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## Palliative Care as a Human Right

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# PALLIATIVE CARE AS A HUMAN RIGHT

## Executive Summary

### Background

Palliative Care associations have articulated a simple, but challenging proposition: that Palliative Care is an international human right. The international human rights covenants and the discipline of palliative care have, as common themes, the inherent dignity of the individual and the principles of universality and non-discrimination.

### Aims

1. to provide a detailed overview of the epidemiological, public health and legal issues underpinning the goal of advancing a human rights approach to palliative care provision.
2. to document the principle readings and resources that would complement this background in the formation of a curriculum on palliative care as a human right.
3. to describe how the findings may be utilized to advance access to palliative care and pain management globally.

### Summary headings

#### *The discipline of palliative care*

When we consider the evidence for the effectiveness of palliative care, the lack of palliative care provision for those who may benefit from it is abysmal. A number of systematic evidence reviews have appraised outcome data from around the world, concluding that palliative care in all its forms (hospice, hospital, home based care, day care) improves outcomes for patients and families. abysmal In addition to that body of evidence, there is a deep humanitarian foundation to Palliative Care.

#### *Scope of the problem*

Worldwide more than 57 million people died during 2002, of these 7 million died of malignant neoplasm and 2.7 million died of AIDS related illness. In 2006, UNAIDS estimates that over 40 million people, 2.3 million of whom are under the age of 15 years, are infected with HIV and are living with the disease requiring disease-specific care integrated with palliative care to ensure that physical symptoms, as well as challenging psychosocial and spiritual issues are addressed. Also, there are growing numbers of individuals with other chronic and life-threatening conditions. Throughout the world, millions suffer and die with end stage cardiac failure, respiratory, renal and hepatic failure. These people are likely to experience problems that would benefit from palliative care at some time. In developed nations, the prevalence of these conditions will increase with the ageing of the population. In addition, life-limiting neurological conditions such as dementia, amyotrophic lateral sclerosis and cerebrovascular disease contribute to the burden of end of life care.

### *Provision*

While there are international data on mortality, there is little, if any, information on quality indicators for end of life care. Most countries do not have palliative care policies, pain policies, integrated palliative care services or hospices.

### *Palliative care, public health and human rights*

Three disciplines (palliative care, public health and human rights) are now interacting with a growing resonance. The maturing of palliative care as a clinical specialty and academic discipline has coincided with the development of a public health approach to global and community-wide health problems. The care of the dying is a public health issue. Given that death is both inevitable and universal, the care of people with life limiting illness stands equal to all other public health issues. Palliative care is a public health priority because of the societal impact on carers and survivors and the significant financial issues that impact on families and communities with chronic disease. As populations age, a clear argument for a public health paradigm has been articulated, because of the number of people affected by providing end of life care and those who experience grieving. The WHO has promoted clear public health policies and recommendations for the rational implementation of pain relief and palliative care. This recognition of palliative care as a public health issue is timely and appropriate.

Equally the promotion and protection of health as a human right have become more favored in recent years, especially in the context of the HIV/AIDS pandemic, womens' health issues and gross human rights violations. The reports that the Special Rapporteur on the Right to Health has delivered to the Human Rights Commission and the UN General Assembly have all had, as their foundation, the promotion of health as a human right

### *The moral foundation of a right to Palliative Care*

Whether one adopts a principlist approach (based on bioethical principles of autonomy, beneficence, non-maleficence and justice) or a virtue ethics approach (the actions of a virtuous health professional) the ethics of the medical care of the patient with a life-limiting illness has a deep humanitarian core – of compassion in approach, meticulous concentration on symptom control, clarity and sensitivity in communication to the patient and family, guiding all through the unique journey of dying. If there is a clear ethical obligation to relieve suffering or act virtuously by doing so, one may argue that from that obligation springs a right.

### *International human rights*

What are human rights? Are they different to other legal rights? Is palliative care an agreed human right, either expressly or by implication? These questions are important. For only if we can achieve a clear conception of the content of any specified human right can we fully understand what it means to assert or deny the existence of that right. The discourse and structure of human rights are not static. The influence of human rights continues to grow and diffuse into international, regional and domestic legal systems.

The international right to health or health care is articulated in a series of Declarations or Conventions from the inception of the United Nations with General comment 14 (para 34) making specific reference to access to "palliative health services".

The World Health Organization defines both health and palliative care broadly. Health includes the health of people with life-limiting illnesses. Arguably a right to the provision of Palliative Care may be implied from this broadly stated right to health. The right to health, as articulated in the International Covenant on Economic, Social and Cultural Rights (ICESCR) has been authoritatively interpreted to include certain “core” obligations and “obligations of a comparable priority” for signatory nations.

The discourse and structure of human rights are not static. The influence of human rights continues to grow and diffuse into international, regional and domestic legal systems. Some theorists insist that only civil and political rights are really human rights, whereas socio-economic “rights” are merely desirable goals dressed up in the more powerful rhetoric of rights. The defenders state that both sets of rights are founded upon the same set of values – human dignity and decency. Rights to adequate nutrition, education and health care are all essential for realizing civil and political rights.

#### *Rights, obligations and challenges*

The holder of a right has the capacity to enforce a duty in a person or institution. The ‘other’ has a duty to fulfill that right. Indeed a basic tenet of the philosophy of rights is that a right can only exist if there is a pre-existing obligation.

Synthesizing these sources (the Committee that oversees the international right to health, the WHO and the international palliative care community), a consensus on the content of the obligation on individual governments in relation to palliative care appears to be emerging. The “core obligations” of the Committee are uniformly echoed. The international Palliative Care community has complemented those obligations with two other critical elements. Collectively they consist of:

1. The creation and implementation of palliative care policies.
2. Equity of access to services, without discrimination.
3. Availability and affordability of critical medications, including opioids.
4. The provision of palliative care at all levels of care.
5. The integration of palliative care education at all levels of the learning continuum from informal caregivers to health professionals.

#### *Other legal foundations*

In addition to the international human rights instruments described above other possible legal sources of a right to Palliative Care emerge from regional human rights instruments, national constitutions that contain a right to health care, statutory law and common law in negligence.

#### *Strategic considerations, mechanisms and recommendations*

The reasons for the articulation of Palliative Care as a human right are multifactorial. A critical issue has been the acknowledgement that the care of people with life limiting conditions throughout the world is neglected, under funded and under-resourced. In the context of Palliative Care and human rights there are clear weaknesses. Those weaknesses are explored. The necessity to recognize, as does the WHO itself, that not all countries can provide every possible option in the manner palliative care is delivered, places limitations on the dividend that human rights can deliver. Clearly then human rights are not the only answer. They are, however, one of a constellation of approaches to improving the care of people with life-limiting conditions.

Nevertheless, employing a discourse of human rights and the obligations that flow from a right to Palliative Care provides several channels of submission and advocacy for human rights organizations, especially liaising with the IASP, IAHP, WPCA and pan-national and national Palliative Care Associations, to advocate in this area. These are described.

### *Conclusion*

While an approach based on human rights has clear limitations it is, nevertheless, a concept that serves to coalesce a broad medical, moral and legal imperative – that the care of patients with life-threatening illness is a fundamental responsibility of governments, societies and health professionals.



## Introduction

The care of people with life-limiting illnesses up to and including their death is a universal challenge. The skills, humanity and resources of all nations are tested. Whether people die in affluence or poverty, amidst sophisticated medical technology or relying on the most basic care, our common needs as human beings are universal: comfort, dignity, and love. The modern palliative care movement has grown in response to that universal challenge. How that care is provided, and what resources are brought to its fulfillment, vary enormously around the world. Cognizant of those discrepancies and determined to improve the care of those facing the diagnosis of life-threatening illness, Palliative Care associations have articulated a simple, but challenging proposition: that Palliative Care is an international human right. This paper examines this statement. It commences by describing the epidemiology of life-limiting illnesses and the continuing barriers to adequate end-of-life care. It examines the interface of three areas of discourse – palliative care, public health and human rights. It will trace the history of a rights discourse in the context of palliative care, the foundations of palliative care in law including the international right to health, and the strategies that may be used to promote the universal access to reasonable and adequate palliative care.

The international human rights covenants and the discipline of palliative care have, as common themes, the inherent dignity of the individual and the principles of universality and non-discrimination. The UN Committee on Economic, Social and Cultural Rights stated that *“Health is a fundamental human right indispensable for the exercise of other human rights. Every human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity”*.<sup>1</sup> When we consider the problems of patients and family members facing the diagnosis of life-threatening illness, palliative care is the practical response ensuring the highest attainable standard of health under the circumstances of declining physical condition and supporting those patients in living and dying with dignity.

## Aims

1. to provide a detailed overview of the epidemiological, public health and legal issues underpinning the goal advancing a human rights approach to palliative care provision.
2. to reference principle readings and resources that would complement this background paper in the formation of a curriculum on palliative care as a human right.
3. to describe how the findings may be utilized to advance access to palliative care and pain management globally.

## The discipline of Palliative Care

The care of the terminally ill and dying have been a preoccupation of humanity since its existence. For millennia, the capacity to cure diseases has been limited. War, infectious diseases, famine, injury and maternal and perinatal mortality all limit life expectancy. Over the last two centuries, significant advances have occurred in the prevention, diagnosis and treatment of illnesses. Western societies, at least, became obsessed by the brilliant progress of effective curative medicine.

The care of those people with irreversible illness fell to the few. Many dying did so with unresolved symptoms, and inadequate psychosocial and spiritual support. The modern Palliative Care and hospice movement arose to address those unmet needs.

Figure 1 – World Health Organization definition of Palliative Care

The World Health Organization (WHO, 2002) defines Palliative Care as *“an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”*<sup>2</sup>

*Palliative Care:*

- *Provides relief from pain and other distressing symptoms*
- *Affirms life and regards dying as a normal process;*
- *Intends neither to hasten or postpone death;*
- *Integrates the psychological and spiritual aspects of patient care;*
- *Offers a support system to help patients live as actively as possible until death;*
- *Offers a support system to help the family cope during the patient's illness and in their bereavement;*
- *Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;*
- *Will enhance the quality of life, and will also positively influence the course of illness;*
- *Is applicable early in the course of illness, in conjunction with other therapies that are implemented to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.*

Figure 2 – World Health Organization definition of Palliative Care for children

**WHO Definition of Palliative Care for Children**

*Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other pediatric chronic disorders (WHO; 1998a)<sup>2</sup>:*

- *Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.*
- *It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.*
- *Health providers must evaluate and alleviate a child's physical, psychological, and social distress.*
- *Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.*
- *It can be provided in tertiary care facilities, in community health centers and even in children's homes.*

Clearly, the definition is broad. Importantly it includes the care of all patients with life-limiting illnesses, not simply cancer. It also emphasizes that Palliative care is more than terminal care. There is a growing recognition that the principles of Palliative Care should be involved at an earlier point in the trajectory of any ultimately life-limiting illness. Indeed, the “death-bed consultation” represents a set of missed opportunities. An earlier involvement with the patient and their family may well have addressed symptoms and made the preparation for the dying calm and dignified rather than agonizing and abject. As the definitions state palliative care *“is applicable early in the course of illness, in conjunction with other therapies that are implemented to prolong life”* and from the paediatric definition of palliative care *“It begins when illness is diagnosed, and continues regardless of whether a child receives treatment directed at the disease.”*

There is no doubt that quality of life and prevention and relief of suffering are admirable goals whether the suffering is physical, such as the suffering caused by pain; psychosocial, such as the stigma experienced by an AIDS patient or the distress of a patient with an altered body image following mastectomy; or spiritual such as the distress of recognizing that one’s life is coming to an end. However, recognition of the fact that a patient has a life-threatening illness is often denied and this denial by health care professionals, patients and family members means that people do not experience the benefit of compassionate comprehensive palliative care.

