

IAHPC News On-Line

Hospice & Palliative Care News & Information



International Association for Hospice and Palliative Care (IAHPC)

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Dear Members and Colleagues:

The July issue of our newsletter is now on our website at
<http://www.hospicecare.com/news/11/07/>.

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Warm regards,

Roberto Wenk, MD, Chair
William Farr, PhD, MD, Vice-Chair and Editor

Message from the Chair and Executive Director

Dear readers:

This month, we want to highlight several advocacy initiatives to improve access to pain treatment and palliative care.

Millions of people experience severe pain every year and don't have access to adequate treatment. Many suffer other physical and emotional symptoms which are treatable and in many cases preventable. There are inexpensive treatments that can relieve most pain and other symptoms that can dramatically improve the quality of life of patients and their caregivers.

This situation is a result of a lack of educational experiences for health professionals in the assessment and treatment of pain and other symptoms, unduly restrictive laws and regulations which limit access to opioids for legitimate medical use, and a lack of recognition by policy makers and legislators about the dire needs of patients with life limiting conditions.

The campaigns and the initiatives that several organizations have adopted and implemented throughout the world during the last 6 months all point clearly to this suffering and the need to take the necessary steps to alleviate this global problem. They are:

1) British Medical Association (BMA) proposal to the World Medical Association: The BMA has submitted a proposal to the World Medical Association to adopt a resolution on the Access to Adequate Pain Treatment. To read the BMA resolution click on http://www.hospicecare.com/resources/pdf-docs/pain-relief-proposed-resolution_bma.pdf. How can you help? This proposal will be presented during the next WMA assembly in Montevideo, Uruguay, October

12-15, 2011. We need national medical associations from around the world to support and endorse this proposal so that it gets approved during the WMA assembly. You can help by contacting your Medical Associations, sending them the draft proposed by the BMA and asking them to send supportive emails to the International Federation of Health and Human Rights Organizations (IFHHRO) at ifhhro.statements@gmail.com Ask them to vote in favor of the resolution when it is presented in the WMA assembly. This is a unique opportunity to bring global support for access to pain treatment. We need your help and support!

2) Treat the Pain: Treat the Pain is a campaign administered by the Union for International Cancer Control (UICC) to advocate for high-quality pain treatment for all those who need it throughout the world, and to connect those with meaningful actions who would like to join the fight. The campaign will use the resources and voices of its members to promote and advocate for universal access to adequate pain relief. The campaign includes the release of *LIFE Before Death*, a series of videos filmed in 11 countries across North America, Europe, Asia, and Africa. To read more about this campaign, watch the videos, and learn how you can become involved, click on <http://www.treatthepain.com/>

3) Palliative Care as a Human Right: Human Rights Watch (HRW) co-sponsored a side event on June 6th with the permanent mission of Uruguay and Brazil during the 17 th Session of the Human Rights Council in Geneva. The key note speaker of this side event was Professor Tabaré Vazquez, past president of Uruguay and current head of the radiotherapy service in the department of oncology at Uruguay's National Institute of Oncology. In addition, there was a panel moderated by Mr. Diederik Lohman, senior researcher at the Health and Human Rights Division in HRW. On the panel were three board members of IAHP: Dr Faith Mwangi-Powell, representing the African Association for Palliative Care, Dr M.R. Rajagopal from Pallium India and Ms. Liliana De Lima, representing the IAHP. During this event, several issues were discussed including barriers to the access of pain treatment, the question of how palliative care fits within the HR conventions, what are the obligations of countries, and a discussion on how countries and permanent missions may engage with governments to improve access to care at the country level. HRW will continue working to see if there is a possibility of:

- a Human Rights Council resolution specifically on palliative care;
- ways to ensure that recommendations are made regarding palliative care as part of the Universal Period Review process; and
- ensuring the place of palliative care in discussions about the rights of older persons.

The photo below was taken during the panel session – from left to right are: Professor Tabaré Vazquez, Dr. Faith Mwangi-Powell, Mr. Diederik Lohman, LDL and Dr. M.R. Rajagopal.



(photo courtesy of Dr. MR Rajagopal)

IAHPC is proud to be part of this movement and we will continue to help as much as possible to achieve these objectives in alliance with all of those around the world who want to eliminate needless suffering. We hope that these campaigns will also inspire all of you to take action and become a part of this much needed and exciting movement.

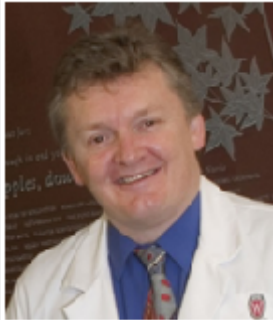
Until next month,

Roberto Wenk, MD
Chair, Board of Directors

Liliana De Lima, MHA
Executive Director

MAKING GLOBAL ACCESS TO PAIN RELIEF PERSONAL!

by IAHPC Board member James F. Cleary, MD, FRCAP, FACHPM, -- from his blog*



April 8, 2011: It is 4:30 am here in Hong Kong. I am awake. Jet Lag.

