
ACCESS TO PALLIATIVE CARE

A NEGLECTED COMPONENT OF THE RIGHT TO HEALTH

A Report on the Human Rights Council Side Event

GENEVA

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On June 6, 2011, in conjunction with the 17th session of the Human Rights Council meeting in Geneva, Human Rights Watch (HRW), the Open Society Public Health Program's International Palliative Care Initiative (IPCI) and Law and Health Initiative (LHI) organized a panel discussion on "Access to Palliative Care: A Neglected Component of the Right to Health." The event was cosponsored by the Permanent Missions of Brazil and Uruguay, as well as the African Palliative Care Association (APCA), HelpAge International, International Association for Hospice and Palliative Care (IAHPC), Pallium India, Joint United Nations Program on HIV/AIDS (UNAIDS), Worldwide Palliative Care Alliance (WPCA).



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BACKGROUND

OVERVIEW OF THE HUMAN RIGHTS OBLIGATIONS TO PALLIATIVE CARE AND PAIN TREATMENT

Palliative care is highly effective in relieving pain and other physical symptoms and can improve adherence to medications. It should be delivered with curative treatment that begins at the time of diagnosis and continues throughout the disease trajectory using a holistic approach that improves the quality of life for patients and their families by addressing not only pain and symptoms, but also psychosocial, legal, and spiritual problems associated with life-threatening illness. Consequently the provision of palliative care, where appropriate, is one part of a continuum of health care for all persons faced with life-limiting illnesses. A right to palliative care can be implied from the overall international human right to health¹, as well as freedom from torture and cruel, inhuman, and degrading treatment.²

Some examples of these obligations include:

- Article 12 of the International Covenant on Economic, Social and Cultural Rights (on the right to the highest attainable standard of health) and article 7 of the International Covenant on Civil and Political Rights (on the right to freedom from torture and cruel, inhuman, and degrading treatment) **require States to take steps to ensure patients have access to palliative care and pain treatment.**
- The United Nations (UN) Committee on Economic, Social and Cultural Rights has affirmed the importance of **“attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity.”**³
- Access to essential medicines, as defined by the World Health Organization (WHO) Action Programme on Essential Drugs, is part of the minimum core content of the right to the highest attainable standard of health. **Fourteen palliative care medications are currently listed on the WHO Model List of Essential Medicines and the WHO Model List of Essential Medicines in Children.** The UN Special Rapporteur on Torture, Cruel, Inhuman or Degrading Treatment or Punishment has stated that **“the de facto denial of access to pain relief, if it causes severe pain and suffering, constitutes cruel, inhuman or degrading treatment or**

¹ Frank Brennan, *Palliative Care as an International Human Right* J Pain Symptom Manage 2007; 33:494-499

² Human Rights Council, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, Juan Mendez, A/HRC/22/53, February 1, 2013, www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf.

³ Committee on Economic, Social and Cultural Rights, *General Comment 14*, para. 25.

punishment.”⁴

- Both the UN Special Rapporteurs on Health and Torture have explained, **“The failure to ensure access to controlled medicines for the relief of pain and suffering threatens fundamental rights to health and to protection against cruel, inhuman and degrading treatment.”**⁵

For more information, view the Open Society Public Health Fact Sheet on Palliative Care as a Human Right:

www.opensocietyfoundations.org/publications/palliative-care-human-right-fact-sheet

⁴ Human Rights Council, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, Manfred Nowak, A/HRC/10/44, January 14, 2009, para. 72. daccessdds.un.org/doc/UNDOC/GEN/G09/103/12/PDF/G0910312.pdf.

⁵ Nowak M and Grover A, Special Rapporteur on Torture and Special Rapporteur on the right to the highest attainable standard of health, Letter to Her Excellency Ms. Selma Ashipala-Musavyi, Chairperson of the 52nd Session of the Commission on Narcotic Drugs, December 10, 2008, p. 4. www.hrw.org/sites/default/files/related_material/12.10.2008%20Letter%20to%20CND%20fromSpecial%20Rapporteurs.pdf.

CONTEXT

“The pain was so bad that my whole body seemed to break. We would call the ambulance every two to three hours because I could not stand the pain. It was intolerable to live like that.”

– Vasili, a sixty six year old cancer patient from Ukraine

People facing life-threatening illnesses or nearing the end of life are often deeply vulnerable. Like Vasili, they may suffer from severe physical pain. They likely also harbor fears around death or incapacitation, anxiety about the fate of their loved-ones, and feelings of guilt because of the burden they have become to their families. At the same time, healthcare systems frequently abandon them as hopeless, compounding their suffering. Many of these people face both physical and mental pain so severe that, like victims of torture, they would do anything to stop it, including taking their own lives.

Much of this anguish, however, is unnecessary. Palliative care, a health service that, in the poignant words of one of its founders, focuses on “adding life to the days rather than days to the life” is highly effective in both managing pain and treating patients’ physical symptoms. It also provides psychological, social, and legal support for patients and families, helping them cope with their fears and anxieties, as well as addressing spiritual and legal questions.⁶ Palliative care can be provided at home, in community health centers, in residential hospices, or in hospitals, and it can be delivered at low cost.

Yet, availability of palliative care globally is patchy and largely inadequate, as health policy makers and doctors tend to prioritize prevention and curative treatment over quality-of-life care.