This lack of palliative care provision for those who may benefit from it is stark when compared to the evidence for the effectiveness of palliative care. A number of systematic evidence reviews have appraised outcome data from around the world, concluding that palliative care in all its forms (hospice, hospital, home based care, day care) improves outcomes for patients and families.<sup>3-9</sup>

In addition to that body of evidence there is a deep humanitarian foundation to Palliative Care. A number of individuals respected in and beyond the Palliative Care community who have made significant statements regarding its importance. To Margaret Somerville *“[n]owhere are the concepts of an ethic of care, human ethics, human rights, and human responsibilities more important than in relation to human dying.”*<sup>10</sup> To Kathy Foley *“[i]t is innately human to comfort and provide care to those suffering from cancer, particularly those close to death.”*<sup>11</sup> Later Foley stated *“there are no villains in this piece but ourselves and our culture, that public health institutions reflect dominant societal values that still deny dying and death, that change to improve care of the suffering and dying is slow and conflicted with the tension between cure and care.”*

## **Scope of the problem**

The WHO reports annually on total deaths<sup>12</sup> worldwide and by region. Statistics from 2002 provide the information that worldwide more than 57 million people died, of these 7.1 million died of malignant neoplasm and 2.8 million died of AIDS related illness. UNAID data from 2006 estimate that over 40 million people<sup>13</sup>, 2.3 million of whom are under the age of 15 years, are infected with HIV and are living with the disease requiring clinical care integrated with palliative care to ensure that physical

symptoms, as well as challenging psychosocial and spiritual issues are addressed. Also, there are growing numbers of individuals with other chronic and life-threatening conditions. These people are likely to experience problems that would benefit from palliative care at some time.

World Health Organization mortality data <sup>12</sup>			
Cause of death	Male	Female	Total
All deaths	29,891,161	27,137,993	57,029,154
Malignant neoplasms	3,973,570	3,147,195	7,120,765
HIV	1,447,097	1,330,077	2,777,174

While these statistics provide us with a concept of the magnitude of the problem they do not describe the length or severity of the illness preceding death. With the advanced medical technology available, at least in first world settings, clinical care has for a long time been focused on cure often resulting in a withdrawal of medical care when clinicians recognized that patients were now terminally ill. Palliative care should be an integral part of every Health Care Worker's (HCWs) training in order that all patients receive quality palliative care when they require intervention. Therefore, palliative care should be provided irrespective of prognosis or proximity to death, but rather according to need, according to whether the patient/family member has a manifestation of pain (physical, psychological, emotional, and spiritual).

### *Malignancy*

Currently, there are 10 million cases of malignancy diagnosed throughout the world per year. It is estimated that by 2020, there will be 20 million new cases per year and that 70% will occur in developing countries.<sup>14</sup> Up to 70% of patients with a malignancy suffer from pain caused by their disease or its treatment.<sup>15</sup> In patients with advanced cancer, pain is described as moderate to severe in 40-50% and as very severe in 25-30%.<sup>16</sup> In addition to pain, other symptoms including nausea, dyspnoea, constipation, anorexia-cachexia, fatigue, anxiety and depression frequently occur.

### *HIV/AIDS*

As stated above there are over 40 million people in the world currently infected with HIV. Of that figure, almost three quarters live in Sub-Saharan Africa. Further statistics from the WHO estimate that there were 4.3mill new HIV infections in 2006. The pandemic grows inexorably. Research in South Africa has shown that 98% of patients with AIDS experience pain, that people with HIV often have multiple pains occurring concurrently and that pain is often neglected or poorly managed.<sup>17</sup> International research supports the finding that the majority of patients with HIV/AIDS will experience pain at some stage of their illness.<sup>18</sup> Most die at home with family and community as carers, leaving a vast legacy of grief, social dislocation, poverty, a growing population of orphans. Famine and deprivation are additional consequences, given the circumstances in which a substantial proportion of the economically productive age group are ill or have died.<sup>19</sup>

The provision of Palliative Care to patients with HIV/AIDS has been shown to improve outcomes.<sup>6</sup> These positive outcomes can be achieved whether or not the patient is receiving anti-retroviral medications. It is important to challenge the current attitude of denial around the management of HIV, in that many public health officials and some HIV clinicians hold the belief that providing anti-retroviral medications and optimum treatment support will impact on the illness so that patients will no longer die of AIDS-related illness. Research shows that in Africa, patients experience distressing symptoms caused by HIV infection, that the symptom burden is significant even while on ARVs and that people are still dying of AIDS-related illness while on ARVs.<sup>20</sup> A prospective census of palliative care need among outpatients attending a health centre for HIV care in Tanzania found that around 50% were appropriate for palliative care referral, and that appropriateness for palliative care was not associated with whether they were accessing antiretroviral therapy.<sup>21</sup> This evidence for the continued presence and burden of distressing symptoms while under antiretroviral therapy has also been evidenced in studies in the UK, and underlines the imperative of palliation alongside treatment.<sup>22,23</sup>

### *Non-malignant disease*

Throughout the world, millions suffer and die with end stage cardiac failure, respiratory, renal and hepatic failure. These people are likely to experience problems that would benefit from palliative care at some time.<sup>6,24</sup> These patients will also have significant physical distress from untreated symptoms and the emotional and existential distress that accompanies life-threatening illness.<sup>25-27</sup> In developed nations, the prevalence of these conditions will increase with the ageing of the population. In addition, life-limiting neurological conditions such as dementia, amyotrophic lateral sclerosis and cerebrovascular disease contribute to the burden of end of life care.

### **How is Palliative Care provided globally?**

A major problem in assessing the quality of end of life care globally is information. Singer and Bowman pointed out that while there are international data on mortality, there is little, if any, information on quality indicators for end of life care.<sup>28</sup> Most countries do not have palliative care policies, pain policies, integrated palliative care services or hospices.<sup>29</sup> As Furst and colleagues state : *“In spite of tremendous engagement of palliative care specialists and volunteers, countless patients at the end of life suffer from treatable pain, anxiety and other symptoms, social isolation and existential solitude.”*<sup>30</sup> While formal palliative care services exist in most developed nations (e.g. primary palliative care, community teams, hospital teams and units, hospices with both inpatients and home care, and day care), in developing countries, the care of people with life limiting illness overwhelmingly falls to the family of the patient and their community. However, although in developed countries patients report a preference for home death, most people in these regions do not die at home and a number of factors are associated with achieving home death.<sup>31</sup>

Throughout the developing world there are centers of excellence and visionaries who strive to improve the provision of end of life care. One example is



Michael Wright and his colleagues comment that *“We have demonstrated that it is possible to map and measure the levels of palliative care development in any given country. More than 150 countries are actively engaged in delivering a hospice-palliative care service or developing the framework within which such a service can be provided. Yet development is patchy, with palliative care approaching a measure of integration with wider service providers in just 15% of countries; in countries with localized provision there are many instances where a service is mostly inaccessible to the whole population. Consequently, despite increasing calls for palliative care to be recognized as a human right, there is a long way to go before palliation is within reach of the global community.”*<sup>37</sup>

Closely linked to the provision of palliative care is the access to pain-relieving medication. The WHO definition of palliative care singles out pain as the prime distressing physical symptom that affects people with life-threatening illness. Among and of life HIV care providers in Sub-Saharan Africa, pain relief provision was identified as a primary challenge.<sup>38</sup>

David Clark and Michael Wright of the End-of-Life Observatory at Lancaster University compared their survey of levels of palliative care development in African countries with the International Narcotics Control Board report on average daily consumption of morphine in African countries. This comparison clearly shows that there is strong correlation between the countries with no reported palliative care activity (21 countries) and countries with no reported morphine use (29 countries).<sup>39</sup>

## **The reasons for deficiencies in the provision of palliative care**

In a document prepared for the EAPC Conference the authors comment that *“In spite of tremendous engagement of palliative care specialists and volunteers, countless patients at the end of life suffer from treatable pain, anxiety and other symptoms, social isolation and existential solitude.”*<sup>40</sup>

The reasons for deficiencies in palliative care provision overlap with the reasons for inadequacies in the provision of health care generally – paucity of resources and a lack of political will in prioritizing health. However, palliative care generally and pain management specifically attract other major barriers. If we first consider palliative care in general – palliative care is seen by patients, family members, medical practitioners and health policy makers to be only terminal care and societal attitudes are such that death and dying are taboo. There is low awareness of the full scope of palliative care and the positive impact it has on quality of life for patients and family members. Prevention and treatment of disease has a much higher priority than provision of palliative care. Harvey Chochinov in his testimony before the Canadian Senate Committee on Social Affairs, Science and Technology made the powerful comment that: *“Unfortunately, in end-of-life care, we do not have a vocal constituency: The dead are no longer here to speak, the dying often cannot speak, and the bereaved are often too overcome by their loss to speak.”*<sup>40</sup>

The barriers to adequate pain management are significant and complex, the most significant being ophiophobia – an irrational fear of the use of opioids. Opiophobia is universal. Culturally and historically enmeshed in societies is the fear of the use of opioids – myths based on fears of addiction, of inevitable sedation and

that the use of opioids will automatically shorten the life of patients. Too often, opiophobia is associated with opioignorance: the inadequate teaching of undergraduate doctors and nurses in pain management. These cultural and educative barriers are compounded by significant political and legal impediments, especially in the importation, manufacture, distribution and prescription of opioids for medical use. In general, public policy regarding opioids is dominated by concerns about illicit drug use and inadequate focus is given to the provision of opioids for medical purposes. In 2004, the International Narcotics Control Board published the per capita use of morphine for medical purposes for all countries for the previous year.<sup>41</sup> Six nations accounted for 79% of all analgesic morphine consumption. Countries comprising 80% of the world's population utilized 6% of the world's consumption of morphine for medical purposes.

