Giving a Voice to the Suffering Silent: 
The Role of Patient Advocacy in Improving Access to Global Pain Care

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ABSTRACT: The undertreatment of pain is a major public health issue worldwide. According to the World Health Organization (WHO), the gold standard for the treatment of severe, chronic pain is morphine; however, access to this treatment in the majority of developing countries is difficult to impossible for a number of reasons. Well-documented and universal barriers include supply and delivery systems that are ill-equipped to adequately manage opioid medication accountability, regulatory barriers and national policies that do not recognize pain as important, and lack of health care professional education and awareness, as well as fear of regulatory retribution. Current research has shown that only 19% of the world demonstrates acceptable environments for hospice, just one illustration of the dire circumstances for people living and dying with pain. For more than a decade, researchers have worked to define barriers to accessing pain care and determine ways to overcome them. Work is underway around the world to help thoughtfully and systematically overcome these barriers. More recently, pain care, particularly for severe pain at the end of life, has been framed as a human right and moral imperative through various professional organization declarations, position statements and published research. This singular message has the power to help overcome the barriers stated above. However, the inclusion of the voice of the humans actually suffering from pain as a transformative force has been largely overlooked as an essential part of the advocacy process. This research explores the role of the patient advocate in helping to improve pain care, and identifies a crossroads of current efforts where efforts to raise awareness among people with pain, providers, policy makers and the general public can and have made a difference. It also explores the possibility of an international information exchange explicitly for the use of pain advocates to share their victories and help determine best practices that can be adapted in countries with similar environmental conditions.
The undertreatment of pain is a public health crisis on a global level. In the United States, information, advocacy and empowerment have been the focus of consumers with pain as a way to improve pain care, led in part by consumer advocacy organizations such as the American Pain Foundation (APF), as well as the American Chronic Pain Association, American Cancer Society and LIVESTRONG. On interpersonal and community levels, social networks and systems have been galvanized to affect policy-level changes, evidenced by the work of the APF Action Network, as just one example. On a global level, however, efforts to improve access to pain care have focused on overcoming barriers with policy changes and improved health care education about pain management. Is there evidence of consumer engagement and advocacy as an effective strategy for improving access to pain care around the world?

Advocacy, as defined by the Global Health Council, is a “set of targeted actions directed at decision makers in support of a specific policy issue.” Advocates certainly include passionate health care professionals: much of the global work in improving access to pain care thus far can be attributed to their efforts. However, advocacy can, and arguably should, include people who are experiencing pain first-hand and their loved ones. Their stories have the power to overcome numerous barriers that people with pain around the world face every day. It is important to note that advocacy as discussed in this paper refers to activities as defined above; one international pain organization shared that their health care professional members were not interested in
“advocacy,” a term that refers to more of a legal advocate in some parts of Europe, however they expressed interest in conducting policy, communication and awareness activities.

It is important to recognize that pain patient advocacy efforts, particularly those with end-of-life pain, are universally challenged because people, and often their families, are in a state of crisis and do not have the strength or emotional resources to call upon to engage in a process of speaking up for change. However, as incremental gains are made throughout the world in accessing pain care, there will be a growing number of people who are, for the first time, able to participate in advocacy efforts. Families who have had either a positive experience with hospice or negative experience without it may want to help others. Therefore, the idea is not that people who are living in agony will ever have the strength to rise from their deathbeds to demand change; part of why pain care is globally neglected is because we know that they can’t. Instead, it is to encourage those whose lives have been changed with appropriate pain care to share their story, and to encourage pivotal decision makers and influencers to recognize and validate the personal pain story as real and important.

The role of patient advocates is briefly mentioned at the end of the Open Society Foundation, International Palliative Care Program’s 2010 report, “Easing the Pain: Success and Challenges in International Palliative care,” – one of the only published references to this group of people and the premise for this research. The report concludes with the following recommendation:

- **Encourage a strong civil society voice, especially among patient advocates.** Educating the public about the right to pain relief and palliative care is essential. Patients and patient
support groups for the elderly, the disabled, and children—along with family members and activists—need to demand relief from pain and access to effective treatments to improve quality of life. Such groups need to put palliative care and pain relief on their advocacy agendas and work to reform government policies that prevent them from receiving quality care at the most vulnerable time of their lives. They need to monitor their governments’ health budgets to be assured that appropriated funds are spent for accessible services.

A World in Pain

Although the World Health Organization (WHO) considers palliative care an integral component of cancer care and has urged countries to improve its availability, too often palliative care continues to receive low priority from health policy makers and health care professionals, and almost no funding. This is despite the fact that experts estimate that 60 percent of those who die each year in the developing world—a staggering 33 million people—need palliative care. In part, this is because most cancer patients in developing countries are diagnosed when they have advanced disease and cannot be cured, so the only treatment option is palliative care.

This number does not account for the myriad of acute and chronic conditions that are not terminal. Low-back pain, fibromyalgia, arthritis, neuropathies and other non-communicable diseases are not addressed with the world’s more pressing health concerns, such as the spread of infectious HIV/AIDS or tuberculosis, and emerging public health threats of obesity and population control. This also does not account for chronic pain associated headache and migraine, of which WHO recently stated were among the most prevalent disorders experienced by mankind.
Chronic pain conditions have been shown to be “life-shortening” as opposed to “life-threatening.” From a public health perspective, large-scale surveys in many countries have established that chronic non-cancer pain ranks as the third most costly health care problem after cancer and cardiovascular disease and that the problem is costlier in developing countries. Poorly relieved pain also leads to accelerated mortality.\textsuperscript{vi}

The United Nations has declared that non-communicable diseases represent a new frontier in the fight to improve global health. Worldwide, the increase in such diseases means that they are now responsible for more deaths than all other causes combined. Commonly known as chronic or lifestyle-related diseases, the main non-communicable diseases are cardiovascular diseases, diabetes, cancers and chronic respiratory diseases. While the international community has focused on communicable diseases such as HIV/AIDS, malaria and tuberculosis, the four main non-communicable diseases have emerged relatively unnoticed in the developing world and are now becoming a global epidemic.\textsuperscript{vii} Communicable or not, pain is a hallmark of HIV/AIDS, cancer, diabetic neuropathy, arthritis, headache and countless other diseases, but has not received the attention that it deserves.