I am attending the 3rd Asian Oncology Summit hosted by Lancet Oncology and Elsevier.

...Up to 70 million people/year may be experiencing untreated severe pain at the end of life in Asia alone....Cancer is and will continue to be a growing problem in Asia along with the other non communicable diseases.... Dr Judith Mackay, a Hong Kong physician,... reminded me that last year during a question time, I had asked, "How many of you, if diagnosed with an advanced cancer, would want access to opioids for the treatment of cancer pain?" I raised my hand from the podium to show I was looking for a response. 3000 hands were raised!...

Judith's hand was raised; she told me today that it was during August when cancer pain relief got personal. If she is faced with an advanced cancer diagnosis, she wants access to opioids for pain relief.... Livestrong has found during interviews in numerous countries that people are consistently concerned about two things: the stigma associated with cancer and fear of cancer pain. Doug Ulman, CEO of Livestrong, had his hand up, as did John Seffrin and Otis Brawley of the American Cancer Society and David Hill and Carey Adams of the UICC to name just few.

I first asked this question while working with Dr Daniela Mosiou and her colleagues in Romania to address the barriers to opioid availability in their country. As part of bringing about major changes in their laws... we were asked to address a meeting of 100 stakeholders at the Romanian Parliament....I said, "I will shorten my comments and simply ask a question." "How many of you, if diagnosed with an advanced cancer, would want access to opioids for the treatment of cancer pain?"...All hands went up progressively around the circle until even the drug police to my immediate right had their hands raised. I then ask, "Why are we denying the people of Romania access to opioids for pain relief?"....

The Pain and Policy Studies Group (PPSG) has been about ensuring the availability of narcotic drugs for the relief of pain and suffering. We do not make decisions on what is an appropriate medical purpose....Dave Joranson took this "concept of balance" from PPSG to the WHO and the second edition has just been released by the WHO, under the leadership of Willem Scholten, and endorsed by the International Narcotic Control Board:

http://www.who.int/medicines/areas/quality_safety/guide_nocp_sanend/en/index.html

We must prevent abuse and diversion while *ensuring* availability for medical purposes.... Should opioid use only be limited to those with advanced cancer? What about those immediately post surgery, those who are have chronic arthritis, and those with pain from HIV and other life limiting situations? What about my mother ...who has significant and debilitating pain from spinal stenosis?

Yes, Judith, this is personal for me, too. Like you, I want ready access to opioids if I am faced with an advanced cancer diagnosis. I want this for me, my wife and my children and I want it for my mother, even though she doesn't have cancer.

And I am sure it is personal for the millions of people around the world who are suffering from pain and have no access to pain relief.

Dr. Cleary is an Associate Professor of Medicine (Division of Heme/Onc) at the University of Wisconsin School of Medicine and Public Health; Director of the Palliative Care Program at the University of Wisconsin Hospital and Clinics; Program Leader of the UW Carbone Cancer Center's Cancer Control Program; Director, Pain & Policy Studies Group; Director, WHO Collaborating Center for Pain Policy and Palliative Care. He is also a member of the Board of IAHPC. For his complete biography please see: <http://www.painpolicy.wisc.edu/PDFs/Bio/ClearyBio.pdf>

*The entire unedited story related in Dr. Cleary's Blog may be found at <http://painpolicy.wordpress.com/>
The above piece was previously published in the aforementioned site and a condensed and edited version is reprinted at http://www.hospicecare.com/news/11/07/pain_relief.html with permission.*

Dr. Cleary is a member of the IAHPC board and his complete bibliography may be found at <http://www.painpolicy.wisc.edu/PDFs/Bio/ClearyBio.pdf>

New WHO publication available to help improve access to treatment

Ensuring Balance in National Policies on Controlled Substances

Guidance for Availability and Accessibility for Controlled Medicines

This book from the World Health Organization provides guidance on policies and legislation with regards to availability, accessibility, affordability and control of medicines made from substances regulated under the international drug control conventions, herein referred to as "controlled medicines"....

This book elaborates on the background and then provides 21 guidelines on various topics: content of drug control legislation and policy; authorities and their role in the system; policy planning for availability and accessibility; healthcare professionals; estimates and statistics; procurement; and nationally listed drugs. Each guideline has an elucidation and a description of the legal context. The Country Assessment Checklist enables the user to determine which guidelines still need to be worked on. A CD-ROM provides additional information.

Target audience: policy-makers, regulators (in government, administrative departments, national competent authorities) and politicians; academia and civil society; healthcare professionals and their organizations; individuals (including patients and their families) and organizations whose area of work or interest is drug control or public health.