In addition to barriers to the use, availability and prescription of opioids, other reasons for deficiencies in the provision of palliative care include a lack of governmental commitment and inadequate education. The WHO has recommended all nations should have a national policy for the implementation of palliative care services. Largely this recommendation remains unheeded. Equally, education in end of life care of both health professionals and the communities they serve remains sporadic at best.

Figure 4 provides a summary of the challenges to Palliative Care provision.

Figure 4 - Challenges to palliative care provision<sup>39</sup>

- Political, social and economic instability
- Low public awareness
- Care for people with life limiting diseases is not seen as a priority
- Uncommitted government/ Ministry of Health
- Absence of policy/ legislation
- Unavailability of opioids
- WHO pain ladder not in use
- Lack of funding
- Entrenched attitudes within the medical profession
- Palliative care seen as a less prestigious discipline
- Absence of palliative care modules/ placements in medical curriculum
- Small number of professionals entering the field
- Uncertainty about the relationship between palliative care and other specialties
- Difficulty recruiting psychologists
- Demands of multidisciplinary team work
- Cultural change
- Education and training of staff
- Accreditation
- Absence of standards
- Taboo around death/disclosure of diagnosis coverage

A further review of the barriers and inequalities on access to, and provision of, palliative care for people with HIV identified a number of factors defined as patient-centered (e.g. acceptance of suboptimal analgesia), clinician-centered (reluctance to address end of life issues and fear of opioids) disease-centered (unpredictability and



integration challenges with treatment) and setting-focused (e.g. low coverage among hospices and rural access to specialist care).<sup>42</sup>

### **Palliative care as a public health issue**

For some years, a current of advocacy has run through the debate on end of life care - that the care of the dying is a public health issue. The proponents of that argument state that given death is both inevitable and universal, the care of people with life limiting illness stands equal to all other public health issues and is often in tandem with them. Dying is associated with suffering, much of which is preventable. Rao and colleagues argued that palliative care is a public health priority because of the societal impact on carers and survivors and the significant financial issues that impact on families and communities with chronic disease.<sup>43</sup> As populations age, a clear argument for a public health paradigm has been articulated.<sup>44</sup> Similarly, to Singer and Bowman, end of life care is a public health issue because of the number of people affected by providing end of life care and those who experience grieving.<sup>28</sup> Webster and her colleagues argued that the scale of death and dying in developing countries necessitates palliative care being *“one public health issue that deserves priority among many others.”*<sup>45</sup> The US Congress in promulgating the decade commencing 2001 as The Decade of Pain Control and Research, stated that inadequate pain management, including at the end of life, was *“a serious public health issue.”*<sup>46</sup>

A consensus has emerged that palliative care can be usefully approached using a public health paradigm. The WHO has promoted clear public health policies and recommendations for the rational implementation of pain relief and palliative care. As Stjernsward and Clark state : *“The application of existing knowledge according to rational public health principles is paramount if we are to reach the majority of those in need of palliative care.”*<sup>29</sup> Rao and colleagues suggested that public health and health care systems should collaborate, citing the model of self-management programs in chronic non-malignant diseases.<sup>43</sup> Singer and Bowman pointed out that public health paradigms provide a useful template upon which to model interventions for palliative care, including *“large scale, culturally specific, educational programs for public health workers and the public; population based strategies to de-stigmatize death and put it into the mainstream of health systems and changes in social policies in relation to care for orphans.”*<sup>28</sup> For Stjernsward, Foley and Ferris a public health strategy *“offers the best approach for translating new knowledge and skills into evidence-based, cost-effective interventions that can reach everyone in the population.”*<sup>47</sup> Foley pointed out the capacity for Palliative Care to prevent both current suffering and future disease: current suffering with the illness itself; and future disease through its objective of care of the family during which people at risk of disease can be counseled to take screening tests. General health outcomes can be improved for family carers during the stressful period pre/post patient death, including bereavement care.<sup>5</sup>

### **The human right to health**

While the modern human rights movement has a long antecedence, the aftermath of the cataclysmic events of World War II saw the international community articulate universal human rights. One of these enumerated rights was the right to health. This will be discussed in detail in a later section. A considerable body of

literature has concentrated on the right to health, especially in the context of the significant inequalities in access to health care throughout the world. Indeed, to Mann, a pioneering theorist in this area, the promotion and protection of human rights and health are “inextricably linked”.<sup>48</sup> Other theorists have been critical of the concept of an individual “right to health” describing it as illusory<sup>49</sup>, meaningless<sup>50</sup> or, in the context of a world with limited resources, unattainable.<sup>51</sup> There has also been emphasis on the provision of health care in terms of equality and social justice<sup>52</sup> or as a foundation of the capability of leading a health life.<sup>53,54</sup> Equally, there has been a wide recognition that the determinants for health care are indivisible – that the provision of adequate water, housing and sanitation are as critical to the health of individuals as the provision of health care.<sup>55</sup>

In the modern era the articulation of an international right to health emerged from the UN Declaration of Human Rights to be expressly stated in the International Covenant on Economic, Social and Cultural Rights and other Covenants. Since then critical links have been made between health and human rights by academia, governments, non-governmental organizations and international bodies including agencies of the United Nations. These links have been directed to advocacy, the provision of services, research and defining health policy. The Declaration of Alma-Ata (1978), adopted by an International Conference on Primary Health Care<sup>56</sup>, reaffirmed the fundamental human right to health care and called on governments to expeditiously provide primary health care. In more recent times this advocacy has accelerated. Catalysts for these linkages have included the HIV/AIDS pandemic, women’s health issues and gross human rights violations in the Balkans and Africa. The first occasion that human rights were explicitly named in a public health strategy was in the late 1980’s when human rights were embodied in the first WHO Global Strategy for the Prevention and Control of AIDS (1987).<sup>57</sup> Two other international conferences – the 1994 International Conference on Population and Development and the 1995 Fourth World Conference on Women, resulted in consensus documents expressly linking health and human rights. In 1997, the UN Secretary General issued a Program for Reform. The program designated human rights as among the core activities of the UN system.<sup>58</sup> This was echoed in 2001 by the UN Human Rights Commission which called for an international recognition of an obligation “*with regard to the promotion of the right to health...*” In the following year the Commission appointed a Special Rapporteur for Human Rights on the international right to health. The resolution establishing this position<sup>59</sup> and the reports that the Special Rapporteur has subsequently delivered to the Commission and the UN General Assembly<sup>60</sup> have all had, as their foundation, the promotion of health as a human right.

The link between health and human rights was also made explicit by the World Health Organization. Gro Harlem Brundtland, the organization’s past Director-General stated that in order for WHO to meet its goals in health care that human rights must be taken seriously.<sup>61</sup> The WHO’s website on Health and Human Rights reminded its members that “*[e]very country in the world is now party to at least one human rights treaty that addresses health-related rights, including the right to health...*”

Significantly, this movement has included another discipline – public health. The Executive Director of the American Public Health Association concluded, in a

co-authored editorial, “*The time has come to herald human rights as both the foundation of public health practice and the compass of public policy actions.*”<sup>62</sup>

## **Towards a synthesis of approach – palliative care, public health and human rights**

Three disciplines (palliative care, public health and human rights) are now interacting with a growing resonance. The maturing of palliative care as a clinical specialty and academic discipline has coincided with the development of a public health approach to global and community-wide health problems. The recognition of palliative care as a public health issue is timely and appropriate. Inevitably, the paradigm of one will inform the other. Over recent years also, both public health and palliative care have reached into the well of a third discipline – human rights. The rationale behind this is multifactorial – the need for a language of universality, the importance of advocacy, and an imperative felt in a time of crisis for a solid theoretical foundation. The effect of this interaction is beginning to be observed.

And so, it was into this milieu of the exploration of the role of a human rights discourse in health care that the articulation of rights to both pain management and palliative care emerged.

## **Pain management and the discourse of rights**

Into the environment of inadequate pain management in many parts of the world, a quiet phenomenon emerged. Frustrated by the widening gap between an increasingly sophisticated knowledge of pain and its treatment, and the effective application of that knowledge, academics and clinicians began to link pain management and human rights. To Somerville, “*to leave a person in avoidable pain and suffering should be regarded as a serious breach of fundamental human rights.*”<sup>63</sup> To Cousins, “*the relief of severe, unrelenting pain would come at the top of a list of basic human rights.*”<sup>64</sup> These assertions were eventually followed by authoritative statements by multiple international and national pain associations articulating a right to pain relief. This advocacy culminated in the promulgation of the inaugural “Global Day against Pain” in October 2004. Co-sponsored by the WHO, the International Association for the Study of Pain and the European Federation of IASP Chapters, the theme of the day was “Pain Relief Should be a Human Right.”

The foundations to a right to pain management are diverse and encompass both ethics and the law.<sup>65,66</sup> Is there a separate but related right to palliative care? Given that a human rights discourse has emerged in the provision of health care generally, it was appropriate to examine this right in the context of end of life care. Necessarily, this will involve examining the nature of both rights and palliative care.

## **The foundations of a right to palliative care**

The statement that “Palliative Care is a human right” is a strong one. Clearly, this statement has a critical role in advocacy on behalf of patients with life-limiting illnesses. But does this assertion have any foundation beyond rhetoric? Rights may

be “a just claim, whether legal, prescriptive or moral.”<sup>67</sup> Is the provision of Palliative Care a “just claim” and if so, what are the moral and legal foundations of this claim? Prior to examining the possible legal foundations of this right, it is apposite to explore the moral foundation to palliative care.

### *Moral foundations to the provision of palliative care*

For millennia, without access to curative medical or surgical treatment for so many diseases, one of the foundations of medical practice was the care of the dying and their families. The approach and philosophy of palliative care has a long antecedence. Hippocrates stated that medicine, in general terms, meant “*to do away with the sufferings of the sick, to lessen to violence of their diseases and to refuse to treat those who are overmastered by their diseases, realizing that in such cases medicine is powerless.*”<sup>68</sup> In the 18<sup>th</sup> century, John Gregory stated “*It is as much the business of the physician to alleviate pain and smooth the avenues of death, when inevitable, as it is to cure disease.*”<sup>69</sup> Similarly, in this century, Stjernsward and Clark opined “*there is a moral responsibility to give those who leave life...the same care and attention we give those who enter life.*”<sup>29</sup> In his message for the 2006 World Day for the Sick, Pope Benedict XVI stated that an essential emphasis of palliative care was the preservation of human dignity. His Holiness expressly stated that the provision of palliative care services was a human right: “*...it is necessary to stress once again the need for more palliative care centers which provide integral care, offering the sick the human assistance and spiritual accompaniment they need. This is a right belonging to every human being, one which we must all be committed to defend.*”<sup>70</sup>

Whether one adopts a principlist approach (based on bioethical principles of autonomy, beneficence, non-maleficence and justice) or a virtue ethics approach (the actions of a virtuous health professional) the ethics of the medical care of the patient with a life-limiting illness has a deep humanitarian core – of compassion in approach, meticulous concentration on symptom control, clarity and sensitivity in communication to the patient and family, guiding all through the unique journey of dying. If there is a clear ethical obligation to relieve suffering or act virtuously by doing so, one may argue that from that obligation springs a right. The moral right to palliative care emerges from, and is directly founded upon, the obligation of a doctor to act ethically.