Countries have specific palliative care obligations under the right to health framework set by the UN Committee on Economic, Social and Cultural Rights, including: developing health policies that address the needs of patients with incurable diseases; ensuring that healthcare providers are trained in palliative care; and providing access to essential medicines.⁷

⁶ According to the World Health Organization definition, “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, psychosocial and spiritual.”

⁷ UN Committee on Economic, Social and Cultural Rights, "Substantive Issues Arising in the Implementation of the International Covenant on Economic, Social and Cultural Rights," General

But research by Human Rights Watch and hospice and palliative care organizations suggests that many countries are not meeting these obligations. In 2010, the Economist Intelligence Unit found that there “are vast populations for whom end-of-life coverage extends to only a fraction of those in need.”⁸ And the World Health Organization estimates that 5.5 million patients with advanced cancer suffer from moderate to severe pain without access to appropriate treatment.⁹

As the world population ages and the prevalence of cancer and other non-communicable disease continues to rise in low and middle income countries, the need for palliative care will continue to grow rapidly. Human Rights Watch (HRW) and the Open Society Foundations (OSF) organized a side panel at the Human Rights Council in Geneva on June 6, 2011, to address the rights and needs of this extremely vulnerable population. Entitled “Access to Palliative Care: A Neglected Component of the Right to Health,” the panel was cosponsored by the Permanent Missions of Brazil and Uruguay, as well as the African Palliative Care Association (APCA), HelpAge International, International Association for Hospice and Palliative Care (IAHPC), Pallium India, Joint United Nations Program on HIV/AIDS (UNAIDS), Worldwide Palliative Care Alliance (WPCA).

PANEL OBJECTIVES

The panel discussion focused on human rights mechanisms to address global challenges that hamper access to pain and palliative care treatment and had five main objectives:

- Follow up on the conclusions of the UN Committee on Economic, Social and Cultural Rights and of the Special Rapporteur on Torture, Cruel, Inhuman or Degrading Treatment or Punishment and give more visibility to the obligations of States;
- Mainstream the understanding that:
 - palliative care is an integral part of the full implementation of the right of everyone to the highest attainable standard of physical and mental health, and
 - failure to ensure access to treatment for severe pain may constitute cruel, inhuman or degrading treatment;
- Engage in dialogue on best practices to be replicated in a human rights approach to palliative care;

Comment No. 14, The Right to the Highest Attainable Standard of Health, E/C.12/2000/4 (2000), para. 43. [www.unhcr.ch/tbs/doc.nsf/\(Symbol\)/40d009901358b0e2c1256915005090be?Opendocument](http://www.unhcr.ch/tbs/doc.nsf/(Symbol)/40d009901358b0e2c1256915005090be?Opendocument)

⁸ “The quality of death: Ranking end-of-life care across the world,” Economist Intelligence Unit, 2010. graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf (accessed November 28, 2012).

⁹ “Briefing Note: Access to Controlled Medicines Program,” World Health Organization Briefing Note, 2009. www.who.int/medicines/areas/quality_safety/ACMP_BrNoteGenrI_EN_Feb09.pdf (accessed November 28, 2012).

- Discuss how the Human Rights Council can use its mechanisms, including the UPR (Universal Period Review) procedure, and work with the World Health Organization and other international bodies to improve palliative care availability;
- Explore opportunities for cross-regional cooperation to promote palliative care as a component of the right to health.

PANEL*

Keynote Speaker

- **Tabaré Vázquez**, Director and Professor, Radiotherapy Service of the Department of Oncology, School of Medicine, La Universidad de la Republica; Head of Radiotherapy Services at the National Institute of Oncology, Uruguay Ministry of Health; former president of Uruguay 2005-2010.

Moderator

- **Diederik Lohman**, Senior Researcher, Human Rights Watch (HRW)

Panelists

- **Liliana de Lima**, Executive Director, International Association for Hospice and Palliative Care (IAHPC)
- **Faith Mwangi-Powell**, Executive Director, African Palliative Care Association (APCA)
- **M. R. Rajagopal**, Chairman, Pallium India

* Please note: for the purposes of this report, the panel transcript has been summarized and condensed in the interest of clarity and brevity. In cases where technical difficulties disrupted recording, panelists have provided substitutive remarks.

KEYNOTE SPEECH

Tabaré Vázquez welcomed attendees and drew from the following prepared remarks to open the panel:

“Let me just share a few ideas to foster a dialogue that needs to be fruitful and ultimately productive.

“Maybe because I’m so familiar with death, I am so passionately in favor of life. This passion for life is also a drive for freedom and democracy.

“Freedom and democracy are such essentially human forces that today they are recognized as rights. This recognition comes somehow late if we consider the history of mankind, but that very same evolution reveals that it was not easy to attain the recognition of rights and that even today there are millions of human beings that cannot enjoy these rights.

“The work of the United Nations’ Human Rights Council, in whose framework we are meeting today, is an example of this. I wish it were not like this, I wish rights were an everyday exercise, something as ordinary as the air we breathe yet reality is what it is and not as we would like it to be.

“I think that rights, apart from being instruments for social organization and coexistence, are the ethics of freedom and democracy. Accordingly, I also believe that palliative care is a formal and ethical component of the right to health. Just as the right to health should be universal and unalienable (otherwise it would not be a right), access to palliative care should be universal for all those requiring it.

“For some of you this may sound obvious or ‘off the wall’ yet I’m saying this because I come from a region that is neither the most conflictive nor the poorest in the world, but it is the most unequal.