WHO estimates that 5 billion people live in countries with low or no access to controlled medicines and have no or insufficient access to treatment for moderate to severe pain. In these countries, each year tens of millions of patients are suffering without adequate treatment: \textsuperscript{viii}

- 1 million end-stage HIV/AIDS patients
- 5.5 million terminal cancer patients
- 0.8 million patients suffering injuries, caused by accidents and violence
- Patients with chronic illnesses
- Patients recovering from surgery
- Women in labor (110 million births each year)
- Pediatric patients

The sheer numbers of people with pain around the world are difficult to imagine; this number can be multiplied many times over when the number of people affected by pain, including spouses, siblings, parents, children, loved ones and co-workers are factored in.

**Global Palliative Care**

Pain can be experienced as mild, moderate or severe. It can be acute or chronic, lasting months or years, or until the end of life. A myriad of options have been shown to effectively relieve pain in different scenarios, including pharmacotherapy, physical rehabilitation, psychosocial support, acupuncture, herbal remedies, injection and infusion therapies, and surgery.\(^{ix}\)

In order to even begin to address the undertreatment of pain, it is necessary to first look at palliative/end-of-life

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**WHO's pain ladder**

*WHO has developed a three-step "ladder" for cancer pain relief.*

If pain occurs, there should be prompt oral administration of drugs in the following order: non-opioids (aspirin and paracetamol); then, as necessary, mild opioids (codeine); then strong opioids such as morphine, until the patient is free of pain. To calm fears and anxiety, additional drugs – “adjuvants” – should be used. To maintain freedom from pain, drugs should be given “by the clock”, that is every 3-6 hours, rather than “on demand” This three-step approach of administering the right drug in the right dose at the right time is inexpensive and 80-90 percent effective. Surgical intervention on appropriate nerves may provide further pain relief if drugs are not wholly effective.

SOURCE: World Health Organization
pain care in the most severe circumstances. Simply put, this means access to opioid pain medication. The WHO Pain Relief Ladder recommends the administration of different types of analgesics based on the severity of the pain and relies on the permanent availability of opioid pain medication as the gold standard for severe pain.

Globally, only about 5-10 percent of patients suffering from moderate and severe pain from cancer, end stage HIV/AIDS and many other causes may be receiving adequate treatment, as defined by WHO (see sidebar). While opioid consumption worldwide continues to rise, disparities among countries have remained the same or increased. Africa accounts for less than 1 percent of global morphine consumption.³

**The United Nations Single Convention on Narcotic Drugs**

The UN Single Convention on Narcotic Drugs, first published in 1961, then revised in 1972, set the wheels in motion for restricted access to morphine around the world in an effort to address the growing scourge of drug abuse. The convention established the International Narcotic Control Board (INCB) to monitor global movement of narcotic drugs, defined schedules of medication to control, and developed reporting systems to monitor usage of controlled substances. However, this effort to help reduce drug abuse and addiction was not intended to come at the expense of pain care. The preamble of this convention states:

> Recognizing that the medical use of narcotic drugs continues to be indispensable for the relief of pain and suffering and that adequate provision must be made to ensure the availability of narcotic drugs for such purpose…¹¹
WHO and the INCB have repeatedly drawn attention to the enormous unmet need for pain treatment and called for countries to meet this need through low-cost palliative care services. According to research from the U.S.-based Pain and Policy Studies Group (PPSG), INCB has acknowledged that opioids are not sufficiently available for medical purposes. WHO and a number of national governments have recognized this reality: the president of the INCB has stated that access to morphine and other strong pain medicines is “virtually non-existent in over 150 countries.”

There are many reasons why these medications are inadequately available, including:

1. a country’s economic and social development (e.g., life expectancy, level of education, and economic factors);
2. the low priority for pain management in a country’s healthcare system;
3. high prevalence of concerns about the development of iatrogenic dependence syndrome (an international term synonymous with “substance dependence” in the U.S.);
4. problems in procurement, manufacture and distribution of opioids, and;
5. unduly-restrictive national drug control policies.

Guidance documents from international bodies such as WHO are important tools to help clarify the intent of global control of opioid pain medication and establish ways to improve accessibility. In March 2011, WHO published updated guidelines, titled “Ensuring Balance in National Policies on Controlled Substances: Guidance for Availability and Accessibility of Controlled Medicines,” which have been endorsed by the INCB. These guidelines address:

- national drug policy;
• assigning administrative responsibility, availability and accessibility of medications based on discrimination and setting;
• education of health care professionals and authority to prescribe controlled substances for pain,
• estimates and reporting; and,
• procurement and national purview to control medicines not controlled by the INCB.

Are the Barriers to Effective Pain Care Universal?

There are many reasons for the enormity of the gap between pain treatment needs and what is delivered, but chief among them is what Human Rights Watch describes as “a shocking willingness by many governments around the world to passively stand by as people suffer.”

Consider:

• Few governments have put in place effective supply and distribution systems for morphine
• Many countries have no pain management and palliative care policies or guidelines for practitioners
• Excessively strict drug control regulations that unnecessarily impede access to morphine or establish excessive penalties for mishandling it are in place
• Lack of mandatory health care professional instruction on pain management and palliative care, and
• Insufficient efforts to ensure morphine is affordable.