### *Legal rights to Palliative Care*

Famously, Jeremy Bentham described the articulation of rights without legal foundation as “nonsense on stilts.” Is the assertion that there is a right to palliative care “nonsense on stilts”? What, if any, are the foundations of legal rights to palliative care?

Depending on the jurisdiction in which they live, patients with life-limiting illnesses may have a constellation of legal rights underlying both pain management and palliative care. Rights derived from the law of negligence<sup>71</sup> elder abuse<sup>72</sup> and domestic health care legislation<sup>73-75</sup> have emerged over the last two decades. They will be discussed later in this paper.

## **The structure of international organizations that are relevant to the provision of Palliative Care**

Prior to analyzing the legal foundations to the provision of Palliative Care it is appropriate to briefly identify the main international and pan-national organizations that are relevant to its provision:

1. *The United Nations* – the supreme body representing all the nations of the world. The International Bill of Rights and other Conventions of the United Nations include the international right to health which is described in detail below. UNAIDS, the Joint United Nations Programme on HIV/AIDS, brings together the efforts and resources of ten UN organizations to the global AIDS response. Cosponsors include UNHCR, UNICEF, WFP, UNDP, UNFPA, UNODC, ILO, UNESCO, WHO and the World Bank. Based in Geneva, the UNAIDS secretariat works on the ground in more than 75 countries worldwide. Although UNAIDS offers a definition of palliative care that can be seen to harmonize with the WHO definition,<sup>76</sup> UNAIDS makes no reference to palliative care in its strategic directions.
2. *The International Covenant on Economic, Social and Cultural Rights (ICESCR) Committee*. This Committee oversees the implementation of this Convention which includes the main articulation of the international right to health. Committees also oversee each of the other Covenants that include a right to health (The Convention on the Elimination of All Forms of Racial Discrimination, The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) and The Convention on the Rights of the Child (CRC)).
3. The United Nations Human Rights Commission. UNHRC is mandated to establish human rights standards and to examine, monitor and publicly report either on a major human rights violations worldwide or human rights situations in specific nations. Complaints can be submitted to the Sub-Commission's Working Group on Communications. When problems are identified the Commission can request the Office of the High Commissioner for Human Rights to provide assistance to governments through its program of advisory services and technical co-operations.
4. *The Special Rapporteur on Health and Human Rights*. The Special Rapporteur was appointed to report to the United Nations Human Rights Commission and General Assembly on all matters relating to health and human rights. The mandate of the Rapporteur is broad and includes a capacity to receive complaints alleging violations of this right and correspond with the relevant governments to clarify, invite comment and, where appropriate, remind governments of their obligations under international law.

- 5 The *World Health Organization* – the supreme international body addressing health. Although the WHO definition of palliative care has generated some debate, it has broadly been adopted and shared globally. WHO has not had staff dedicated to palliative care, although it is mentioned specifically in documentation, and it has rested mainly as an interest within the cancer division.
- 6 *The International Narcotics Control Board (INCB)*. Established by the Single Convention on Narcotic Drugs 1961, as amended by the 1972 Protocol. Its responsibility is to collect information and report on the production, manufacture, distribution and use of opioids throughout the world – licit and illicit.
- 7 *International professional bodies:*
  - (a) The International Association Hospice and Palliative Care (IAHPC): the IAHPC is an international body that aims to increase the availability and access to high quality hospice and palliative care for patients and families throughout the world by promoting communication, facilitating and providing education, and as an information resource of palliative care.
  - (b) Worldwide Palliative Care Alliance (WPCA): the WPCA is a network of national hospice and palliative care associations around the world working together to support efforts to develop hospice and palliative care services globally
  - (c) Pan – national Palliative Care Associations including the European Palliative Care Association, the African Palliative Care Association, Asia Pacific Hospice Network
  - (d) The International Association for the Study of Pain (IASP): the IASP brings together scientists, clinicians, health care providers and policy makers to stimulate and support the study of pain and to translate that knowledge into improved pain relief worldwide

## **The international human right to health**

### *An outline of International Human Rights Law*

What are human rights? Are they different to other legal rights? Is palliative care an agreed human right, either expressly or by implication? These questions are important. For only if we can achieve a clear conception of the content of any specified human right can we fully understand what it means to assert or deny the existence of that right. An understanding of what the assertion of a human right means is required to establish their truth and what they logically imply.

Human rights have as their core the recognition that all human beings have an equal moral worth and that they are the beneficiaries of human rights simply because they are human. Simplistically, they are standards of behavior that the international community or individual governments expect from themselves.

The objectives of human rights are broad. As Henkin stated they are “*Essentially ideological, idealistic, humanitarian...[whose] true and deep purpose is to improve the lot of individual men and women everywhere.*”<sup>77</sup> To Bailey the purpose of human rights “*is to define what rights are essential if all of us are to live lives in a secure and healthy environment that provides` maximum opportunities for ourselves and the communities to which we belong, and which operates on principles of justice and equality.*”<sup>78</sup> The area of law that deals with this is Human Rights law. At the international level, its premise is that nations that sign an international covenant of human rights have an obligation to respect, promote, protect, accept and fulfill the articulated human rights of its citizens.

The concept of human rights has a long history with notable articulations including the Magna Carta (1215), the Petition of Rights (1627) and the Bill of Rights (1688) in England, the Declaration of Independence (1776) and later the Bill of Rights in the United States, and the Declaration of the Rights of Man and Citizen (1789) in revolutionary France. It was, however, the catastrophic suffering of World War II that impelled the international community to declare that the protection of human rights was a matter of universal concern. The Charter of the United Nations<sup>79</sup> (1945) contained the first explicit recognition in international law that an individual was entitled to the observance of fundamental rights and freedoms. Article one of the Charter states that one of the purposes of the newly founded United Nations was that of co-operation

In 1948 the UN General Assembly unanimously adopted the Universal Declaration of Human Rights (UDHR). This document further articulated the concept of fundamental and universal human rights. The Universal Declaration was followed by two other international covenants – the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR) which further enumerated a list of fundamental human rights. Together these three documents are known as the International Bill of Rights<sup>80</sup>.

The International Covenant on Civil and Political Rights set out rights that were seen to be universally and immediately enforceable (e.g. the right to vote, the right not to be tortured, and the right to free speech). A complaint mechanism was established in the First Order Protocol to the ICCPR which allowed individuals, once they had exhausted all remedies, to make a complaint to a United Nations Human Rights Committee.

The International Covenant on Economic, Social and Cultural Rights articulated rights including the right to compulsory free education for children, the right to a fair wage, the right to safe and healthy work conditions, the right to be free from hunger and the right to health. These rights were seen to be aspirational – rights to be achieved progressively over time by each signatory nation to the maximum capacity of their available resources.<sup>81</sup>

It was recognized that the massive differences in the economic resources of countries to fulfill each of these rights meant that they could not be immediately and universally enforceable. Nations are expected to report regularly to an expert Committee on “*the measures which they have adopted and the progress made in*

*achieving the observance of the rights recognized” in the Covenant.<sup>81</sup>*

In addition to these international documents, the period since World War II has also seen the rise of a human rights advocacy around the world with formal declarations of human rights standards by regional authorities and individual nations entrenching human rights guarantees in their domestic constitutions. These will be examined later in this paper. None of the above has occurred without controversy, both practically and theoretically. Nevertheless, as Steiner and Alston state :  
*“Although the frailties of human rights as an ideal or ideology or state practice are evident, that ideal has become part of modern consciousness, a lens through which to see the world, a universal discourse, a potent rhetoric and aspiration.”<sup>82</sup>*

The discourse and structure of human rights are not static. The influence of human rights continues to grow and diffuse into international, regional and domestic legal systems. An example of that diffusion is the African Charter on Human and Peoples’ Rights. In a continent with multiple cultures and languages coupled with enormous unmet needs and inadequate resources, the Charter stands for a paradigm of the dignity of the individual and universal access to care without discrimination.

### *The international human right to health*

The international right to health or health care is articulated in a series of Declarations or Conventions from the inception of the United Nations.

The Universal Declaration of Human Rights states: *“Everyone has the right to a standard of living adequate for the health of himself and of his family...”<sup>83</sup>*

The International Covenant on Economic, Social and Cultural Rights (ICESCR) states:

- Article 12:
1. The State Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.
  2. The steps to be taken... to achieve the full realization of this right shall include those necessary for:
    - d) The creation of conditions, which would assure to all medical service and medical attention in the event of sickness.<sup>84</sup>

In addition, the right to health is articulated in several other international covenants. The International Convention on the Elimination of All Forms of Racial Discrimination (ICERD) (1965) states in Article 5(e) (iv):

State Parties undertake to prohibit and to eliminate racial discrimination in all its forms and to guarantee the right of everyone, without distinction as to race, color, or national or ethnic origin, to equality before the law, notably in the enjoyment of the following rights:

(e) Economic, social and cultural rights, in particular:



(iv) The right to public health, medical care...

The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) (1979) states in Article 11.1(f):

State Parties shall take all appropriate measures to eliminate discrimination against women in the field of employment in order to ensure...the right to protection of health...

(f) The right to protection of health...

and, in Article 12:

1. State Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on the basis of equality of men and women, access to health care services...

Article 24 of the Convention on the Rights of the Child (CRC) states:

1. State Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness...State Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services...

4. State Parties undertake to promote and encourage international co-operation with a view to progressively the full realization of the right recognized in the present article. In this regard, particular account shall be taken of the needs of developing countries.

Other potential sources of a human rights foundation to palliative care emerge from the International Covenants :

- (a) Dignity – the inherent dignity of the individual is a consistent theme of the Covenants. The preservation of patient dignity is a central tenet of palliative care.
- (b) *“No one shall be subject to...inhuman or degrading treatment”* (International Covenant on Civil and Political Rights (ICCPR) Article 7). An example here would be a nation prohibiting the availability of opioids for medical purposes.
- (c) The right *“to seek, receive and impart Information”* (ICCPR Article 19(2)). An example would be a nation deliberately withholding information on analgesia for medical purposes (including information on the medical use of opioids) or palliative care.
- (d) The right to non-discrimination and equality (ICCPR Article 26; ICESCR Article 2 (2); CRC Article 2; CEDAW Articles 11 and 12). An example would be a nation denying by law access to palliative care services to refugees or non-citizens. Arguably, a broader example would be a health system where poverty prevents access to palliative care services.