“Over the last twenty years, Latin America has made progress in terms of individual freedoms, democratic institutionality and legitimacy of its governments; during the last decade, its real GDP experienced an annual growth, on average, of 5.5% until the global financial crisis of 2008; it quickly recovered from that crisis and, according to estimations available, in 2010 its real GDP grew by 6%; poverty was reduced from 44% to 33% of the population. And yet, according to the UNDP Human Development Report, in 2009, ten of the fifteen most unequal countries in the world were Latin American.

“And going beyond the Report, a visit to the most populated cities in our countries would be enough to witness the striking contrast between the wealthy and the underprivileged. This contrast is expressed in a wide range of factors: the color of your skin; access to education and training for jobs; access to health care and social security; housing location and conditions; ‘connectivity’ in the information society; mobility and transportation; use of free

time and cultural goods and services; the way people speak and dress, and even circumstances and conditions relative to birth and death. Nothing can escape this curriculum.

“The right to health, undoubtedly, covers prevention and treatment of disease. And, in turn, it includes the treatment of pain, both in terms of its physical effects as well as psychological effects in the patient and his/her environment, because in a situation of illness, nobody suffers alone.

“We also know that many diseases can be prevented or cured and that **suffering associated to many diseases can also be avoided or alleviated.**

“Therefore, the World Health Organization declares that: ‘Palliative care is an approach that improves the quality of life of patients and their families facing the problem 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, psychosocial and spiritual.’¹⁰

“This is a broad definition and, I believe, accurate because it is not limited to terminal stages but rather covers different diseases or situations and includes a complete spectrum of ages. The development and promotion of palliative rights implies:

- a) **Policies based on ethical principles:** inviolability of human life, the right to die with dignity, therapeutic proportionality, precautionary principle, non-abandonment principle, to name a few.
- b) **Qualified training of healthcare providers.** As the Chair of this Panel correctly pointed out in an article published last year, according to a survey by the Worldwide Palliative Care Alliance in 69 countries of Latin America, Asia and Africa, in Latin America 82% of physicians had not received training on pain control during their professional education. This percentage falls to 71% in Asia and 39% in Africa.¹¹
- c) **Truthful information to the patient and family;** avoiding paternalistic or escapist attitudes, taking into account the basic principles in clinical ethics: neither with malice nor on charity; autonomy and fairness¹²
- d) **Clear and consistent legal regulations regarding availability and administration of medicine (drugs) to alleviate pain.** In this sense, we do not undervalue international conventions or current national legislations, but we recognize that there still is room for improvement in terms of gaps and inefficiencies.
- e) **Adequate cost of such medicine.** The article already cited verifies that the average cost of a dose of morphine is twice as much, or more, in low and middle-income countries

¹⁰ “WHO Definition of Palliative Care.” World Health Organization, 2009.
www.who.int/cancer/palliative/definition/en/

¹¹ Diederik Lohman et al: “Access to treatment of pain as a human right.” BMC Medicine, 2010.

¹² PAHO: “Cuidados Paliativos: guía para el manejo clínico.” Second edition, s/f, p.13

than in industrialized countries and it goes on to mention some of the reasons for this gap. In addition, it is reported that some countries are already producing liquid oral morphine or in tablets at a much lower cost.¹³

“Pain is not exclusive to cancer. Yet as an oncologist I must reiterate what you already know: **that the incidence of this disease is growing markedly.** At a world level, every year, approximately 9 million people are affected by cancer and 70% of them die from this disease. Two thirds of such cases occur in developing countries that only have 5% of the total resources in cancer control.¹⁴

“Let us take the case of Latin America and the Caribbean: it was estimated that in 2002 almost half a million people died of cancer. It is also estimated that by 2020 cancer will be responsible for nearly 840.000 deaths.¹⁵

“One may say that the past is over and the future is yet to come. I agree. But let us focus on the present time: How many of the million cancer patients in the world today receive palliative care at different stages of their disease? What sort of care do they receive? Who provides that care? What are the results? I do not know. I do not have updated and reliable information in this regard. I do not know whether that information is available.

“This uncertainty strengthens my conviction (though it may sound contradictory) that **also in terms of oncology countries may reveal different levels of development.**

“Oncologic development or underdevelopment can be determined by the following factors:

1. Policies and outcomes in terms of cancer prevention or early detection.
2. Ratio between number of detected and cured cases of cancer.
3. Ratio between cost of treatment and number of patients cured.

“There are other indicators, of course, but in this area I chose to underline these ones because they are inherent to health as a right and to palliative care as a component of the right to health.

“As an oncologist there is something else I must not forget to include in this message: cancer is neither an inexorable disease nor inexorably mortal. The risk of getting cancer can be attenuated; by early detection and adequate treatment, a very high percentage of cases can be cured. It is a bad friend, but it is not unbeatable.

“Let us focus on the types of cancer connected to tobacco consumption. Remember that according to estimations by deDoll and Peto¹⁶, tobacco use accounts for 35% of all types of cancer (lung, oral cavity, pharynx, larynx, esophagus, pancreas, liver, kidney).

¹³ Lohman et al, ob.cit

¹⁴ PAHO: “Cuidados Paliativos: Guía para el manejo clínico”. Second edition. s/f, p. 3

¹⁵ “Guía de la UICC para Latinoamérica” International Union against Cancer, 2006.