Unlike so many global health problems, pain treatment is not about money or a lack of drugs, since morphine costs pennies per dose. The culprits are bureaucratic hurdles and the chilling effect of the global war on drugs.
– The UBC PAIN Project

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Fears that medical morphine may be diverted for illicit purposes are a key factor blocking improved access to pain treatment. While states must take steps to prevent diversion, they must do so in a way that does not unnecessarily impede access to essential medications. INCB has stated that such diversion is relatively rare.\textsuperscript{xvi}

In their 2009 report “Please Don’t Make Us Suffer Any More: Access to Pain Care as a Human Right,” Human Rights Watch described the following well-documented and universal barriers to access to pain care:

- **SUPPLY:** (Failure to ensure a functioning and effective supply system)
- **POLICY:** (Failure to enact palliative care and pain treatment policies; excessively restrictive drug control regulations or enforcement practices, fears of legal sanction among health care providers)
- **EDUCATION:** (Lack of training for health care workers)\textsuperscript{ xvii}

An outgrowth of their earlier work, in June of 2011 Human Rights Watch published the results a survey that mapped barriers to pain care access based on opioid consumption. Their findings confirmed these widely-researched barriers and provided specific, new information that helps to better inform the scope and severity of these barriers to pain care on a global level. This report relies on interviews with country representatives; interestingly, not even established experts can agree upon or cite information that correlates with each other about barriers. The report is a starting point for comparison with other countries and further exploration about individual country infrastructure, as it looks at a single, albeit critical measure of a country’s pain
management landscape. An appreciation of these barriers can help inform patient advocates and identify opportunities where they can effect positive change.

Not surprisingly, Human Rights Watch uncovered an enormous unmet need for pain treatment around the world. Fourteen countries reported no consumption of opioid pain medicines between 2006 and 2008, meaning that there are no medicines to treat moderate to severe pain available through legitimate medical channels in those countries. In a further eight countries that do not report opioid consumption to the International Narcotics Control Board the situation is likely similar, as countries that participate in the international drug control regime undertake not to export opioids to these countries. Thirteen other countries do not consume enough opioids to treat even one percent of their terminal cancer and HIV/AIDS patients.xviii

The combined suffering due to lack of opioid pain medicines worldwide is staggering. Human Rights Watch calculations estimate that more than 3.5 million terminal cancer and HIV/AIDS patients alone die each year without access to adequate pain treatment. This includes at least:

- 1.7 million terminal cancer and HIV/AIDS patients in Asia,
- 1.2 million in sub-Saharan Africa,
• 480,000 in Europe,
• 180,000 in the Middle East and North Africa, and
• 100,000 in the Americas.

It must be emphasized that these are very conservative estimates, which assume that all opioids are used to treat this patient group. This is why it is lower than WHO’s estimate that each year 5.5 million terminal cancer patients and 1 million patients in the last phases of HIV/AIDS suffer without pain treatment.\textsuperscript{xix}

\textit{Supply & Delivery Systems}

Opioid analgesics are controlled medicines. As such, their manufacture, distribution and prescription are strictly regulated; these medications cannot be traded freely on the market. In countries where most people have access to the medicines they need most of the time, consumption of opioids is much higher than that which is necessary to treat terminal cancer and HIV/AIDS patients. Countries who can treat only those patients still have a very long way to go to ensure all patients in need can access essential pain medicines.\textsuperscript{xx}

Presumably, an environment that is accepting of compassion at the end of life and has built an infrastructure to support that environment is ideal. Unfortunately, this is not the case for 81 percent of the world, according to research from the Worldwide Palliative Care Alliance (WPCA), who conducted a mapping exercise to determine the global palliative care environment based on capacity building efforts and provision of care.\textsuperscript{xxi} The countries are categorized based on the following criteria:
1) No known hospice-palliative care activity;

2) Capacity building activity;

3a-b) Isolated/Generalized palliative care provision;

4a-b) Preliminary/Advanced stages of mainstream integration.

TABLE 1: Gross changes in the number of countries in each category from 2006-2011

<table>
<thead>
<tr>
<th></th>
<th>Group</th>
<th>2006</th>
<th>2011</th>
<th>Change=n</th>
<th>Change= %</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Group 1</td>
<td>78 (33%)</td>
<td>75 (32%)</td>
<td>-3</td>
<td>-1%</td>
</tr>
<tr>
<td>2</td>
<td>Group 2</td>
<td>41 (18%)</td>
<td>23 (10%)</td>
<td>-18</td>
<td>-8%</td>
</tr>
<tr>
<td>3</td>
<td>Group 3</td>
<td>80 (34%)</td>
<td>91 (39%)</td>
<td>+11</td>
<td>+5%</td>
</tr>
<tr>
<td>4</td>
<td>Group 4</td>
<td>35 (15%)</td>
<td>45 (19%)</td>
<td>+10</td>
<td>+4%</td>
</tr>
</tbody>
</table>

The detailed analysis allows researchers to examine the few bright spots, such as improvements in African countries Malawi, Tanzania, Zambia, and Zimbabwe. Hospice bed availability, medication availability and the establishment of a national association of palliative care also reflected positively on several countries in Central and Eastern Europe. There is no doubt that these small gains on paper are the result of extraordinary and painstaking efforts to change systems at every level. In fact, the countries that are experiencing environments of change may be the most open to the inclusion of voices of people with pain and their families in helping to shape policy and curriculum as a part of the formative stage. This could conceivably represent nearly half (49%) of the world.xxii

National Pain & Palliative Care Policies

WHO has stressed the importance of comprehensive strategies to improve access to palliative care.xxiii Human Rights Watch sought information about the availability of national palliative care policies; whether palliative care was addressed in national cancer and HIV control policies...
or plans; and whether oral and injectable morphine were included on national essential medicines lists. Their research uncovered the following:

**National Palliative Care Policies**: Of the 40 countries surveyed, 29 did not have a national palliative care policy. Those that did include: Argentina, Brazil, Indonesia, France, the Philippines, Poland, South Korea, Turkey, Uganda, the UK, and Vietnam. Although survey respondents were not directly asked about implementation, in two of these countries, Argentina and Brazil, the respondents told Human Rights Watch that the governments were not actually implementing the palliative care policies. In Indonesia, survey respondents said that policies were only partially implemented.