It is important to emphasize several aspects of the right to health as articulated in the Covenant on Economic, Social and Cultural Rights. Firstly, the right is not absolute, to be fulfilled immediately. As stated above, there was a clear recognition that resources varied significantly throughout the world. Rights articulated in this Covenant were seen as aspirational – rights to be achieved progressively over time to the maximum capacity of each signatory nation state. Secondly, the Covenant imposes obligations solely on governments that are signatories. It does not obligate private citizens, including health professionals. Finally, there is no appeal process or mechanism for complaint. Nevertheless, signatory nations are expected to regularly report to a Committee overseeing the Covenant. Individual complaints may also be made to two other committees that oversee covenants that include the right to health – the CEDAW and ICERD. Complaints can also be made to the Human Rights Commission.

There is no express right to palliative care in the three documents that make up the International Bill of Rights. Nevertheless, the World Health Organization defines both health and palliative care broadly. The Constitution of the WHO defines health as “*a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity*”.<sup>85</sup> Health includes the health of people with life-limiting illnesses. The provision of palliative care, where appropriate, is one part of a continuum of health care for all persons. Therefore, an argument can be made that a right to palliative care can be implied from the overall international human right to health. Also General Comment 14 (para 34) CESCR stipulates that “States are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons, ..... to preventive, curative and **palliative** health services”<sup>1</sup>

The next issue is the content of the right to palliative care within the continuum of health care for all persons. This is a vital question. For as Leary stated in the context of the overall right to health, if we are concerned that a right to health “*becomes a right in action and not just ‘a right on the books’, the content of the right must be elaborated, the duties and obligations implicit in the right must be clarified and means of implementing it must be developed.*”<sup>86</sup>

## **Rights and obligations**

At this point it is important to distinguish between two interrelated concepts – rights and obligations. Classically the holder of a right has the capacity to enforce a duty in a person or institution. The ‘other’ has a duty to fulfill that right. Indeed a basic tenet of the philosophy of rights is that a right can only exist if there is a pre-existing obligation. Under the Covenant the express responsibility for the provision of the international right to health lies with the signatory parties – individual governments. The right is vested in all human beings. The obligation is vested in all signatory nations.

Assuming that a right to palliative care can be implied from the overall international human right to health what is the content of the right and, correlatively, what is the content of the obligation?

## The content of the right to palliative care

There are several potential dangers in promoting a human right to Palliative Care. The first is one of interpretation. What exactly is the content of the right?: A right to an integrated palliative care service?, The right of access a Palliative Care in-patient unit?, The right to a “good” and “dignified” death?

A logical point of departure in this discussion is the WHO definition of Palliative Care (2002)<sup>2</sup>:

*Palliative Care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.*

While not without vigorous debate, it represents the most authoritative modern definition of palliative care. Other definitions have been subsequently suggested and, no doubt, will continue to do so as the discipline of palliative care matures. The architecture of this right will evolve. What any individual, or community of individuals, should expect from this right ought to commence with an international definition. How that expectation should be met, with what resources and at what level of care from informal to specialist level, must remain a general question with a local context.

## The content of the obligation

The content of the obligation to a purported human right to palliative care emerges from statements by the relevant international bodies: the Committee that oversees the international right to health care, the WHO and the international Palliative Care community itself through a series of statements and declarations.

### *The ICESCR Committee*

In 2000, the Committee overseeing the ICESCR issued a General Comment on the right to health, stating what it saw as the “core obligations” of all signatory nations, irrespective of resources.<sup>56</sup> They include obligations to ensure access to health facilities, goods and services on a non-discriminatory basis, to provide essential drugs, as defined by the WHO, and to adopt and implement a national public health strategy. Interpreting this Comment in the context of palliative care, this would oblige nations to ensure a universal access to services, the provision of basic medications for symptom control and terminal care, including analgesics and the adoption and implementation of national pain and palliative care policies.

In addition to the “core obligations” the Committee also enumerated obligations “of comparable priority”. These included : “...*To provide education and access to information concerning the main health problems in the community, including methods of preventing and controlling them...*” and “*To provide appropriate training for health personnel, including education on health and human rights...*” In the

context of palliative care, a “main health problem” in all countries, this would obligate governments to ensure the education of health professionals in the principles and practice of palliative care and, further, provide access to the general community to information regarding it.

### *The World Health Organization*

For palliative care, a further guide to minimum standards expected by the international community emerges from WHO recommendations. These include that all countries should adopt a national palliative care policy, ensure the training and education of health professionals and promote public awareness, ensure the availability of morphine in all health care settings and that all countries should ensure that minimum standards for pain relief and palliative care are progressively adopted at all levels of care. The symmetry is clear. In terms of palliative care, the obligations of governments, as interpreted by the Committee that oversees the international right to health, accords exactly with the recommendations of the pre-eminent world health body.

Recognizing the widely divergent capacities of countries, the WHO set out general recommendations for different resource settings. For countries with low resource settings, home-based care is probably the best way of achieving good quality care. In countries with medium level resources, services should be provided by primary health care clinics and home-based care. In high resource settings, there is a variety of options including home-based care.

### *International statements by the Palliative Care community*

Several international statements have been made, over recent years, asserting that the provision of palliative care is a universal right. Collectively they represent powerful advocacy, statements of intent and objective and provide a sense of the architecture and content of this purported right.

The Cape Town Declaration<sup>87</sup> emerged from a conference of African palliative care trainers held in South Africa in 2002. Conscious of the appalling unfolding tragedy of HIV/AIDS, the poorly met needs of cancer patients and the inadequacy of governmental response throughout the African continent, the Declaration asserted four main propositions:

1. Palliative Care is a right of every adult and child with a life-limiting disease.
2. Appropriate drugs, including strong opioids, should be made accessible to every patient requiring them in every sub-Saharan country and at all levels of care, from hospitals to community clinics and homes.
3. The establishment of education programs at all levels of the learning continuum...for all formal and informal caregivers, including medical and nursing trainees, community workers, volunteers and informal caregivers.
4. Palliative care should be provided at all levels of care: primary, secondary and tertiary. While primary care is emphasized, secondary and tertiary level teams are needed to lead and foster primary level care.

In 2004, the International Working Group (European School of Oncology)<sup>88</sup> released a position paper “*A new international framework for palliative care*”. It stated that “*there should be free access to palliative care ... for all cancer patients, as a fundamental human right.*” The ESO working group defined palliative care as:

*...the person centered attention to physical symptoms and to psychological, social and existential distress and cultural needs in patients with limited prognosis, in order to optimize the quality of life of patients and their families or friends.*

Based on that definition they proposed two further refinements which reflect the levels at which palliative care can be delivered:

*Basic palliative care* is the level of palliative care which should be provided by all health professionals, in primary or secondary care, within their duties to patients with life-limiting disease.

*Specialized palliative care* is the standard of palliative care provided at the expert level, by a trained multi-professional team, who must continually update their skills and knowledge, in order to manage persisting and more complex problems and to provide specialized educational and practical resources to other non-specialist members of the primary or secondary care teams.

The Korea Declaration emerged from the 2<sup>nd</sup> Global Summit of National Hospice and Palliative Care Associations (2005).<sup>25</sup> It stated, amongst other points, that governments must include hospice and palliative care as part of all government health policy, integrate hospice and palliative care training into the curricula of health professionals, ensure the availability and affordability of all necessary drugs, especially opioids, eliminate regulatory and legal barriers to opioid availability and strive to make hospice and palliative care available to all citizens in the setting of their choice.

Another significant international statement that has clear implications for the provision of palliative care was the Montreal Statement on the Human Right to Essential Medicines (2005).<sup>89</sup> The Essential Drug List provided by the WHO is a model policy guide for the national determination of essential drugs. Relevant to palliative care, that list includes opioids. The Statement emerged from an international workshop of governments, international agencies, civil society groups and academic institutions. The Statement expressly links the international right to health with the universal access to these essential medications. In response to a request from WHO, the International Association for Hospice and Palliative Care convened a group of palliative care experts, in 2006, to develop a list of Essential Medicines for Palliative Care<sup>90</sup>

### *Towards a transdisciplinary consensus on the content of obligation*

Synthesizing these sources (the Committee that oversees the international right to health, the WHO and the international palliative care community), a consensus on the content of the obligation on individual governments in relation to

palliative care appears to be emerging. The “core obligations” of the Committee are uniformly echoed. The international Palliative Care community has complemented those obligations with two other critical elements. Collectively they consist of:

1. The creation and implementation of palliative care policies.
2. Equity of access to services, without discrimination.
3. Availability and affordability of critical medications, including opioids.
4. The provision of palliative care at all levels of care.
5. The integration of palliative care education at all levels of the learning continuum from informal caregivers to health professionals.

### **What are the difficulties in promoting an international human right to Palliative Care?**

A threshold question is why should a rights discourse be introduced into the context of patients with life limiting illnesses? There are several responses to this question. The proposition that there is a universal right to Palliative Care has not been introduced into a legal or ethical vacuum. People, whether dying or otherwise, have a constellation of rights recognized by the law which are present and continue uninterrupted until death. These includes rights as citizens of their own country, their personal rights in property, their right to make an informed consent for medical treatment and a testamentary right to devolve their assets upon death. In addition, depending on the jurisdiction in which they live, patients with life-limiting illnesses may have a constellation of legal rights underlying both pain management and palliative care. Rights derived from the law of negligence<sup>91</sup> elder abuse<sup>92</sup> and domestic legislation<sup>93-95</sup> have emerged over the last two decades.

Internationally, the delivery of palliative care includes goals of promoting quality of life and dignity in death for patients with incurable illness. Many organizations providing palliative care promote access to such care without discrimination. It is those themes – the inherent dignity of the individual and the importance of universal accessibility without discrimination – that also underlie international human rights.

#### *The difficulties with a rights discourse*

In the modern world, the rhetoric of rights is ubiquitous. Nevertheless, a robust debate has occurred between human rights theorists regarding the role of “rights”. One argument proposed by skeptics of rights is that while rights that are enshrined in The International Covenant on Civil and Political Rights (including the right to free speech and the right to assembly) are appropriate, the rights articulated in The International Covenant of Economic, Social and Cultural Rights (including the right to health) are denuded of meaning by the extraordinary inequality of resources and the relative incapacity of struggling states to afford to provide such rights. Some theorists insist that only civil and political rights are really human rights, whereas socio-economic “rights” are merely desirable goals dressed up in the more powerful rhetoric of rights. Such critics, like Maurice Cranston, argue that if the objects of socio-economic rights were provided to everyone, it would impose outrageous costs on society.