¹⁶ Doll, R and Peto, R. The causes of cancer. Oxford University, 1981. Cited in the UICC Guide for Latin America, 2006

“The implementation of tobacco-control policies reduces the risk of cancer and, consequently, the number of cases that require palliative care. It may sound impolite to say this in this group. Yet, not to mention it would be—apart from a big mistake—irresponsible and, at least in my view, an ethical omission. Preventing a problem is the best way to solving it. It is not always possible, but it is easier than it looks.”

Mr. Vázquez expanded on the topic of tobacco-use control, noting that Uruguay was “the first ‘smoke-free’ country in the Americas and the seventh in the world, pursuant to the World Health Organization’s Framework Agreement on Tobacco Control, whose approval at the 56th World Health Meeting, held in May 2003, was endorsed by our country, signed in June 2003, and ratified by legislation in July 2004.” He emphasized that this legislation required “the persistent commitment of many: government, the scientific community, the political system, the medical union and other healthcare workers’ unions, the education system; bar, restaurant, grocery stores and kiosk owners’ associations... even smokers who were aware of their problem and its consequences, they all contributed to the tobacco smoke-free country we enjoy today.”

Mr. Vázquez added that although too little time has gone by “to measure and assess substantial changes in the epidemiological profile of a country,” recent studies “hint at a downward trend in the case of Acute Myocardial Infarction and lung cancer incidence.” He qualified, “And let me insist: they hint at, they do not yet show. Nevertheless, it is a step forward.”

Mr. Vázquez concluded, “I have tried to contribute some insights to approach – from several perspectives – a necessary and possible objective: **health should become a right for all and every individual life should be dignified at all times.**”

PANELIST DISCUSSION

Mr. Lohman thanked Professor Vázquez for his opening remarks and added that , like tobacco control in Uruguay, palliative care also requires the same kind of “persistent commitment from the government, and from the healthcare sector, from civil society” for its development worldwide.

Responding to the various issues covered in the keynote speech, the panelist discussed the following key issues:

- 1) *Pain Prevalence and Impact on Patients*
- 2) *Palliative Care Availability*
- 3) *A Successful Model*
- 4) *The Role of the Human Rights Council*

Issue 1: Pain Prevalence and Impact in Patients with Incurable Diseases

Large Vulnerable Population

Ms. De Lima noted that estimates indicate that approximately one percent of the population in every country needs pain management in the form of palliative care, and the need is greater in countries where patients are diagnosed in the last stages of diseases or have less access to treatment. Indicators suggest that the vast majority of patients do not have access to pain management, including most of the 80% of the patients with cancer who need strong pain relievers. In all, an estimated 65 million people need access to pain management programs. Children are especially vulnerable among this group.¹⁷

Effects of Pain

Without treatment, this pain can be severely debilitating. Dr. Rajagopal shared stories of patients he has seen over the years who have suffered deeply from pain. He recalled witnessing the experience of his neighbor, terminally ill with cancer, when he was a medical student 45 years ago, sharing, “Through the day and night, I could hear screams... There was nothing I could do, and I’m ashamed to say that because I did not know what to do, I [could not help].” More recently, a young patient of his “had such

¹⁷ WHO. Access to Controlled Medications Programme. *Improving access to medications controlled under international drug conventions*. Geneva: United Nations, 2009

agony, he had pain from cancer, that he would fight sleep so that his mother doesn't hear him scream." And another patient's painful vascular disease was so severe "he attempted to h[a]ng himself. His children, 11 and 8 years, heard something, ran, lifted him up and save[d] his life for the time being."

Dr. Rajagopal emphasized that these experiences are by no means atypical; rather, at least 40 million cancer patients in India have similar stories, as well as many millions more worldwide.

Moreover, pain is not unique to patients with cancer. For example, Dr. Mwangi-Powell noted that that pain management is just as critical for HIV/AIDS patients, citing that UNAIDS statistics estimate there are 24.5 million people with HIV/AIDS in Africa¹⁸. She shared the story of a patient who was dying of cancer and HIV/AIDS in 2003 in Kenya. Although doctors were unwilling to diagnose the patient, everyone suspected she had HIV/AIDS. Dr. Mwangi-Powell recalled that the patient told her aunt, "I cannot sleep. I feel like things are crawling all around my body.... it's very, very bad.... [I]f my pain can be controlled, if my symptoms can be controlled, if I can stop my coughing... maybe I can actually take care of my own business. I can just be fine. That's all I ask for." But the patient died without receiving the pain management she needed.

Issue Two: Palliative Care Availability

Pain is Unnecessary

The panel emphasized that the pain experienced by this large population is not a necessary component of their circumstances; palliative care can and should be delivered to alleviate their symptoms. In particular, Dr. Rajagopal noted that pain relief in the form of morphine can be administered "safely and effectively." He added that in India, morphine costs only \$.02 for an average patient, and in Uganda a patient can have morphine for a week for the price of a loaf of bread.

Palliative Care is Inaccessible

However, palliative care remains largely inaccessible. Dr. Rajagopal commented that patients do not realize how easy it should be to get help, and the medical world does not currently have the will to make it more available. He lamented, "It's almost unbelievable that the medical system can be so insensitive to human suffering."

Ms. De Lima highlighted three reasons why palliative care is neglected:

1. ***A lack of policies integrating palliative care into the health care system.***
As a result, palliative care is not delivered, there is no reimbursement for services, and there are no systems in place to provide the care itself within the institutions.