**National Cancer Control Policies and Plans**: National cancer control policies and plans of 24 of the 40 countries surveyed make reference to pain management or palliative care. Eight countries do not have a national cancer control policy or plan at all. In some countries, like India, the reference to palliative care is essentially rhetorical as it is not backed up by an action plan, targets, or budget allocation. It is not clear in how many of the other countries surveyed that is the case.

**National HIV/AIDS Control Policies and Plans**: In 23 countries surveyed, national AIDS control policies did not make reference to palliative care, including three high burden countries—Cameroon, Ethiopia, and Kenya. AIDS control policies in 11 countries surveyed made reference to palliative care, including a number of high burden
countries like South Africa, Tanzania, Nigeria, and Uganda. Four of the countries surveyed do not have a national AIDS control policy at all. xxvii

There is clearly much room for improvement in the development of national policies to create environments where pain and palliative care are recognized as critical components to overall health care.

*Health Care Professional Education*

Inadequate training in pain is strongly implicated in insufficient treatment. An expert panel convened by the Mayday Fund reported: . . . *current systems of care do not adequately train or support internists, family physicians and pediatricians, [who are] the other health care providers who provide primary care in meeting the challenge of treating pain as a chronic illness. Primary care providers often receive little training in the assessment and treatment of complex chronic pain conditions. They tend to work under conditions that permit little time with each individual and few options for specialist referrals.* xxviii

The European countries surveyed by Human Rights Watch have the most extensive availability of training in pain management of any region. In France, Poland, and the United Kingdom, training in palliative care is compulsory for all undergraduate medical students. In 2009 Germany introduced legislation that will make training in palliative care compulsory for all undergraduate medical students by 2014. In all other countries surveyed, with the exception of Russia, palliative care instruction was available in at least some undergraduate medical programs. xxix
A member survey of the International Association for the Study of Pain (IASP) found that in assessing challenges to improving pain management on a national level, lack of pain specialists was cited by 100 percent of respondents. Ninety (90) percent of respondents indicated that pain specialists represented 5 percent or less of the health care providers in their nation, with 47 percent of respondents indicating that 5 percent or less of pain specialists were MDs.xxx

The importance of health care professional education surrounding pain care can not be overstated. These practitioners, often primary care physicians as opposed to pain specialists or oncologists, are on the “front lines” of patient care. An “uneducated” physician can feel that he or she has no tools in their arsenal and develop a callous attitude toward their suffering patients. Even the most compassionate providers can also feel that their “hands are tied” when it comes to providing relief if they are relying on outdated teachings about pain care, or if there are justifiable concerns over regulatory retribution.

**Approaching Access to Pain Care as a Human Right**

Currently, WHO recognizes access to essential medicines as a human right among the priorities of implementation of pharmaceutical policies, and WHO’s joint effort with the United Nations Committee on Economic, Social and Cultural Rights, the body in charge of the surveillance of the International Covenant of Economic, Social and Cultural Rights (ICESCR). This has resulted in the inclusion of access to essential

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*Many people interviewed by Human Rights Watch who had experienced severe pain in India, expressed the exact same sentiment as torture survivors: all they wanted was for the pain to stop. Unable to sign a confession to make that happen, several people told us that they had wanted to commit suicide to end the pain, prayed to be taken away, or told doctors or relatives that they wanted to die.*¹
medicines in the core content of the right to health. The Committee states that the right to health contains a series of interrelated and minimum elements, such as availability, accessibility, acceptability and quality of health goods, services and programs. In this framework, medicines must be available in sufficient quantity, without discrimination, overcoming physical and economical constrictions and respecting medical ethics, provided that they are scientifically and medically appropriate. These four elements are in line with the WHO statement that essential medicines are intended to be available within the context of health systems in adequate amounts at all times, in the appropriate dosage forms, with assured quality and information, and at a price that the individual and the community can afford.\textsuperscript{xxxi} WHO’s Model List of Essential Medicines includes morphine in oral tablet, oral solution, and injectable formulations; clearly, this theory does not meet practice.

\textit{How can positioning access to pain care as a human right support advocacy efforts?}

A special-theme \textbf{Bulletin of the WHO} on Intellectual Property Rights and Public Health states: “Approaching access to essential medicines as a right not only opens a subjective dimension that refers to individual enforceability of the right to health, but modifies issues such as the relationship between access to medicines and intellectual property rights, strengthening the patient’s position. Likewise, it allows a merely ethical valorization to be overcome in favor of the analysis of actions adopted in the framework of public health in a context of legal enforceability.” Further, a human rights approach applied to access to essential medicines such as morphine have the potential to provide new tools for analysis, action, accountability, and alignment of policies and advocacy work. \textsuperscript{xxxii}
Nearly 20 years ago, Margaret Somerville, a preeminent scholar of medical law, made a case that the relief of suffering is a common goal of both medicine and human rights, and that the relief of the pain and suffering of terminally ill patients is a human right.\textsuperscript{xxxiii} Subsequently, a number of international organizations have built upon that premise to establish access to pain care as a fundamental human right over the past decade, including:

- Standing Committee of the Canadian Senate;
- The Cape Town Declaration;
- The European Committee of Ministers;
- The International Working Group (European School of Oncology);
- Pope Benedict XVI; and,
- The Korea Declaration.\textsuperscript{xxxiv}

More recently, the Union for International Cancer Control (UICC) included “Universal Availability of Effective Pain Control” in its World Cancer Declaration (2009) and the IASP issued the “Declaration of Montreal” in September 2011. These declarations have been collectively useful for the continued establishment and recognition of the human rights case for access to pain care, but have also received various levels of commitment from their sponsoring organizations toward promotion and awareness of the declarations themselves. Therefore, while declarations can be a useful tool in helping to establish support and galvanizing action, they run the risk of serving as empty vessels if not structured as a part of a more comprehensive effort.