The defenders of socio-economic rights as rights equal to, and as legitimate as, civil and political rights, state that both sets of rights are founded upon the same set of values – human dignity and decency. In addition, the ICESCR expressly recognizes the disparities in resources and encourages nation states to pursue these rights progressively. Another argument is based on indivisibility : one cannot enjoy civil and political rights if one is unable to feed oneself, read the ballot paper, or be healthy enough to go to the polling station. Rights to adequate nutrition, education and health care are all essential for realising civil and political rights.

Another controversy in rights discourse is cultural relativism: that rights may be viewed differently across cultures, and that, as the argument goes, rights are essentially a western concept. Is a “universal right to palliative care” flawed by cultural relativism? Firstly, it is important to recognize that the *manner* in which end-of-life care is provided cannot be universal - that palliative care services need to be conscious of the cultures, norms and ethos of communities in terms of illness and death. The rituals around death are a classic point of cultural expression. But while the manner of that delivery may vary, the *fact* of death is the universal. All people, irrespective of culture and resources, meet death with similar needs – physical, emotional and spiritual. How they are delivered will vary according to the circumstances.

In essence, the underlying value of a human being is not different across cultures but the expression of rights may differ between different cultures; moreover, culture is constantly changing and, in many parts of the world, we have seen a convergence of culture and respect for rights over the last decades.

And so here is another interface between a discourse in rights and public health. One of the fundamental tenets of public health is the importance of sensitivity, in the provision of any health services, to the cultural milieu of the population being served. So is it with palliative care. The relativism comes perhaps not from the advocacy of rights but the manner in which that right is fulfilled.

### *The danger of misinterpretation*

A further issue is one of misinterpretation. One possible point of misinterpretation is that the right to palliative care is seen as a right to demand any intervention or resource the patient or their family sees fit. Another point of misinterpretation is that the right implies a guarantee that the patient will have a “good and dignified” death. In many ways, the process of dying is a mystery. While we are increasingly equipped to deal with the challenges presented to us as health professionals, many aspects of that mystery are beyond our control. The right to palliative care can only mean a reasonable and proportionate response to the needs of patients. It can never mean an absolute guarantee that suffering will never occur. If an international obligation was expected at that level no government could meet it. Equally, at an individual perspective, if the right was placed at a level of perfection, no health professional could possibly fulfill their responsibility to fulfill that right. The WHO definition describes “impeccable assessment and treatment”. It describes the endeavour, not the result.

### *The danger of arguing in isolation*

The World Health Organization and multiple international statements on palliative care have recognized the stark reality – that at a global level, specialist palliative care services are rarely available and that in the majority of countries only the most basic, home-based care is being provided. Clearly, this must have implications for any discussion of palliative care as a universal right. Indeed, when one examines the provision of end-of-life services internationally, are we not talking about the provision of simply *good health care* that includes palliative care? For if we are focusing on the comfort of a patient with a life-limiting illness, surely that must include water, food, an habitable environment, warmth, bedding and sanitation as much as symptom control. Indeed, it would be artificial to separate a “right to palliative care” from a general right to health, housing, water and sanitation. All are interconnected. All determine good health, even and including at the end of life. That interconnectedness was made express by the General Comment on the Right to Health. There, the Committee stated the right to health includes not only appropriate health care but also water, adequate sanitation, food, housing and health-related education.<sup>1</sup> Similarly that interconnectedness is entirely consistent with the philosophy underpinning the definition of palliative care as the “total care” of the person.

### *The tension between public health imperatives and human rights*

Another potential limitation on human rights is the difficulty in achieving the optimal balance between respecting human rights and the accomplishment of public health objectives. An example, often cited, is the approach of a national health system to control an outbreak of an infectious disease. Issues of compulsory testing, quarantining individuals, limitations on travel and placing strict limitations on the manner treatment is delivered (eg. only through directly observed therapy) all may potentially conflict with human rights. Certainly the International Covenant on Civil and Political Rights expressly mentions public health as a valid justification for restricting such rights as freedom of movement and expression, and rights to assembly and association.<sup>96</sup>

The current policy on access to antiretroviral medications (ARVs) in the Republic of South Africa provides another example of this tension. Necessarily that tension will be exquisite in a country that has an obligation to provide health care that derives from both an international obligation (under the ICESCR) and its own domestic constitution. Theoretically, access to ARVs is universally available. However, concerns about the risk of the development of viral resistance because of a less than universal compliance with ARV treatment, necessitated a public health policy of delaying the commencing of ARVs for those patients deemed to at risk of poor compliance (those that miss clinic appointments in the treatment preparedness phase, those who are substance abusers and those with untreated depression). Arguably such a policy is discriminatory and contrary to the International Covenants which include access to health. In response, the covenants recognise the right to health is relative, not absolute. Indeed in the midst of a pandemic the public health imperative of reducing the risk of viral resistance overrode the rights – based argument.



Clearly these are difficult and challenging cases and various writers have urged a sense of mutual respect between the public health and human rights communities.<sup>97</sup> As the editors of *Health and Human Rights – A Reader* stated :

*“There is a need for genuine collaboration and open communication between the public health community and the human rights community. This is a substantial challenge, and one that requires careful attention to often unspoken assumptions and differences in attitude and language; it truly requires a transdisciplinary effort...Ultimately, the common goal of human well-being – through both public health and human rights strategies – will lead us forward.”<sup>98</sup>*

### *Enforcement of the right*

Further significant limitations to the international human right to health, as articulated in the ICESCR, are the issues of adherence and enforcement. The Covenant prescribes that all signatory nations report regularly to the Committee overseeing the Covenant describing the progress they are making in the realization of the rights contained in the Covenant. The Committee has no powers of enforcement or sanction. So, if for instance a country legislated that opioids would be only available for medical purposes to the military and not civilians in that country, causing a catastrophic impact on palliative care services, the Committee could not force that country to repeal that law.

However, while the Committee does not have an enforcement capacity, it does have a moral and persuasive one. To that end, the Committee could reinforce statements already made by other international bodies including the WHO and the International Narcotics Control Board recommending that countries liberalize opioid laws and report the true opioid requirements of their population. Furthermore, the Committee could remind signatory nations of their core obligations with respect to palliative care.

Another significant agent for persuasion, education and advocacy that has emerged in recent years is the office of the Special Rapporteur of the Human Rights Commission on the right to health. According to its founding resolution the Special Rapporteur can receive complaints alleging violations of this right and correspond with the relevant governments to clarify, invite comment and, where appropriate, remind governments of their obligations under international law. Finally, there is a recourse of complaint to Committees overseeing the CEDAW and ICERD and, where appropriate, the UN Human Rights Commission itself.

### **History of a human rights discourse in Palliative Care**

Margaret Somerville is a pre-eminent scholar of medical law. She is the Professor of Law and Professor in the Faculty of Medicine at McGill University in Montreal. Her work in this area has been seminal. Indeed, it is to her writings that any search for the theoretical foundation of the statement “palliative care is a human right” should commence. In 1982, she opined that the unreasonable failure to provide pain-relief treatment constituted negligence.<sup>99</sup> In 1992, she extended this

argument to incorporate an approach based on human rights. Commencing with the concept of suffering Somerville argued that there is a “common thread linking respect for persons” with “respect for their human rights, medicine, ethics and law. Each one, whether a value, activity, undertaking, or discipline, involves trying to relieve human suffering...”<sup>100</sup> Indeed, “to leave patients in avoidable pain and suffering should be regarded as a serious breach of fundamental human rights.”<sup>101</sup> Somerville reached this conclusion by linking all disciplines:

*“We should recognize the following principles : the informing principle of human rights is one of respect for persons; respect for persons is a universal requirement that, in some societies, we implement through the concept of legal rights; the concept of respect for persons is inextricably linked to that of human ethics, as well as, ideally, to that of legally enforceable human rights; and to leave people in avoidable pain and suffering is to show them great disrespect for them and to breach fundamental requirements of human rights and human ethics”.*

Later Somerville more expressly linked human rights with end of life care:

*...to leave [dying people in unbearable pain] that way when their pain could be relieved would be a breach of the most fundamental principles of human rights and a grave affront to respect for persons and their dignity... Nowhere are the concepts of an ethic of care, human ethics, human rights, and human responsibilities more important than in relation to human dying...<sup>10</sup>*

In recent years the association between palliative care and human rights has entered the discourse. Several international statements have been made asserting that the provision of palliative care is a universal right. In 2000, a Standing Committee of the Canadian Senate proclaimed that end of life care was a right of every citizen.<sup>102</sup> In 2002, the Cape Town Declaration stated that “*Palliative care is a right of every adult and child with a life-limiting disease*”.<sup>87</sup> In 2003, the European Committee of Ministers adopted a Recommendation which stated, in part, “*palliative care is ... and inalienable element of a citizen’s right to health care*.”<sup>103</sup> In 2004, the International Working Group (European School of Oncology) released a position paper on palliative care internationally. It stated that “*there should be free access to palliative care ... for all cancer patients, as a fundamental human right*”.<sup>88</sup> In 2005, the second Global Summit for National Hospice and Palliative Care Associations agreed on the Korea Declaration which stated that “*Governments must ... make access to hospice and palliative care a human right*.”<sup>25</sup> Pope Benedict XVI on the 15<sup>th</sup> World Day of the Sick (2006) stated “*This (palliative care) is a right belonging to every human being, one which we must all be committed to defend*.”<sup>71</sup>

These statements emerge in an era where human rights are being repeatedly articulated, promoted and debated. In the context of health, a rights discourse highlights a need. It uses a language of universality. It speaks with a moral voice. It emphasizes an obligation but cannot compel compliance. It is a beginning but certainly not an end.

## Other legal foundations to the provision of Palliative Care

### *Regional human rights instruments*

In addition to the international human rights instruments described above several regions in the world have charters that articulate a right to health care. They include the European Social Charter<sup>104</sup>, the African Charter on Human and Peoples' Rights<sup>105</sup>, the African Charter on the Rights and Welfare of the Child<sup>106</sup> and the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights, known as the "Protocol of San Salvador".<sup>107</sup> There are no regional human right instruments in the Asia-Pacific region.

Other regional instruments offer indirect protections through other health-related rights, include the American Declaration on the Rights and Duties of Man, the American Convention on Human Rights, the Inter-American Convention on the Prevention, Punishment and Eradication of Violence against Women and the European Convention for the Protection of Human Rights and Fundamental Freedoms and its protocols.

Regional human rights commissions overseeing these instruments have shown a willingness to find in the right to health a duty on individual governments to provide specific services.<sup>108-110</sup> That has implications for the provision of all health care services, including palliative care. We shall return to this later.

### *National constitutions*

Over 60 nations have constitutions that include a right to health or health care.<sup>111</sup> None expressly state a right to palliative care.