¹⁸ UNAIDS *Fact Sheet: Sub-Saharan Africa*, 2005.
en.wikipedia.org/wiki/List_of_countries_by_HIV/AIDS_adult_prevalence_rate

2. ***A lack of relevant training for healthcare professionals and healthcare workers.*** As a result, healthcare workers do not have the expertise needed to recognize the palliative care needs of a patient and appropriately evaluate dosage without having to refer patients to a separate facility. This training should be incorporated as a basic component of training for physicians, nurses, pharmacy schools, and social workers.

3. ***A lack of access to essential medicines, including those needed for palliative care.*** Ms. De Lima's team has been working with WHO and the Director of the Program for Access to Controlled Medications, Dr. Willem Scholten, to examine this issue. They have identified several reasons why these medicines are not more accessible:

- A. *Inadequate supply chain mechanisms/Lack of distribution*
- B. *Unwillingness by doctors and other health workers to prescribe strong pain medication such as opioids*
- C. *Unnecessary regulation around control of narcotics*
- D. *Regulatory Barriers that Increase the Cost of Essential Medicines*

Barriers to Essential Medicines

Regarding point 3, Ms. De Lima added that medical professionals are fearful of being prosecuted for prescribing what may be considered too much of a controlled medication. The panelists agreed that regulation of essential medicines is obligatory, especially of morphine which is closely linked to heroin. However, Dr. Rajagopal stressed that the approach to regulation has been unnecessarily, and harmfully, stringent.

Ms. De Lima concurred that unnecessary barriers do not promote safety but rather prevent patients from accessing medication they need. For example, patients may be required to travel from a rural location to their country's Ministry of Health (as required in Nicaragua and Guatemala) for a prescription validation, and then return to their pharmacy for the medication. Such extensive travel may be impossible for a patient in severe pain, and unnecessarily compromises their ability to acquire the treatment they need.

Cost as a Factor

Ms. De Lima and Dr. Mwangi-Powell noted that wholesale cost of morphine sulphate in the international markets is low and therefore can be imported in bulk quantities to be reconstituted in oral solutions that can be sold at very low prices at the retail level. This has been successfully implemented in Uganda ensuring access to pain treatment to many patients.

Unfortunately, many governments fail to adopt this strategy and allow only importation and dispensation of more expensive dry formulations of morphine and other opioids. In addition, other costs, such import tariffs and distribution costs, are typically transferred to the medications and become quite expensive at the retail level and ultimately for the

patient hindering access.¹⁹ In middle income and low income countries, pain medications are usually not covered by insurance and therefore have to be paid out of pocket by patients.

Both Ms De Lima and Dr. Mwangi-Powell raised the need for governments to adopt the strategy used by Uganda to improve patient care.

Dr. Mwangi-Powell shared the story of her close friend Lidia, who was dying in a hospital outside of her home country of Uganda. Unable to work, preparing to die, Lidia returned home to Uganda where she was immediately taken to a hospice. Dr. Mwangi-Powell described, “They controlled her symptoms. They controlled her pain. They started treating her. She was [improving] within a few days. She could walk, she could feed, she could work.” Her improvement was so dramatic, Dr. Mwangi-Powell shared, that currently “Lidia is one of the biggest advocates for palliative care in Uganda.”

Dr. Mwangi-Powell highlighted that the difference between the experiences of the two patients she talked about, is a difference between their respective country’s approach to palliative care. In Lidia’s home of Uganda, pain medication is accessible and palliative care is a national priority, ensuring that Lidia could access the care she needed at no cost. And yet, Dr. Mwangi-Powell noted that the patient in Kenya was in the relatively richer country. She concluded that access to palliative care is not an issue of resources. Its government’s willingness to support and integrate it into existing systems as has been done in Uganda.

Issue 3: A Successful Model

The Ugandan Ministry of Health has prioritized policy change to enable access to palliative care. For example, Ugandan nurses who go through a nine-month palliative care course are allowed to prescribe opiates. Palliative care was included as part of the National Health Strategic Plan in 2004, with the goal of improving training and access to pain medication.

The success story of Uganda, described Dr. Mwangi-Powell, is “a story which shows how people’s society, the hospice movement, the government, [and] advocates came together and they said we can do something about this. But I think most important thing is a good political will. When there’s no political will things become very difficult.” She noted that the support available in Uganda is the reason why her organization the African Palliative Care Association is based there, adding, “[W]e want to preach, we want to say it can happen somewhere, because it has happened in the country where we are based.... It’s not a mission impossible. It’s possible....”

¹⁹ De Lima L, Sweeney C, Palmer JL, Bruera E. “Potent Analgesics are more expensive for Patients in Developing Countries: A Comparative Study.” *Journal of Pain and Palliative Care Pharmacotherapy*. Vol 18 No 1, 2004.

Issue 4: The Role of the Human Rights Council

Ms. De Lima added that the Human Rights Council, and representatives from all sectors, can play a significant role in ensuring that palliative care becomes more available in countries around the world. She explained that there are three main avenues for change:

1. ***Palliative Care as a resolution / Essential Medicines as a right***

“The Human Rights Council adopts resolutions on the right to health. Advocate so that a resolution on palliative care is adopted or included in an existing resolution. Access to opioids and other controlled medications should be in the language of this resolution.”

2. ***Universal periodic reviews***

Palliative care should be included as one of the criteria under which UPRs are used, and under which countries have to submit and undergo reviews. This will ensure that palliative care is on country agendas.