Considering this in his research about the premise of pain care as a human right and its promotion, Brennan concludes: “Given the enormous unmet needs of patients with life-limiting
illnesses in the world, it is not surprising that advocates have promoted the provision of palliative care as a human right. Indeed, those statements have emerged in an era where links are being generally made between health and human rights. A human right to palliative care may be implied from the international right to health care. However, that right should not be seen in isolation. If the goal is freedom from unnecessary suffering, then the provision of all possible measures to ensure that relief is met must be present including adequate housing, nutrition, water, and sanitation. For the progressive fulfillment of a human right to palliative care, much will be required: flexible and creative public policy, greater access to opioids for medical purposes, tireless advocacy, comprehensive education, professional leadership, and continued calls upon individual compassion for this most vulnerable group of people.\textsuperscript{xxxv}

When viewed against the lens of human rights, governments have an obligation to take measures to protect their citizens from inhuman and degrading treatment. Failure of governments to take reasonable measures to ensure accessibility of pain treatment, which leaves millions of people to suffer needlessly from severe and often prolonged pain, raises questions whether they have adequately met this obligation.\textsuperscript{xxxvi}

**Discussion: Where is the Patient Voice around the World to Improve Pain Care?**

While there are a number of recommendations and efforts to reduce barriers to pain care access aimed at health care professionals, the inclusion of a global, regional or national strategy to leverage the pain patient and caregiver voice to improve pain care is few and far between.
The U.S. Institute of Medicine’s “Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education and Research,” a seminal report released in June 2011, is one of the rare cases that mentions the role of patient advocacy as part of a national strategy to help improve pain care in the United States. The report provides the perspective lacking in many of the global assessments of pain care: just because access is far better compared to the rest of the world, it does not mean that people do not also suffer needlessly in America. The report states that, on the federal level, informing the public about pain has not received sustained priority attention from the Centers for Disease Control and Prevention (CDC), the Office of the Surgeon General, the Agency for Healthcare Research and Quality (AHRQ), or the National Institutes of Health (NIH).\footnote{xxvii} Interestingly, the report confirms that the barriers to pain care cited by other research are the same in the United States, including lack of research, policy and systems barriers, and a paucity of health care professional education about pain.

\begin{quote}
"The saddest part is...there has been no systematic evaluation of the problem; in some pockets like in Kerala or in Uganda, some enterprising pioneers bring in a system that’s locally suited. But they’re in pockets...I’m praying for the day that they’ll be an evaluation of the burden of suffering in the developing world and an action plan aimed at overcoming it." – M.R. Rajagopal, UBC PAIN Project
\end{quote}

Further, while several key national consumer pain advocacy organizations are included in the report, the authors highlight the lack of large-scale, systemic, coordinated and strategic ways that have been effective in tackling other public health concerns, such as tobacco control, cancer and end-of-life issues. In these cases, consumer and patient advocacy have led to increased public awareness, changes in health behaviors, increased research and policy changes.\footnote{xxviii} The IOM report has shed light on the fractious consumer pain advocacy community in just one country – albeit a country with enviable access to pain management compared to other countries. Still, it
enforces the absolute necessity of uniting with a single message to truly make a difference from an advocacy perspective.

Public education is a normal public health activity; indeed, “inform, educate, and empower people about public health issues” is one of the Ten Essential Public Health Services that every public health agency is expected to provide. Public education enhances the effects of each of the concentric circles of major influence on disease control: policy, community-wide environmental control measures, community awareness support and action, work and school support, clinical expertise, family involvement, and patient self-management.\textsuperscript{xxxix}

Faced with a scarcity of official recommendations to conduct patient advocacy work, a number of efforts have recently begun to raise awareness of the undertreatment of pain around the world and the power of personal testimony. Organizations such as the IASP and WPCA have begun including the consumer voice, together with core strategies to address well-documented barriers discussed above. However, their primary audiences are health care professionals who treat people with pain, including terminally ill patients. While patients and their caregivers may benefit from materials developed for this audience, they are not designed for, nor necessarily useful for a general consumer advocate. And, while individual stories have been effectively utilized to raise awareness of inequities in pain care, it has not been driven by a mass effort on behalf of patients, caregivers and surviving loved ones. Patient advocacy efforts are an effective way to lead change efforts, but presents an untapped potential for the pain patient community.
Regional Drug Availability Workshops and International Pain Policy Fellowships are led by the previously-mentioned Pain & Policy Studies Group (PPSG), a WHO Collaborating Center at the University of Wisconsin, and funded through the International Palliative Care Initiative of the Open Society Foundation. PPSG is the only policy center in the world that works specifically on opioid availability. Aside from the workshops and fellowships, PPSG provides updated data, documents, and other resources such as the annual consumption rates of morphine in countries worldwide. Their work is evident in much of the progress that has been made. Other programs such as WHO’s Access to Controlled Medicines Programme (ACME) help create an environment of receptivity for consumer advocacy, where public testimony and awareness could be viewed as a informative to the process.

Incremental, but meaningful changes are being made to improve pain care in parts of the world. These bright spots are highlighted and celebrated as success stories. Against all odds, Uganda has been identified as a beacon of hope in sub-saharan African pain care, as barriers were identified and overcome with dizzying speed. In the last 10 years, Uganda has led the African continent in efforts to improve access to palliative care, making significant progress on a number of fronts. (See case study below)

Case Study: Uganda

The introduction of morphine – described by Dr. Anne Merriman, founder of Hospice Africa and Hospice Africa Uganda as “essential component of health care” was a particular challenge in an African country such as Uganda in 1993. Uganda, which lacks economic resources, has few doctors (1: 19,000 population), and nurses (1:5,000 population) and where 57% of the population never see a health worker. Traditional healers are the first point of contact (1:450 population). However, the universal barriers to pain care faced by people around the world, in addition to the particular challenges cited above, have been overcome with common sense, dedication and remarkable swiftness. Government support of improved pain care efforts was crucial. With the help of the Ministry of Health, oral affordable morphine was brought into Uganda in September 1993.