In the cases of *Washington v Glucksberg* (1997)<sup>112</sup> and *Vacco v Quill* (1997)<sup>113</sup> the US Supreme Court expressed sympathy for a constitutional right to adequate palliative care, including pain management. Justice Breyer stated that individual states that refuse to address these issues would "infringe directly upon...the core of the interest in dying with dignity" which involves "*medical assistance and the avoidance of unnecessary and severe physical suffering.*"<sup>112</sup>

In South Africa two cases involving a constitutional right to health are illustrative of the extent and limits of such rights in any given setting, especially in the context of limited resources. Section 27 of the South African Constitution states:

1. Everyone has the right to have access to
  - a. health care services, including reproductive health care;
  - b. sufficient food and water; and
  - c. social security, including, if they are unable to support themselves and their dependants, appropriate social assistance.
2. The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realization of each of these rights.

### 3. No one may be refused emergency medical treatment.

In *Minister of Health v Treatment Action Committee* (2002)<sup>114</sup> the Constitutional Court of South Africa held that, in the circumstances of the “incomprehensible calamity” of the HIV/AIDS pandemic, the constitutional right to health required the government to devise and implement a comprehensive program to provide access to anti-retroviral medication to pregnant women and their newborn children. Conversely, the same court in *Soobramoney v Minister of Health (Kwazulu-Natal)* (1997) held that the constitutional right to health was not absolute and “*that there will be times when this requires [the state] to adopt a holistic approach to the larger needs of society rather than to focus on the specific needs of particular individuals in society.*”<sup>115</sup>

Another example of the interpretation of a constitutional right to health is the judgement of the Supreme Court of Venezuela in *Cruz Bermudez, et al v Ministerio de Sanidad y Asistencia Social*.<sup>116</sup> The plaintiffs, who had HIV/AIDS, argued that the government had violated their rights to life, health care and access to scientific advances by not providing them with antiretroviral medications. The Ministry of Health rejected the plaintiffs’ argument. It did so mainly on the basis of economics. It argued that the government could not afford to fund ARVs to all persons living with HIV/AIDS. The Supreme Court looked to the right to health care drawn from both the national constitution and the ICESCR, of which Venezuela was a signatory. The Court held in favour of the plaintiffs. To reconcile health imperatives and budgetary constraints the Court found that the Ministry of Health had mechanisms available to it under domestic law to seek additional funds for this purpose. The *Burmudez* case is important for several reasons. Firstly, it is an example of a senior appellate court refusing to accept a statement of financial constraint as a reason, in itself, of a government’s lack of compliance with a right to health care. Secondly, the Court expanded the effect of its judgement by stating it applied not only to the individual plaintiffs but to all persons living with HIV/AIDS in the country. And finally, as stated above, it is an example of a Court turning to a right to health care in both its domestic and international articulation to find the source of national government obligations.

### *Statutory regimens*

If the ultimate objective of patient advocates is to establish a right to Palliative Care and pain management that is both unambiguous and legally enforceable, the best framework for such a right is, arguably, a statutory one. Pain management is a central element of palliative care and access to pain control has been the aspect of palliative care that has received attention from legislatures. There are several models for a statutory framework. The first is an explicit statutory statement of the right to pain relief. The *Medical Treatment Act* (1994) of the Australian Capital Territory states “...*a patient under the care of a health professional has a right to receive relief from pain and suffering to the maximum extent that is reasonable in the circumstances*” and, further, “*in providing relief from pain and suffering to a patient, a health professional shall pay due regard to the patient’s account of his or her level of pain and suffering.*”<sup>117</sup>

The second model is a statutory protection for doctors. An example is contained in the South Australian *Consent to Medical Treatment and Palliative Care*

Act (1995) that protects medical practitioners, in their care of terminally ill patients, from any criminal or civil liability if they administer treatment “*with the intention of relieving pain and distress*” providing such treatment is given with consent, in good faith, without negligence, and in accordance with “*proper professional standards of palliative care.*”<sup>74</sup>

The third model is a wider package of statutory requirements for pain management and education. An example is a California statute<sup>76</sup> that imposed three obligations. The first is a duty for doctors who refuse to prescribe opioids to a patient with severe chronic intractable pain to inform the patient that there are physicians who specialize in the treatment of such pain. The second is a duty of all doctors to complete mandatory continuing education in pain management and the treatment of the terminally ill. The third is the requirement of the California Medical Board to develop a protocol for investigation of complaints concerning the under treatment of pain and to include in its annual report to the state legislature a description of actions relating to that practice.

These recently enacted statutes in Australia and California are models for any future legislative activity. Indeed, they offer professional or lay groups a powerful agenda to lobby legislators to reform local statutes. The strongest possible statutory foundation to support best practice in pain relief would involve core aspects of the above legislation. The essential components of such legislation are:

1. Reasonable pain management is a right.
2. Doctors have a duty to listen to and reasonably respond to a patient’s report of pain.
3. Provision of necessary pain relief is immune from potential legal liability.
4. Doctors who are neither able nor willing to ensure adequate analgesia must refer to a colleague who has this expertise.
5. Pain management must be a compulsory component of continuing medical education.

In the USA the Wisconsin Pain Initiative, a WHO Demonstration Project and the Mayday Project have promoted state legislative reform, especially in the availability of opioids for medical purposes and the protection of physicians in their therapeutic use of opioids. As a necessary adjunct to these reforms the Federation of State Medical Boards have developed model guidelines for the use of state medical boards in the overseeing of such opioid use.<sup>117</sup> In January 2003 the Pain and Policy Studies Group, Wisconsin launched an initiative to help improve the availability of opioid pain medications in eastern Europe and Romania.<sup>118</sup> The group have also been active in Africa, in collaboration with the African Palliative Care Association and the National Hospice Palliative Care Organisation (USA) holding multinational advocacy workshops in Uganda, Ghana and Namibia to influence legislation and improve access to essential pain medication, including opioids.<sup>119</sup>

A remarkable legislative reform came in Uganda in 2004. The national government recognized a simple fact. Like so many countries, especially those with limited resources and scarce medical personnel, palliative care patients often had great difficulty in accessing opioid analgesics. A regulation was made by the Minister of Health authorizing nurses with palliative care certificates to prescribe narcotic analgesics “as part of the palliative care of patients.”<sup>120</sup>

In terms of a formal basis for palliative care more broadly one model is state sanctioned Charters of Patient Rights. These may or may not be enshrined in legislation. In South Africa the national Department of Health has proclaimed a National Patients' Rights Charter. It states that "[e]veryone has the right to access to health care services that include :

(c) provision of special needs in the case of .... persons in pain, persons living with HIV or AIDS patients;...

(e) palliative care that is affordable and effective in cases of incurable or terminal illness".<sup>121</sup>

### *Public interest litigation*

An example of litigation based on the public interest in better pain management occurred in India in 1998. On behalf of the nation's cancer patients and Drs. SR and RB Ghooi, the All India Lawyers Forum for Civil Liberties filed a public interest suit in the Delhi High Court. They requested a court order to state governments to simplify the procedures for the supply of morphine for cancer patients. The applicants were successful. The Court ordered that every application for licenses or supplies of morphine must be attended to expeditiously. State governments were asked to allot morphine without delay and aggrieved persons were granted the freedom to approach the Court if dissatisfied. Again, a rights-based discourse entered the final judgment: "*It is a right of patients to receive any medication they need, particularly morphine. Any official standing in the way will be viewed very seriously by the court.*"<sup>122</sup>

### *Negligence and pain*

As stated above Margaret Somerville has long argued that the unreasonable failure to provide adequate pain relief constitutes negligence. There is a solid foundation for this assertion. The emphasis in law regarding medical negligence is the taking of reasonable care in all aspects of patient management. There are several aspects of pain relief where doctors may potentially breach their standard of care: an unreasonable failure to take an adequate history of pain from the patient (*Giurelli v Girgis*)<sup>123</sup>; an unreasonable failure to adequately treat pain (*Estate of Henry James v. Hillhaven Corporation*)<sup>124</sup>; and in the context of uncontrolled pain, an unreasonable failure to consult an expert in pain management (a general principle of referral is stated in *Dillon v LeRoux*<sup>124</sup> and *O'Shea v O'Sullivan*)<sup>125</sup>.

Somerville also points to what she refers to as "systems negligence" when health care institutions fail to take reasonable steps to establish systems that offer patients ready access to pain management.<sup>101,126</sup>

### *Negligence and Palliative Care*

Similarly, a right to reasonable palliative care may derive from the law of negligence. The standard of care in palliative medicine may, in addition to the above areas of pain management, also include taking an adequate history, examining the patient, addressing symptoms and, where reasonable, referring on to other experts.

The unreasonable failure to do any of the above may constitute a breach of the doctor's duty of care to a patient with a life-limiting illness. It is important to note that the law of negligence consistently requires of doctors only what is reasonable in the circumstances of the case. In many jurisdictions the courts will be guided by current accepted professional standards shown by, amongst other things, authoritative guidelines in Palliative Care practice.

### *Elder Abuse*

Another area of jurisprudence that may expand is the law's examination of pain management and palliative care in the geriatric setting. The question of when inadequate pain management of an elderly person constitutes elder abuse was argued in *Bergman v Chin*<sup>127</sup> with reference to California's Elder Abuse and Dependent Adult Civil Protection Act.<sup>128</sup> Mr. Bergman was an 85-year-old man who was admitted to hospital with lower back pain. Within days he was diagnosed with metastatic lung cancer and multiple bone metastases. Throughout his six-day admission the patient consistently rated his pain intensity in the 7 to 10 range (on a scale of 0 to 10), and on the day he was discharged the level was 10. He died at home 4 days later. Although the doctor testified that he followed established protocols in prescribing pain medications, the court ruled that the treatment fell within the statutory definition of elder abuse.

### *Criminal law*

Criminal law is relevant to a discussion of pain relief: is it possible for a health professional to be criminally culpable in giving analgesia? For that liability to be found the court would need to find beyond reasonable doubt that the health professional intended to shorten the life of the patient. While some jurisdictions allow euthanasia in some circumstances, the vast majority of pain and palliative medicine is based on a measured, proportionate response to pain in which the intention is to relieve pain and not to accelerate death. Traditionally, the doctrine of double-effect has been applied here: the criminal law concentrates on intention, so that if the intention of the doctor is to relieve pain and not to shorten the life of the patient then the act of prescribing and dispensing analgesia is not a criminal act.<sup>129</sup>

Some jurisdictions, including three in Europe (the Netherlands, Belgium and Switzerland) and one in the United States (Oregon) have legalized euthanasia and/or physician-assisted suicide. Clearly the interface of pain management and the criminal law in those jurisdictions will reflect the precise wording of the relevant legislation and criminal code.

## **The strategic considerations behind casting access to Palliative Care as a human right**

Over recent years the right to the provision of palliative care has been repeatedly articulated. Why is this occurring? What factors have led to this point in the maturation of palliative care? What is the rationale behind these statements?

