and limitations, creating a barrier to discussion of realistic functional goals and reasonable outcomes of therapy.

Often, people with pain have concurrent addiction and behavioral issues, but such patients are viewed as such a significant burden on the health care system’s human, emotional, and financial resources that they receive substandard care. As a result of the fear of stigmatization by the public, providers, and the entire system of care, many people with pain make the decision to refuse opioid therapy due to fears of addiction and refuse seeking medical care for their pain because they believe no other options for managing their pain exist.

A significant amount of confusion exists, even among stakeholders working in pain management, with regard to the benefits and harmful side effects of long-term opioid therapy (such as opioid-induced hyperalgesia and endocrinopathy), the potential for misuse or abuse, and the difference between dependence and addiction. One law enforcement representative stated that he was surprised to find that terminological confusion existed among providers because it was a significant issue for many in the legal and regulatory arenas. This conceptual confusion is understood by stakeholders to exist at all levels. These biases are understood to be prevalent not only among patients and providers but also law enforcement officials and legislators. The uncertainty about terminology and how such words themselves are used, misused, and abused has resulted in difficulties not only in caring for people with pain but also for the formulation of quality policy guidelines and their effective implementation.

## Discussion

The results from the focus groups revealed six primary themes related to the diagnosis and treatment of chronic pain common across geographic regions and stakeholder groups. Notably, each of the six themes identified by meeting participants within and across focus groups contained an ethical component, usually focusing upon justice considerations and the rights of those living with pain. These ideas were embedded in empiric claims about the status of pain care in the United States. Therefore, understanding the issues in pain management as moral problems became the overarching theme that emerged from this analysis.

It is also notable that defining the critical issues in chronic pain as moral issues is groundbreaking. As of May 2, 2011, a PubMed search using the keywords “chronic pain” + “ethics” yielded only 249 results. When articles focused upon palliative care and basic neuroscience are removed, the entire literature consists of approximately 75 articles. The paucity of discussion of this topic in the medical literature suggests a true need for reframing discussions regarding chronic pain.

It is no longer a question that the diagnosis and treatment of pain is a complex endeavor that poses significant challenges to both providers and our system of care [6]. The experience of pain demands investigation of the biological, psychological, sociological, and spiritual aspects in order to treat it appropriately [7]. Interventional medical modalities and interventions, and the number of physicians performing interventional techniques for pain, have seen a dramatic increase over the last decade [8]. This represents a growing problem of both overuse and misuse in pain management. Unfortunately, the corporate climate of medicine in our society [9], notably the part played by insurance industry reimbursement structures and policies [10], has sustained and exacerbated the access and quality care issues that providers and people in pain face.

While chronic or persistent pain issues can afflict everyone across all socioeconomic groups, ages, races, and localities, it is not the case that individuals within these groups can access treatment for their pain equally. Stakeholders commented frequently about this. The burdens associated with seeking pain treatment disproportionately affect those who are poorer, younger or older, have other comorbidities, or are disenfranchised in other ways in society. The reality of inadequate access to pain care among vulnerable groups discussed at the PAINS Regional Meetings is reflected in recent literature, including the significant disparities to accessing pain care based on socioeconomic status and race or ethnicity [11–13], geographical location [14,15], age [16,17], and the direct and indirect effects of the insurance and health care industries [9]. Yet, one ought not get caught in the naturalistic fallacy believing that what is reflects what ought to be. As stakeholders across disciplines in pain medicine commented repeatedly, these disparities are a reality that ought not be permitted to exist in our society.

Stakeholders' views about pain education as either inadequate or variable in scope and effectiveness are echoed in the peer-reviewed literature. There remains considerable confusion among providers about proper standards or guidelines when providing care [18]. While new educational programs have been shown to be effective in cultivating competence in pain knowledge [19], there remain significant deficiencies in the amount of pain education that all providers receive [20]. Furthermore, in the face of declining federal funding for pain-related research [21], the call for increased research to inform education, practice, and policy is necessary to correct what has emerged as a public health epidemic [22].