3. ***Raising awareness within government***

Advocates must call on their governments to answer questions around palliative care, including how it is being implemented, and what is being done with respect to policy, education, and access to medicine. Governments must be made aware that there is a need for palliative care that is not being addressed.

PANEL SUMMARY

Mr. Lohman summarized the discussion with the following points:

- ***Illnesses like cancer and HIV cause great suffering***
This suffering in some cases is so terrible that it makes people want to end their lives because they can't bear to live with pain.
- ***Treatment for this suffering is possible, but inaccessible***
This pain can be treated with inexpensive medications fairly easily, but nonetheless treatment is not available in much of the world.
- ***There is a lack of health policies addressing these issues***
There is a lack of health policies addressing the needs of patients with incurable illnesses and a lack of training of healthcare providers on palliative care.
- ***Existing regulations impede assistance***
Problematic regulations impede the availability of essential medications for palliative care.
- ***Change is possible with political will***
With political will, this situation can be improved, as Uganda highlights. Despite not being rich in resources, Uganda has made a palliative care a priority through the cooperation of the government, medical providers, and civil society. Mr. Lohman added that Uganda is not the only country that has made progress in this area -- parts of India, as well as Colombia, Uruguay, and Vietnam have also seen some success. He concluded, "Political will helps to move forward the palliative care agenda and helps to make sure that people don't have to die in terrible pain."

Q&A SESSION

Mr. Lohman opened the floor for comments and questions.

Comment on Access to Morphine

Mr. Willem Scholten, team leader in the WHO for Access to Controlled Medicines, commented about the possibility for improved access to morphine, emphasizing that when dosed properly, morphine is very safe. It is often associated with death, but that association stems from the fact that it is often only prescribed to those who are terminally ill. It simply makes pain bearable.

There is also a fear of morphine dependence. Unfortunately, many of the studies on this issue are not very well done; however, evidence suggests that if prescribed for pain treatment, dependence is highly unlikely.

A study by Nobel found that in over two thousand patients, only one became dependent. And there are also theoretical neurobiological explanations how this is possible when you prescribe morphine to a pain patient that he doesn't become dependent on it.

The other thing is that in 2012 we will celebrate that we have had 100 years of drug control. It was in 1912 that we had the First Opium Convention and several other conventions and protocols. Currently we have conventions from 1961, 1971, and many of the diplomats present here will be familiar with those because they are part of the delegation to the Commission on Narcotic Drugs in Vienna. And here in Geneva, we deal with health and human rights issues. And there's one of the problems I think for overcoming this problem, because in Vienna people say, well, health we deal with in Geneva. If you are here, you say, oh, but we will deal with controlled substances in Vienna. So, it's very important that diplomats communicate on this issue with their colleagues in their missions in Vienna about access to controlled medicines, which is part of both domains."

Mr. Scholten added that the WHO recently published policy guidelines on the issue of access to morphine, in a report called "Ensuring Balance in National Policies on Controlled Substances, Guidance for Availability and Accessibility for Controlled Medicines."²⁰ These 21 guidelines address all controlled medicines, with a focus on achieving a balance between maximizing medical access and limiting the potential for dependence.

²⁰ "Ensuring Balance in National Policies on Controlled Substances, Guidance for Availability and Accessibility for Controlled Medicines," World Health Organization, 2011. www.who.int/medicines/areas/quality_safety/guide_nocp_sanend/en/

Furthermore, Mr. Scholten noted that many organizations have been working on this issue, including the WHO Collaborating Center for Policy and Communications in Cancer Care in Medicine, the African Palliative Care Association, the Open Society [Foundations], and Human Rights [Watch].

“What can be done, then, is to review the legislation in the country because there are often so many inappropriate rules that don’t help to prevent the dependence and the diversion. But at the same time, these rules form undue barriers for the treatment. Well, the amount that can be prescribed for instance. And then, similarly to a legislation review, to go over policies, to see what needs to be done with official policies to make these medicines available. And then, also, not that yourselves would do that, but medical training is also very important as many medical doctors are not trained for providing pain relief. So, there are a number of things that governments can do to improve the situation in their country. Thank you.”

Question 1: How Can We Reduce Fear of Prosecution for Prescribing Palliative Care Medications?

Ms. De Lima responded that there are four steps her team at the IAHP follows to help ensure that regulators and prescribers work in tandem.

- A. Facilitate an environment of collaboration between the prescribers and the regulators, who have often never met before
- B. Clarify WHO guidelines
- C. Identify the local barriers that hinder access to medicines and address them at country level including regulations and policies that support access to essential medication
- D. Determine who will be advocates

Although this model has worked well, Ms. De Lima warned that success requires:

- Sufficient number of prescribers working as advocates for patients.
- Buy-in from the government with access to their drug regulator agency (e.g., Ministry of Health or Ministry of Defense).
- Willingness among the relevant parties not just to create change on paper but also to follow through.

Dr. Mwangi-Powell added that it’s critical not just to create new policy, but to identify opportunities for improvement within existing policy, since developing new policy can take a long time.

Question 2: To What Extent Is It Productive to Focus on Palliative Care as a Human Rights Issue?

Mr. Jamshid Gaziyeu (staff of the Special Rapporteur on the Right to Health) noted that palliative care is typically seen as a medical issue. He asked to what extent focusing on palliative care as a human rights issue has been productive, and what challenges arise in doing so.