In its five-year Strategic Health Plan for 2000-2005, Uganda became the first African country to state that palliative care was an essential clinical service for all citizens. Since then, the government has worked to improve the availability of narcotic medications. It added liquid morphine to its essential drug list and adopted a new set of
Guidelines for Handling of Class A Drugs for health care practitioners, also a first in Africa. The Ministry of Health also started importing oral morphine powder and providing oral morphine solution to public health facilities at no cost. Since 2000 opioid consumption in morphine equivalence has increased four-fold from less than 0.2 mg per person to almost 0.8 mg per person in 2008.\textsuperscript{xlv}

Dr. Merriman cites several steps to improving availability of pain care: systems change that allowed for the importation of opium powder; policy changes that broadened the base of opioid prescribers to include midwives; increased palliative care education among health care providers; practical oral administration that was affordable and could be delivered at home; and, protocols for addressing side effects. Strategic advocacy efforts with government officials and health care professionals were helpful in initiating the change, but was not a stand-alone.\textsuperscript{xlv} This sustained shift in improving access to pain care has led the Open Society Foundation and other international organizations to herald Uganda as a “pioneer in palliative care” and a “best practice” for reform efforts.\textsuperscript{xlvi,xlvii}

Rigorous efforts by policy makers and health care professionals have made the hope of good pain care a reality. Interventions such as the PPSG action plans have been effective across a variety of health systems to improve pain care, but do so without the inclusion of personal testimony. The success of following this model have been described in Columbia, Romania, India, Uganda, Italy, and Vietnam, with significant improvements in policies.\textsuperscript{xlviii} In all of these countries, though, accessing pain care is still problematic.

These are important and hard-won victories. Efforts are measurable, but nowhere near the volume to achieve a critical mass of change that only a motivated patient population can provide. Without concerted efforts to share this information, this movement is in jeopardy of losing momentum. As the pain advocacy community is disjointed in the United States, so, too, is it disjointed around the world. Table 2 outlines initiatives by major international organizations who are dedicated to improving pain care and their relevance for consumer advocates. As noted above, these programs and materials might be useful for patients and their families, but are not designed with this audience as the end user. This overview provides a snapshot of how the patient community has been overlooked and the opportunity for expanded efforts.
<table>
<thead>
<tr>
<th>Organization, Leadership</th>
<th>Effort(s)</th>
<th>Description</th>
<th>Relevance for Patient Advocacy</th>
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</thead>
<tbody>
<tr>
<td>International Association for the Study of Pain, Kathy Kreiter, Executive Director</td>
<td>International Pain Summit 2010, Declaration of Montreal, World Year Against Pain</td>
<td>The summit framed the issue of access to pain care as a human right and included profiles of one person with pain and one caregiver.</td>
<td>A number of “desirable characteristics” were outlined in terms of ways to improve access to care, including public awareness. The “responsible parties” targeted to undertake this task is listed as: Providers of health care, patient organizations, and health educator programs However, consumer advocates are not an audience of IASP, nor does the organization intend to reach this audience. Additionally, IASP communications center around newsletter alerts and in-person meetings as a form of information exchange, which is not ideal, realistic or intended for broad-scale consumer consumption. However, the organization does take responsibility for declaring themes for “World Year Against Pain” and the creation of materials translated into a number of different languages that can be utilized by consumer advocates to support their efforts. Usage of these materials is not tracked.</td>
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<tr>
<td>Worldwide Pain Care Alliance (WPCA), David Praill, WPCA Co-Chair (Help the Hospices, UK); Cynthia Goh, WPCA Co-Chair (Asia Pacific Hospice Palliative Care Network)</td>
<td>World Hospice &amp; Palliative Care Day</td>
<td>Each year since 2006, World Hospice and Palliative Care Day has focused on advocacy, public awareness, and fundraising, with activities ranging from radio campaigns to conferences to concerts. The day provides a moment in time for both consumer and professional pain care advocates to conduct outreach activities. A growing number of events and countries have been recorded by WPCA since then.</td>
<td>World Hospice &amp; Palliative Care Day is facilitated by UK-based “Help the Hospices.” WPCA is a global alliance of several regional hospice alliances, such as the African Palliative Care Association, Latin American Palliative Care Association and the International Association for Hospice &amp; Palliative Care. A loose online information exchange is provided for World Day activities. While a number of events were posted about local events, there was very little discussion leading up to it, or following.</td>
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<tr>
<td>Global Access to Pain Relief Initiative (GAPRI)</td>
<td>Treat the Pain.com is GAPRI’s consumer website; focus on promotion of LIFE Before Death documentary dissemination and promotion</td>
<td>Filmed in 11 countries, the documentary film LIFE Before Death tells the stories of the remarkable health professionals battling the sweeping epidemic of pain.</td>
<td>GAPRI website offers a real opportunity for pain advocates to take action, but does not offer any platforms for connection or exchange of information. The LIFE Before Death film is produced by IASP, UICC, the Mayday Fund, the Lien Foundation, and the Institute for Palliative Medicine at San Diego Hospice International Programs.</td>
</tr>
<tr>
<td>Organization</td>
<td>Faculty/Initiative</td>
<td>Description</td>
<td>Why bother to encourage patient advocacy efforts when the systems are not in place to accommodate their demands? An exchange with Indian palliative care expert and advocate Dr.</td>
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<tr>
<td>International Association of Hospice &amp;</td>
<td>Faculty development programs and fellowships</td>
<td>Works to overcome health care professional education barriers through fellowships and access to global database of pain research</td>
<td>IAHPC is dedicated to improving pain care through health care professional education. Consumers are not their intended audience.</td>
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<tr>
<td>Palliative Care, Liliana De Lima,</td>
<td></td>
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<td>Executive Director</td>
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<tr>
<td>Open Society Foundation, Kathy Foley, MD</td>
<td>International Palliative Care Initiative</td>
<td>The International Palliative Care Initiative uses a targeted, multi-pronged, public health approach to advance the following priorities: reform health policy; make available essential medicines for pain relief and palliative care; educate health care professionals and policy makers; and raise public awareness about palliative care and the rights of patients and families.</td>
<td>OSF’s International Palliative Care Initiative, in partnership with the American Cancer Society, held a two-day seminar in Budapest, Hungary in 2009 that brought together teams of cancer and palliative care experts from Albania, Armenia, Georgia, Hungary, Moldova, Romania, Serbia, and Ukraine. At the seminar, participants discussed ways of improving the ability of patients and civil society organizations to advocate for effective palliative care and pain relief policies. Each of the eight country delegations delivered presentations on palliative care policies and national cancer plans in their countries, as well on current efforts of patient advocacy groups on these issues. The participants discussed advocacy strategies to improve existing policies, and planned efforts to strengthen collaboration and facilitate the exchange of ideas on patient advocacy, palliative care, and cancer. The delegations also developed action plans to engage in-country partners on advocacy efforts.</td>
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<tr>
<td>Pain &amp; Policy Studies Group, Jim Cleary,</td>
<td>WHO Collaborating Center for Policy and Communications in</td>
<td>Facilitate workshops and information exchange to assist local leaders in developing policies based on best practices.</td>
<td>By design, does not include the voice of the patient advocate.</td>
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<tr>
<td>MD</td>
<td>Cancer Care; International Fellowship Program on Opioids</td>
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**Recommendations**