Book and reference list **freely downloadable** online in 14 languages at http://www.who.int/medicines/areas/quality_safety/guide_nocp_sanend/en/index.html and the Repository of the WHO Library: <http://dosei.who.int/uhtbin/webcat>

Available in hardcopy in English and French:

[E]: 78 pages, ISBN 978 92 4 156417 5, Order no. 11500807
[F]: 78 pages, ISBN 978 92 4 256417 4, Order no. 21500807
Price. CHF/US\$ 25.00, In developing countries: CHF/US\$ 17.50
Email: bookorders@who.int
Web site: <http://www.who.int/bookorders>

Human Rights Watch Reports on "Uncontrolled Pain" in Ukraine

Tens of thousands of patients with advanced cancer in Ukraine unnecessarily suffer from severe pain every year because they cannot get effective, safe, and inexpensive pain medications, Human Rights Watch said in a recent report. The 93-page report, "Uncontrolled Pain: Ukraine's Obligation to Ensure Evidence-Based Palliative Care," describes Ukrainian government policies that make it impossible for cancer patients living in rural areas to get essential pain medications....

View report at <http://www.hrw.org/node/98656>

The report identified three key obstacles to proper pain treatment in Ukraine:

1. The lack of oral morphine. Only injectable morphine is available.
2. Drug regulations. In its efforts to crack down on illicit drug use, Ukraine has adopted some of the most restrictive drug regulations in the world, without appropriate regard to the need for access to drugs on medical grounds.
3. Training of health care workers. Medical students and young doctors do not receive adequate training in modern pain treatment approaches.

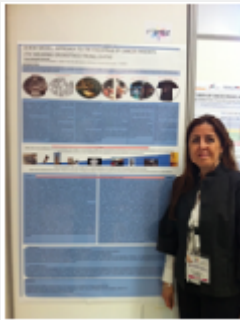
These three obstacles combine to deny patients adequate medical treatment, Human Rights Watch said....

Take action: Click here <http://www.hrw.org/en/features/ukraine-pain-free> and write a letter to Ukraine's minister of health urging him to introduce oral morphine.

The entire article may be found at http://www.hospicecare.com/news/11/07/human_rights.html

Diederik Lohman
Senior Researcher
Health and Human Rights Division
Human Rights Watch

An IAHPC Traveling Scholar's Report –Turkey



I want to thank the International Association for Hospice & Palliative Care for providing financial support to participate in the 12th Congress of the European Association for Palliative care in Lisbon (18-21 May 2011).....

This congress was useful in that it will help me to provide optimal care for my terminally ill patients....

I am a young physician and I see myself as "a street academic " with a foundation of academic theories and practical life experiences. Now, as an anesthetist in an eye hospital I am not content here in Turkey because of the many difficulties-- everything develops slowly here. It is impossible to do it alone and therefore support and expertise from abroad could help Turkey move in the right direction sooner rather than later.

In this congress, I saw how far behind my country is in palliative care and opioid use. What do I do? The UK and the USA are probably the top centers of palliative care and hospice. I believe that earning a PhD in palliative care in one of these countries is a necessary prerequisite for my personal and professional development so that I may be more effective in moving palliative care forward in my country.

Read the entire scholar's report at http://www.hospicecare.com/news/11/07/travel_scholar.html

Dr. Serpil OZSEZGIN OCEK
Anesthesiology and Reanimation
Izmir-TURKEY

Also from Dr. Serpil Osezgin Ocek -- A regional report -- Turkey

I am an Anesthesiologist and Reanimation specialist living and working in Turkey. More than 74 million people live in

Turkey but unfortunately, there is no palliative care specialisation in Turkey. The medical oncology units and departments of algology in major hospitals provide pain control and symptom relief. Oncologists and pain specialists in hospitals report that they are actively working to establish palliative care....

Narcotics are often available to meet the needs of dying patients with chronic pain. Many private pharmacies however shun the bureaucracy and the potential liability that goes with dispensing "green" prescriptions (addictive or abusable drugs) and "red" prescriptions (narcotics). Our hospitals and their staffs are not organised or trained to provide palliative care....

There is a lack of education of our health care personnel, and we lack a range of strong opioids because only slow release morphine, transdermal fentanyl and tramadol are available. The fear of psychological or physical addiction to strong opioids is prevalent.... Therefore, the use of opioids in Turkey is limited....

After becoming aware of this situation, I opened a private Pain-free Life Centre in 2000 in order to deal with the management of pain in end-stage cancer patients. I admitted cases from my colleagues who could not manage cancer patients with complications and insufferable pain. I tried to find solutions to their problems of pain and other complications....