Mr. Lohman responded by first noting that human rights work is about giving a voice to people who would otherwise go unheard. In the context of palliative care, patients themselves often do not have the strength to speak out for their needs themselves. And their relatives are too overwhelmed with the burden of caregiving to be advocates as well as caretakers, and subsequently often prefer to forget the torment of watching their loved ones die. He expanded, “[L]ooking at palliative care from a rights perspective is about giving voice to people who are dying in their homes [and] villages from cancer, who do not have the ability to go out into the streets [crying out], ‘We are in pain... Government, what are you doing to make sure that I don’t have to suffer?’ These people are mostly invisible, and one of the reasons that palliative care has been neglected over the years is that a cancer patient who is dying simply doesn’t have a voice.”

He highlighted the case of HIV as a positive example of where that voice is being heard. However, he noted that the time between diagnosis and the onset of physical symptoms gives HIV advocates an opportunity to have their own voice, whereas not all illnesses allow for that.

Although palliative care is often considered a medical issue or a public health issue, one of the advantages of viewing it under a human rights framework is the ability to highlight the responsibilities of government to prioritize palliative care under international human rights law. The Right to Health and the general comments by the Committee on Economic, Social and Cultural Rights define a number of components that are considered the minimum core context of the Right that all states irrespective of resources have to implement. One of these is access to essential medicines as defined by the World Health Organization, including morphine, which has been on the WHO essential medicines list for almost 35 years. So, in this context, there is a clear obligation to help poor countries ensure that morphine is available for the patients who need it. Similarly, countries have an obligation to develop health policies that address the needs of the full population.

However, Mr. Lohman added that in many countries despite these obligations, a cancer control program, for example, will address prevention issues, early detection, and treatment, but palliative care is either not mentioned at all or it is mentioned but there is no funding attached.

In addition, he noted that the Committee has also said that training of healthcare professionals is of importance, and yet as discussed earlier by the panel, few healthcare professionals receive any training on palliative care.

Therefore, Mr. Lohman concluded, it is critical to examine government policies and insist, “You are not living up to your obligations.” He added, “[T]he more articulation of the right to palliative care we have, the more advocates in their countries can use that to go up to the government and say, ‘Here, this document mentions palliative care, and what are you doing to make sure that palliative care is available?’ So... if you can raise the issue of palliative care as a human rights issue, it is something that we will then use in countries around the world to ask tough questions of governments.”

Ms. Tamar Ezer from the Open Society Foundations’ Law and Health Initiative added that the barrier to palliative care is not a question of resources, and it is not a question of technology or new medications that need to be developed, because effective and cheap medicines to treat pain exist. Rather, it is a question of political will and government inaction. As a result, human rights advocates can play an important role in ensuring States fulfill their obligations. She explained, “Access to palliative care and pain relief is fundamentally a human rights issue. It is about dying and living with dignity. This is a concept very much at the heart of human rights.” She stated that the Special Rapporteurs of both Health and Torture have spoken on this issue, and it is time for the Human Rights Council to address it seriously.

Ms. De Lima added a personal note to help illustrate palliative care as a human rights issue. She shared a story about her experience in Colombia when she was working in the university hospital, where cancer patients were seen not by appointment, but on a first-come first-served basis. She described, “So, patients would come in just starting the night before. And you could see them lying on the floor. It was a very sad and terrible scene. When I walked by and I heard the patients moaning and crying, and they had already been seen by the doctor, I ask the nurse, “Why are they still, crying, why are they still screaming?” And she or he would respond, those are the patients we can’t do anything for them anymore.”

Ms. De Lima concluded, “[T]hat’s the kind of care that a lot of the patients face in the world right now, because they are not curable, they are left out and they fall through the cracks. And a lot of those patients are not heard.... Nobody knows that they exist and they die in pain.”

CLOSING REMARKS

Mr. Lohman turned to Mr. Vázquez for closing remarks. Mr. Vázquez began his remarks by noting, “I think that at this age in the 21st century, the world and the societies must get back some lost paradigms,” adding, “One of the paradigms we seem to have lost is that medicine’s motto is to cure sometimes and alleviate always. And when we lose that north, we begin to take paths that complicate the practice of our profession, and in getting back our human rights and rights to live and inherent to health.”

Mr Vázquez expanded, “Regarding the issue of opiates in particular, I think there is a very heavy legislation, because we have reasoned—and that’s another paradigm we have lost—we have reasoned for the exception, not the rule. There is a very heavy rule regarding the use of opiates because it is true that there were colleagues in our profession that prescribed indiscriminately morphine, being able to use another pain medication. But those were the few. I think that was the exception. The medical group in general, in the world, handles responsibly the issue of drugs.

“Secondly, there is also the myth that if we use morphine in patients, we make them addict[ed] to morphine. Dr. Scholten has been very clear, explaining some scientific international studies that show this is not the case. Therefore, I think the existing legislation, and a regulation about this is undoubtedly necessary, is too heavy for physicians to use, not only with a conscience piece of mind but also with a legal piece of mind, the use of opiates. And this is a task not only for the physicians, but also a task for professionals, attorneys, and the political system, the governments.”