The public health issue of the abuse and diversion of prescription pain medication presents a profound problem for medical professionals, policy makers, and the law enforcement community [23]. With increased burden of possible professional or legal sanctions, malpractice suits, and damage to reputation or career, provider readiness to utilize opioids, or to treat people in pain in general, is likely to decrease. Many providers stated that they are disinclined to take on the extra burden of detailed documentation required as a preventive measure in case of investigation or payer audits of their practices. Sensational reporting in the media about prominent cases and the crackdown on practices and providers by state medical associations and regulatory agencies has increased anxiety among professionals, and the people they seek to treat. The fear is that further undermining of provider-patient relationships and opportunities for appropriate pain care will result.

The need to address such a complex issue must be balanced against the competing concerns of the ability of people in pain to access and obtain the care they deserve, and the professional's ability to provide such care. While contracts and agreements may make providers feel more comfortable about prescribing and treating patients who need opioid therapy [24], their utilization cannot be

allowed to compromise the integrity of the provider–patient relationship and the integrity of a person suffering with pain [25].

As a society, there is limited understanding and concern about pain, particularly regarding the undertreatment of chronic pain. The acceptance of undertreated pain as an important social and public health issue has been unable to gain widespread traction. Creating a unified approach to deal with the complex phenomenon of interlocking sociocultural, economic, regulatory, and professional issues at play has eluded professional societies, advocacy groups, and others to date. Yet, there is a strong sense among those working in and around pain management that there is an urgent and strong moral responsibility to redress these shortcomings surrounding chronic pain. There is an embracing of the need for public awareness and solidarity among organizations and professions if progress is to be made.

Much of what is required to improve chronic pain care in the United States rests upon generating new evidence and education. Because we lack sufficient information about what constitutes quality pain care and have limited ability to understand the etiology and/or lived experience of chronic pain, resources must be devoted to filling in these gaps in knowledge and perception. In addition, the barriers that prevent utilization of existing evidence-based approaches (such as multimodal treatment) must be broken down through undergraduate and continuing medical education.

The adoption of new standards for quality chronic pain care will require substantial amounts of advocacy involvement and political activity within the medical profession, state legislatures, and the federal government. A unified effort on the part of professional pain societies, disease advocacy groups, people in pain, and individual providers will demand significant amounts of coordination and consensus. Yet, this is the only clear way that progress can be made to ensure that quality care is the only morally acceptable way of providing care to people experiencing chronic pain. In the same way that researchers, advocates, and politicians must support new standards of care, public policy dealing with issues related to chronic pain must also be bolstered by that same trifecta.

Of course, there is some concern about the relationship between industry and the professional and advocacy organizations they fund. Questions have been raised as to whether the interests of persons living with pain can be best advocated for by groups who are dependent upon industry funding. This potential conflict of interest is concerning if advocacy groups promote solutions that benefit their benefactors. It is hoped that a unified, diversified coalition funded by a variety of stakeholders including but not limited to industry can reduce this potential conflict.

The abuse and misuse of prescription pain medication is a serious issue garnering serious attention [26]. While attempts are being made to clarify concepts and knowl-

edge about the misuse of opioids [27], about the terminological distinctions and effective utilization of opioids as a pain management tool [28], and the true nature of the risks that providers face when prescribing opioids [29], it is clearly evident among stakeholders that concerns about the misuse and abuse of opioids or the misunderstandings about chronic pain are a significant barrier to care.

Yet, concerns about the misuse and abuse of opioids or the misunderstandings of chronic pain ought not be a barrier to quality pain care. Providers, patients, and the public must be provided the scientific data about opioid use, its benefits and side effects, and the alternatives to opioids that are viable options for patients. Patients and providers must also be educated that pain, as a chronic disease, requires a long-term treatment plan and that no single approach is a panacea. Because the public remains largely uninformed about chronic pain as a chronic disease, there remain gaps in understanding about realistic functional goals and reasonable outcomes of therapy. Patients often have unrealistic expectations of opioids and refuse to consider options besides pharmacology, making it difficult to introduce a multimodal model of care.

At its most basic level, barriers related to chronic pain diagnosis and treatment are prevalent within provider–patient relationships. What is critical to understand is that professional integrity and judgment should be the foundation of this relationship, and trust between patient and provider must be cultivated and allowed to flourish in all settings. It is these elements in the provider–patient relationship that have been lacking particularly in pain management. Policies, reimbursement structures, or regulations that interfere with this relationship can only be justified by strong and convincing evidence that it benefits the public good or individual patients in substantial ways. The trust that all patients place in their providers and the system of medical care cannot be allowed to erode through laws and regulations that interject themselves into this intimate relationship.