Why bother to encourage patient advocacy efforts when the systems are not in place to accommodate their demands? An exchange with Indian palliative care expert and advocate Dr.
M.R. Rajagopal elicited the following impassioned sentiment: "... I react violently against the suggestion that patients in pain should not be encouraged to speak up for pain relief lest they get frustrated. How can we sweep something like this under the carpet? We practically torture them and then discourage them from speaking up? But yes, they do not have usually have the strength to speak up and hence it would be the relatives or friends who can speak up. I think it has to happen first. Or at least side by side with attempts at policy change. Professional education, pain policies and systems all change too slowly, particularly in developing countries. We know from experience that the public voice forces administrators, politicians and professionals to change."

1) **Encourage the international pain community to actively invite and accept testimony about personal pain experience when developing policy, creating public awareness campaigns and educating health care professionals.** The active inclusion of the patient voice has been largely absent from an international pain advocacy movement. This is not to say that patients and their families have not been featured as a part of advocacy efforts; indeed, these stories are truly the most compelling component of the current campaigns such as LIFE Before Death and the UBC PAIN Project. These individual stories have been utilized to put a face to the devastation that withholding pain care can bring, and this illustration is an important one. However, there is little evidence that they are actively working to improve pain care, or have been asked to be a part of that process.

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*In a global village, everyone is a neighbor. But who will carry the torch for knowledge exchange and inspire hope?*  
– Lien Foundation

1
Good global public health interventions and programs are developed with input from “local” representatives and constituents. Professional organizations and their leadership must consider input from the “residents” of this world of agony to help inform their good intentions. In doing so, not only will the policies be better for it, but it will help patient advocates gain a better understanding of leveraging the power of their stories. It will further extend the positive effects of programs like the PPSG fellowships by cultivating advocacy for the first waves of patients whose pain has been treated, and their families.

2) **Expand the global pain advocacy movement beyond cancer and end-of-life care.** While cancer and end-of-life pain care are certainly a critical component to improving access to pain care, it must not be limited to those categories. To quote international pain advocacy leaders James Cleary, Paul Hutson and David Joranson: “A global pain relief initiative also runs a significant risk if it is limited to cancer pain as it may inadvertently increase disparities in pain treatment for those suffering from pain related to AIDS and other conditions for which the therapeutic use of opioids is indicated. This may be particularly true in sub-Saharan Africa where the number of patients with HIV-related pain is significant. However, even in Africa the burden of cancer is anticipated to overtake that of HIV, with cancer being the leading cause of death globally soon after 2020. The paucity of physicians in many countries including those of Africa makes access to opioids unlikely if prescribing is limited to physicians.”

3) **Leverage the power of social networking to connect the global pain advocacy community.** In its “Relieving Pain in America” blueprint, the IOM recommended that
consumer advocates and organizations “Research evidence-based public health strategies directed at consumers that can be applied to the goal of reducing barriers to pain care.”

Executed thoughtfully, the use of mass media (television, print), small media (brochures, posters) and social media (Facebook, Twitter) are all public health strategies that are endorsed by the U.S. Centers for Disease Control and Prevention’s “Community Guide” as an evidence-based and recommended best practice.

While several organizations described above have made efforts to provide information that can be useful for consumer pain advocates, there is no one, single, global pain advocacy information exchange or social network. Currently, information exchange is either one directional (organization to constituent, often health care professional), or, as in the case of World Hospice & Palliative Care Day, bi-directional (organization to/from constituent). This research has identified an unmet need for a multi-directional information exchange where primarily consumer pain advocates can share their experiences, key learnings, and information about how they measured levels of success with their campaigns. As the PPSG regional workshops have demonstrated, there is no global blueprint for pain care advocacy efforts. However, this type of informal and interpersonal information exchange can provide a source of information, inspiration and support to consumer pain advocates as they find their voice. Country-specific consumer pain organizations can also make materials available for local translation and cultural adaptation. This would be framed as an idea exchange as opposed to a road map; visitors would be able to view case studies, ask questions, comment, etc., but would ultimately be responsible for determining if these consumer advocacy efforts have local or regional applications based on current levels of accessibility to pain care.
There are, quite literally, billions of people around the world who are engaged on social networking sites such as Facebook (800+ million), Tencent QQ (674 million), Qzone (480 million), Netease (360 million) and Windows Live Messenger (330+ million), to name a few. In the last several years, the use of social media and networking tools to share health messages has grown significantly, and continues to trend upward. Using social media tools has become an effective way to expand reach, foster engagement and increase access to credible, science-based health messages. Social media and other emerging communication technologies can connect millions of voices to facilitate interactive communication, connection and public engagement.