Mr Vázquez explained that he believes there are three components to ensuring that “palliative care and pain treatment are really considered within the health topic, which is an inalienable human right.” These are:

1. ***An Ideological component.***

Mr. Vázquez: “Health as a human right is an obligation of the government. The government is the one that has to enact policies related to health, and [...] palliative care and pain treatment. We cannot leave that in the hands of the market. If the government has to play an important role in the lives of the countries, undoubtedly, among others, in terms of health, the public health policies must be carried out by the government, and not left in the hands of the market, that will end up speculating obviously, from the point of the view of the market, the business, defending its own interests over human rights to health.

2. ***A political component.***

Mr. Vázquez: “At a national level, at a political level, it’s an obligation of the government to defend the health of its people and its population beyond any other consideration, even over a financial consideration. Because assigning resources to health is not an

expense, not even an investment, it is about considering a human right, the right to life and health, the right to a life with dignity. And it is an obligation of the government to consider and provide guidelines in that direction. And in international politics, I humbly think that it's an obligation of the United Nations and the United Nations Human Rights Commission to include in the Millennium Goals... the issue of chronic non-communicable diseases and the issue of palliative care and pain treatment.

"...I think it's an obligation of the United Nations to take this path because ultimately, the world population is not asking more than the rights that are granted for the simple fact to live, the right to life and the right to health. I think that sooner rather than later, the United Nations should pick up these complaints and include palliative care and pain treatment in the Millennium Goals, as the issue of HIV/AIDS was justly included.... There are no financial resources to research from the basic and clinical point of view the terrible impact that chronic non-communicable diseases have, such as cardiovascular diseases, diabetes, cancer, traffic accidents take so many young lives and they become in an epidemic in many of our countries, are yet not included in the Millennium Goals."

3. ***A psychosocial component.***

Mr. Vázquez: "I would like to emphasize especially on this point. As a government official that I was initially, at a local government like the Montevideo government, later as a President of the Republica Oriental del Uruguay, I learned by doing, from the practical point of view, that a government can have the best intention and to push forward, along with the Legislature, the best law, the best legislation, drafted by the best technical, by the best jurists, by the best constitutional legislators. The Executive Office, a President, can issue a decree. It is technically indisputable, drafted by the best technicians. But if the political consensus and social consensus is not achieved in order to move forward those laws or decrees, they end up as papers stored in a desk. We have to authenticate, both the laws as well as the decrees. We have to open participation to the citizens. And about this issue of palliative care and pain treatment, surely the society as a whole will be very fertile to work, to achieve the goal for them to be considered as human rights. Because the society is the one that suffers. Because the truth is told by the people."

Mr. Vázquez continued, "And for the people to take part, for the people to ultimately support governments, non-governmental organizations, the legal system as a whole, the governments and the non-governmental organizations must inform adequately to the entire society. With this information, they can take a path that will surely be a certain path towards the achievement of the mentioned goals, considering, for example, in this case, palliative care, palliative care treatment, pain treatment as a right. That's why I mentioned the Uruguayan example about tobacco, because that was achieved, what the country achieved was not the task of a single person or a single government. It was a constant and permanent work for decades, informing and education the population, and getting the society involved: non-governmental organizations, unions, company unions, worker's unions, healthcare professionals, non-healthcare professionals, non-governmental organizations, the society as a

whole, the educational system, and finally, the political system saw the response of the society.

“And in my country the tobacco-free law was approved unanimously by all political parties integrating the Legislature, two from the ruling party and two from the opposition.... That is the key, from my humble point of view, of the success to achieve, drive this work you are all doing, so just, so valuable, so necessary, and for you to be able to achieve the final goal, involving the society as a whole, involving the legal system, and taking, ultimately, from the ideological point of view, that these issues cannot be in the hands of the market, because the market is for profit. The market is for profit in the capitalist world in which we live. What the Marlboro ad was showing, the two cowboys that were shown smoking—you have seen it—one in the night, full of stars, by a campfire, smoking Marlboro, and brimming with health, and the other one that was shown later herding a huge amount of equines, horses, a huge herd, very strongly, both of them smoking, both actors who starred in those roles, both died of lung cancer. What did Phillip Morris care about the death of those actors...? What does Phillip Morris care about the death of so many people for tobacco use? If a client dies, there will be others because they are going to look for more through ads. What they care is simply to make money. And the government and the societies, and non-governmental organizations..., what they are interested about is human rights, is the health of the people. The government is the one that has to watch over that health....”

Mr. Vázquez concluded, “That’s why I think that meeting like this one, and their extension towards the society and the political system, are vitally important. And the representatives of the governments present here, getting this information, I think, again, that they have the obligation to insist upon their governments to move forward adequate health legislation for people to live with the dignity they deserve.”

Mr. Lohman thanked Mr. Vázquez and closed the panel, noting: “There are few certainties in life. One is that we will all die, and none of us wants to die in pain. So, I think that the kind of consensus in society that Professor Vázquez was speaking about should exist in every country. We very much hope that we can work with all of you, with the Human Rights Council, to create the political will and the momentum that’s needed to make sure that no one has to die in pain. We neglected a little bit to talk about the rights of older people, which of course, they are being discussed here at the Human Rights Council and the UN more generally at the moment. Of course, the rights of older people are very closely related to access to palliative care, because as people get older, cancer incidence, increase dementia, other diseases become more and more prevalent. A lot of older people will need palliative care, and the numbers of older people requiring palliative care will only increase as the years go by.

“And so, I hope very much that in the discussions that you will be having in the coming days, this afternoon even, the issue of palliative care will be discussed when talking about the rights of older people. With that, I want to thank you very much for coming to this event. It’s been a privilege for us to having you here.”