What purpose do they serve? And finally, in practical terms what strategies may emanate from casting access to palliative care as a human right?

The reasons for the articulation of Palliative Care as a human right in these statements and declarations are multifactorial. Certainly, a critical issue has been the acknowledgement that the care of people with life limiting conditions throughout the world is neglected, under funded and under-resourced. There is a growing sense of urgency that these deficits are intolerable, that we have within our capacity to treat multiple symptoms and can ensure people die in comfort and dignity and that governments need to take this aspect of health more seriously. Indeed, for many, that sense of urgency reaches levels of anger and professional rage that millions die with hopelessly inadequate symptom control. And, given that dying is a universal experience, it is not surprising that, as a point of advocacy, palliative care is described as a fundamental human right.

But beyond advocacy there are two other consequences of this statement: the first is one of intention; the second strategic. By stating that the provision of Palliative Care is a human right so expressly, the signatories of the Cape Town and Korea Declarations declared to their members and the international community that Palliative Care is no longer a luxury of resource-rich nations, it is a universal right with an international responsibility. The second consequence is that it places the provision of Palliative Care squarely within another discourse – international human rights. That discourse has its own history, structure and mechanisms. By doing so, it broadens the capacity of national and international Palliative Care communities to argue that excellence in end-of-life care is more than simply good and compassionate medicine; it has an equal foundation in international human rights law. This, in turn, opens up an entirely separate avenue for advocacy for Palliative Care, based on the minimum obligations on individual countries in its provision.

## **Human Rights mechanisms that could be used to advance access to Palliative Care**

### *International*

A right to health is articulated in the International Covenant on Economic, Social Cultural Rights. Although the Committee that oversees that Covenant does not have a complaint mechanism or a power of enforcement it does have the power of moral persuasion. In addition it has an expectation, obligated in the Covenant, that nations will periodically report to it on their progress in fulfilling the enumerated rights. Most nations have signed this Convention. Before the international community they have endorsed this Covenant, including a right to health, which includes palliative care. In 2000, this Committee has set out the “core obligations” of signatory nations, irrespective of resources, to comply with a right to health care.

A strategy that would be appropriate and flow from the above would be a submission to the Committees by the international Palliative Care community:

- (i) outlining the specific national and international issues involved in Palliative Care



- (ii) inviting it to expressly question signatory nations on their compliance with the “core obligations” relating to palliative care
- (iii) inviting it to make a statement endorsing Palliative Care as part of health care, the core obligations expected of nations and, as an international body, endorsing the work of the WHO and the International Narcotics Control Board.

There are two further channels of submission and advocacy. The first is a recourse of complaint to the UN Human Rights Commission. The second is the office of the Special Rapporteur to the UN Human Rights Commission on the right to health. The mandate of the Rapporteur is very broad and includes a capacity to receive complaints alleging violations of this right and correspond with the relevant governments to clarify, invite comment and, where appropriate, remind governments of their obligations under international law.

Another possible strategy at the international level, using the international right to health as its foundation, is the promotion of an International Convention on Pain. The World Health Organization has the power to make international treaties (exercised only once in the Framework Convention on Tobacco). Obviously, therefore, the formation of such a Convention would require the leadership of the WHO. The objective of such a Convention would be to commit individual nations to balanced opioid policies and fulfilling their international obligations in the provision of pain and palliative care services. Opioid policies have both national and transnational dimensions and reforms have been piecemeal at best. An international convention would unify this model and advance the process of prioritizing palliative care in the many countries that remain without policies. Other significant bodies that would need to be part of this process would be the International Narcotics Control Board, the International Association for the Study of Pain, the International Hospice and Palliative Care Association and the Worldwide Palliative Care Alliance.

### *Regional human rights instruments*

As stated above the right to health is recognized in various regional human rights instruments. To what extent could they be employed to promote the universal access to palliative care?

As a source of advocacy they are important instruments to argue before nations who are signatories to these instruments. How seriously do individual countries take their commitments to human rights? Reminding those nations that they are signatories to *both* international and regional instruments articulating a right to health care is a critical first step.

But beyond advocacy, to what extent are human rights (including the right to health) in these regional instruments judiciable? In each there is a mechanism for adjudicating disputes. In terms of a regional right to health care examples are few but worth exploring. In *SERAC and CESR v Nigeria*<sup>130</sup> the African Commission on Human and Peoples’ Rights found that the Federal Republic of Nigeria had, in relation to the activities of oil companies in the Niger Delta, violated the right of the Ogoni people to enjoy the best attainable standard of physical and mental health. In addition, regional mechanisms have found breaches of other health-related rights. In

*ICJ v Portugal*<sup>131</sup>, the European Committee of Social Rights examined the issue of child labor in Portugal. In finding a breach of the European Social Charter, the Committee expressed concern that a significant number of children worked in sectors which “may have negative consequences on the childrens’ health as well as their development.” In *Lopez Ostra v Spain*<sup>132</sup>, the European Court of Human Rights found that environmental harm to human health may amount to a violation of the right to a home and family and private life. An example of a regional body being prepared to take into account the right to health was an admissibility decision in *Jorge Odir Miranda Cortez et al. v El Salvador*<sup>133</sup>, where the Inter-American Commission on Human Rights held that while it was not competent to determine violations of Article 10 (the right to health) of the Protocol of San Salvador, it would “take into account the provisions related to the right to health in its analysis of the merits of the case, pursuant to the provisions of Articles 26 and 29 of the American Convention.”

Based on this, albeit limited, jurisprudence what situation in the context of Palliative Care could justify a challenge to a regional human rights commission? One example could be a nation with draconian opioid laws that denies the entire population, or a section of the population access to opioids for medical purposes, including end of life care. Another would be where a nation neglects to provides any services for people with life – limiting illness. Arguably, those nations violate their citizens’ right to adequately Palliative Care within an overall right to health.

### *National constitutions*

As stated above a significant number of nations have a right to health enshrined in their constitution. What strategies relevant to the promotion of Palliative Care could flow from these constitutional guarantees? As with every aspect of the provision of health, a national government could be challenged for inadequately fulfilling that right. In this context that challenge could lie in its failure to provide Palliative Care services or medicines for symptom control.

A critical factor in the interpretation of any constitutional right to health (and indeed all cultural, economic and social rights) is whether it is expressly limited by resource availability. In short, is the right absolute or relative? We have discussed an example earlier in this paper. Under the South African Constitution the right to health care is limited: “*The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realization of each of these rights.*”<sup>134</sup> In *Soobramoney v Minister of Health (Kwazulu-Natal)* the Court held that the South African constitutional right to health was not absolute and “*that there will be times when this requires [the state] to adopt a holistic approach to the larger needs of society rather than to focus on the specific needs of particular individuals in society.*”<sup>135</sup> That section of the South African Constitution which refers to “available resources” needs to be read together with section 7(2) which requires the state to “*respect, protect, promote and fulfil the rights in the Bill of Rights*”. And so if the state took *unreasonable measures* (by, for instance allocating large funds to areas of the health budget that were not essential and a miniscule amount to Palliative Care in the context of the pandemic) it could be challenged.<sup>135</sup>

In a constitutional framework that constrains cultural, social and economic rights (such as the right to health) by resource availability (or as rights to be achieved

progressively) a key argument for any challenge in the context of palliative care would be an economic one. What is the cost of providing adequate Palliative Care services throughout a country? What are the costs of providing essential medicines, including opioids, to those with life-limiting illnesses? How can governments, burdened by impoverishment and national debt hope to respond? One answer to this conundrum comes from the recommendations of the World Health Organization for the provision of palliative care in different resource settings, from home-based to a broader range of options. For a government to state that it simply could not provide Palliative Care services would be a false rejection of the argument of universal access. All governments can do something. Legislating for all health care workers to receive training in palliative care is an achievable first step for any government.

*The potential for human rights organizations to become involved in advocating for access to palliative care: some recommendations*

In summary, therefore, there are multiple potential opportunities for human rights organizations, especially liaising with the IASP, IAHP, WPCA and pan-national and national Palliative Care Associations, to advocate in this area including:

- (a) Submission to the Committees overseeing the international right to health especially the International Covenant on Economic, Social and Cultural Rights;
- (b) Submission to the Special Rapporteur to the UN Human Rights Commission on the right to health on the provision of palliative care;
- (b) Submissions to national governments to comply with their “core obligations” under the Convention to provide health care in the context of Palliative Care;
- (c) Assisting individual governments in this process of compliance, including opioid law reform, by facilitating liaison with expert bodies such as the International Association for the Study of Pain, the International Hospice and Palliative Care Association, the Wisconsin Pain and Policy Study Group;
- (d) Where relevant, submissions to national governments (and departments of health within those governments) reminding them that they are signatories to regional human rights instruments that include a right to health care, which includes palliative care;
- (e) Where relevant, submissions to individual governments that their national constitution contains a right to health or health care, that this includes palliative care and that even within a resource limited environment many practical steps can be taken to alleviate the suffering of people with life-limiting illnesses.
- (f) Working with professional bodies to promote to Medical and Nursing schools the importance of education of Palliative Care principles and the fundamentals of opioid use, symptom control and end-of-life care.

## **Are human rights the only answer?**

Famously, Ronald Dworkin stated that “rights are trumps” - that the declaration of a right is compelling and irresistible. This is not the case here. In the context of a Palliative Care and human rights there are clear weaknesses. A less than universal acceptance of a rights discourse, the lack of an instrument to absolutely enforce compliance with international, regional and national human right norms, the necessity to recognize, as does the WHO itself, that not all countries can provide every possible option in the manner palliative care is delivered, all place limitations on the dividend that human rights can deliver. Clearly then human rights are not the only answer. They are, however, one of a constellation of approaches to improving the care of people with life-limiting conditions. The inspiration and advocacy of local champions, the pursuit of research in pain and symptom management, the refusal by health professionals to accept that appalling care needs to remain appalling, the work of Palliative Care associations in the promotion of their work to health policy makers, the remarkable leadership and practical work done by the Pain Policy Study Group (Wisconsin) in opioid law reform in many countries, all have and will continue to effect great progress. All bring benefit. Equally, all could employ a human rights approach as at least one foundation to their work, advocacy and planning. Human rights provide both a theoretical underpinning and a practical avenue for challenge and change.

## **Conclusion**

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 made between health and human rights, palliative care and public health. A universal human right to palliative care may be implied from the international right to health care. However, that right should not be seen in isolation. All possible measures to ensure that relief is met must be present – including adequate housing, nutrition, water and sanitation. Overarching themes of dignity and non-discrimination are common to both palliative care and international human rights. 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. While an approach based on human rights has clear limitations it is, nevertheless, a concept that serves to coalesce a broad medical, moral and legal imperative – that the care of patients with life-threatening illness is a fundamental responsibility of governments, societies and health professionals.

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