Sample implementation could include the use of buttons and badges to share a call to action about right to effective pain care, content syndication of materials, RSS feeds, featured podcasts and blogs from members. The creation of the documentary shorts of LIFE Before Death and UBC PAIN Project are natural and current subjects for video sharing to inspire consumer advocacy efforts. Lastly, social networking can be started through a simple Facebook page, or be more controlled through a more resource-intense and costly closed system, which would offer the advantage of being adjunct to a consumer’s social network of choice.

Sustainability

Sustainability, of course, is an important consideration, however not all of the recommendations stated above need to be costly. Major global funders with a passion for improving access to pain
care include the Open Society Foundation’s (OSF) International Palliative Care Initiative, the Mayday Fund, LIVESTRONG and the Lien Foundation. International aid organizations such as the President’s Emergency Plan for AIDS Relief (PEPFAR), and the Global Fund to Fight AIDS, Malaria and Tuberculosis have been encouraged by Human Rights Watch to support palliative care efforts. The OSF 2010 report “Easing the Pain: Successes and Challenges in International Palliative Care” includes a discussion of donor funding. A consideration would be housing this exchange within a consumer organization who serves people with pain as this type of international collaboration among local pain advocacy organizations is not apparent. It could also be a stand-alone entity.

Conclusion

People with acute or chronic pain often are unaware of their treatment options or may hold inaccurate or value-laden beliefs about pain that obstruct the path to treatment and relief. They deserve information that can help them understand and address their condition. Approaching access to pain care from a human rights perspective has been an effective strategy in helping to frame this public health problem in a way that crystalizes the idea that pain treatment should not be withheld. This skillfully laid groundwork needs to be taken further by raising awareness among people with pain to know their rights and speak up in defense of them. This can and should involve the very people suffering. Their stories are real and they matter; their efforts can and do make a difference.

Patients are the ones who will actually make a change – Kathy Kreiter, Executive Director, IASP

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There must be a critical mass that involves not just the tireless work of health care professionals and leaders who have devoted their lives and careers to this cause, but also caregivers, people with pain and “champions” as described so eloquently by the Open Societies Foundation:\textsuperscript{lvii} 

…palliative care does not happen without those few extraordinarily impassioned, disciplined, talented, indefatigable people: the champions. So intrinsic to the process are champions that the International Palliative Care Initiative and the Pain & Policy Studies Group count them as among three necessary criteria for investing in their policy reform, along with a committed government and a regulatory structure that can be changed.

The champions may come to palliative care from frustrating professional experiences, such as watching patients die in great pain. They may come to it—as so many people in the developing world do—having sat by the bedsides of their own family members and friends, as they suffered and died of AIDS or cancer. But what distinguishes the champions from the others who have witnessed the same tragedies is their extraordinary desire to do something about it, their charisma, their ability to get things done in the face of enormous challenges, and their refusal to give up.

Current pain advocacy efforts are making a difference and have paved the way for consumer advocacy involvement. This research has uncovered a number of exciting activities underway with the goal of improving pain care. PPSG is expanding their report card analysis to create a tool to better evaluate and compare pain policies around the world, with support from LIVESTRONG. Awareness efforts have also made gains. World Hospice & Palliative Care Day has grown from 226 events in 60 countries in 2006, to more than 1,000 events in approximately
80 countries, just five years later in 2011.\textsuperscript{lviii} The LIFE Before Death documentary series is continuing its global rollout. To maximize the impact of these advocacy opportunities and others, they should not be conducted at, or for, people with pain and their loved ones, but alongside them.

“We need to be such a nuisance that officials say, ‘...it’s easier to do what they’re asking us to do, than to have to keep up with them knocking on our doors...if we applied ourselves, this could be addressed in a few years.’”

– Diederik Lohman, Human Rights Watch, UBC PAIN Project\textsuperscript{1}
Appendix: Organizations, Efforts and Projects Working toward Improved Access to Global Pain Care

Access to Controlled Medicines Programme (ACME)

The Access to Opioid Medication in Europe (ATOME) project
http://www.atome-project.eu/index.php

Drug Control & Access to Medicine Consortium
http://www.dcamconsortium.net/

Human Rights Watch
www.hrw.org

International Association for the Study of Pain (Includes contact information for country and regional professional pain societies)
www.iasp-pain.org

International Hospice & Palliative Care Organization
www.hospicecare.com/

Open Society Foundation/International Palliative Care Initiative
http://www.soros.org/initiatives/health/focus/ipci/events/cancer_20090824

OSF: “Stop the Torture” Activism Campaign
http://www.stoptortureinhealthcare.org/about-denial-of-pain-relief

Pain & Policy Studies Group
http://www.painpolicy.wisc.edu/

Lien Foundation (LIFE Before Death documentary)
http://www.lienfoundation.org/specialproj.html

LIVESTRONG
www.livestrong.org

Worldwide Palliative Care Alliance (Includes contact information for regional alliances, such as the African Palliative Care Alliance)
http://www.thewpca.org/

World Hospice & Palliative Care Day
http://www.worldday.org/

Union for International Cancer Control (UICC)/Global Access to Pain Relief Initiative (GAPRI)
http://www.treatthepain.com/treat-the-pain-about-us
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xii Briefing Note: Access to Controlled Medicines Program,” World Health Organisation Briefing Note, February 2009.


M.R. Ragagopal; email exchange, November 11, 2011.