There is a prevailing view among those who participated in the PAINS Regional Meetings that because pain affects most persons, there should exist an equal opportunity to be free from the effects of pain. In ethics parlance, this view can be understood as the formal principle of justice, treating equals equally and unequals unequally, requires this of us as a society from a fairness perspective [30]. The reduction of disparities in access and quality for women, children, the elderly, and those of lower socioeconomic status is therefore morally required from a justice perspective. While these groups disproportionately suffer from access and quality care issues in the health care system generally, it is particularly important in the chronic pain setting. Moreover, these are not the only groups who face problems with access and quality care for their chronic pain. Nearly all people with pain experience problems in accessing the appropriate services and resources or receive suboptimal care. Lacking standards of care and qualified practitioners in pain medicine is a disparity that other chronic disease patients do not face. And so, the



notion of justice as it relates to pain is further complicated by the long-held belief that physicians are obligated to relieve suffering. Eric Cassel asserts that suffering occurs when an impending destruction of the person is perceived. Our stakeholders revealed that people living with inadequately treated chronic pain suffer not only physically but in all aspects of personhood.

## Conclusion

If the estimates about the prevalence of chronic pain are correct, there exists a silent majority of people in our country that either experience pain or know someone who does. Addressing the primary ethical considerations embedded in this problem is a moral imperative for our society. To begin, chronic pain ethics needs to be focused upon and framed by the experiences of people living with chronic pain. A moral foundation is required, based in an understanding of the suffering experienced by people whose experiences have been invalidated, who continue to encounter a culture of stigma and distrust, and find their dignity undermined by a system and a society that appears disinterested in taking a stand for the care and consideration to which they are entitled.

Defining the landscape for chronic pain ethics must highlight not only the shortcomings in chronic pain treatment in the United States, its structural barriers and policy problems, but will necessarily focus upon an action-oriented approach justified by ethical claims. Understanding these six themes as moral issues that require the attention of patients, providers, and policy makers provides both the impetus and justification for addressing each of them in a timely, patient-centered, and publicly justifiable manner.

Raising awareness among the public about chronic pain is essential to changing the prevailing view that pain is merely a symptom and that people who suffer from complex pain syndromes are problematic patients who abuse drugs, feign illnesses, or worse. Legitimizing chronic pain as a disease, one that disrupts the life narrative and creates discontinuity in the person's work, life, and self, is critical. This shift of public perceptions about the use of opioid therapy and other aspects of chronic pain care will allow those who suffer to find validation for a true medical problem.

This level of social change is likely to only be possible through the coordinated effort of all interested and effected parties. A coordinated effort between academic research centers, research universities, advocacy groups, foundations, think tanks, patient groups, and others must begin in order to raise awareness about the undertreatment of chronic pain. Those living with such pain are often the least capable of advocating for themselves or the changes necessary. People with pain suffer feelings of isolation and disillusionment with our system of care; they are frustrated that they are not being heard by health care professionals or society at large and that their needs are invalidated because of other practice, professional, and policy concerns. They must be empowered to effect

change in society alongside researchers, providers, advocates, and policy makers.

Each regional focus group was closed with a discussion about the feasibility of a national effort to address the undertreatment of people living with chronic pain and if such a concerted effort would be helpful to those in attendance. With respect to the latter question, a resounding yes was heard. However, issues regarding how to go about creating such a strategy and implementing it remain uncertain. Tapping into this potential and resolving the problems will require establishing a moral and ethical framework that resonates with people and stakeholders at each and every level.

What we do know is that a moral consensus exists about the need for improving pain care. The steps required to respond to this call to action will require further research and exploration. But the first step in this process, the uncovering of the shared ideas and ideas of those within the chronic pain community, has illuminated discrete areas where improvements can be made and the moral justification for doing so. This, we believe, is the first step on a pathway to social change to eliminate disparities in pain care, legitimizing chronic pain as a disease worthy of sound research and evidence-based policy, and that will reduce the stigmatization, ignorance, and harm experienced by those who live with chronic pain.

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