...When I first opened my practice I had to pretend to be a psychologist, dietician, physiotherapist and a grief therapist while taking care of them in hospital or at their home during their last stages....I was able to provide intensive care in their homes by being available at all times, 24/7.

Dealing with death openly is considered taboo in Turkey and as a community we exhibit thanatophobic attitudes towards present and potential death phenomena. Commonly observed thanatophobic attitudes of healthcare providers, especially doctors, facilitate isolating the patients in a condition of despair and exhaustion. As the population ages, all physicians are confronted with increasing numbers of dying patients. This is stressful for them and they need to care for themselves emotionally and learn to deal with the fatigue associated with compassionate care. I have noted considerable changes in my own thinking about death during the ten years since starting the Center for Painless Living. My challenge is to find effective ways to share my experiences and knowledge with others in order to improve end of life care wherever I can.

Dr.Serpil OZSEZGIN OCEK

To read the entire report please go to http://www.hospicecare.com/news/11/07/regional_report.html

Article of the Month

Assessment of palliative care cancer patients' most important concerns

Baile WF, Palmer JL, Bruera E, Parker PA
Supportive Care Cancer 2011; 19: 475-481

Medical problems are only a part of the concerns of cancer patients that cause suffering. It is well known that the treatment of TOTAL PAIN is a major objective of palliative care but in order to personalize treatment it is important to assess on a regular basis all the issues confronting patients.

The aims of this study were:

- to assess the concerns of patients who attended a palliative care clinic and determine their association to the level of distress provoked,
- to examine the ratings of physicians regarding patient concerns, and
- to assess the concordance between patient and physician ratings....

The patients indicated that they were most concerned about:

1. not being able to do their usual activities;
2. the future;
3. caring for themselves.

They were less concerned about

1. not getting enough support from others and
2. spiritual/religious issues

It was found that the higher levels of patient concerns were associated with greater anxiety ($r=0.52$) and depressive symptoms ($r=0.04$) and lower self-efficacy. Patients with more concerns had more symptoms of anxiety ($r = 0.52$) and depression ($r=0.40$) and lower self-efficacy ($r= -0.37$).

The mean HADS anxiety score was 6.9 while 42% scored 8 or higher which indicates a high level of anxiety. The mean HADS depression score was 7 and 44% scored 8 or above, which indicates potentially significant depressive symptomatology.

Evaluations by the physicians indicated that they thought patients were most concerned about:

1. the future;
2. not being able to do usual activities;
3. treatment

The physicians believed that patients had fewest concerns about

1. intimate/sexual relationships and
2. spiritual/religious issues.

Interestingly, the physicians reported higher levels of concern in each area compared to the patients.

The study of concordance between patients' and their physicians' ratings showed no significant agreement between physician and patient ratings. The highest concordance was for the patients' concerns about 1. the future and 2. caring for themselves.

Why I choose this article?

This article reminds us that in addition to medical problems, patients may have concerns regarding various aspects of their life that are clearly related and affected by their disease. Moreover, they may suffer from depression and/or anxiety symptoms that are higher in patients with more concerns. Many problems may not be recognized or may be over or underestimated if they are not assessed on a regular basis. The evaluation of the total needs of patients as well as the causes of their suffering is the only way we can effectively provide the necessary elements of total care.

The entire article may be found at <http://www.hospicecare.com/news/11/07/aom.html>

Reviewed by Dr. Carla Ripamonti (Italy).

Dr. Ripamonti is a member of the IAHP Board and her bio may be viewed at http://www.hospicecare.com/Bio/c_ripamonti.htm

Palliative Care Book of the Month

END OF LIFE.

Nursing Solutions for Death with Dignity.

Keegan and Drick

A vision for more holistic care around the time of death. Recommended.

To read the review go to <http://www.hospicecare.com/news/11/07/reviews.html>

Another Review

GOVERNING DEATH AND LOSS.

Empowerment, involvement, and participation.

Steve Conway (ed.)

What people are thinking and doing, around the world, to help our communities cope better with death and loss.

To read the review go to <http://www.hospicecare.com/news/11/07/reviews.html#1>

Dr. Roger Woodruff (Australia).
(June 2011)

Dr. Woodruff is a Lifetime member of the IAHP board and his bio may be found at http://www.hospicecare.com/Bio/r_woodruff.htm

Announcement

Changing the behavior of oncologists in Jordan. The authors state, "We conclude that "Western style" experiential training that contradicts very traditional approaches to doctor-patient communication in a traditional Arab country is effective." Read the letter to the editor in the following reference.

Amineh A.S. Al-Tamim and Mohammad Bushnaq: Communication and Skills Workshops for Oncologists in Jordan. *Journal of Palliative Medicine* 2011; Vol 14 (4), 387.

Membership numbers

We wish to thank all of the following people and institutions for their support during the past month.

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Webmaster's Corner

Each month we publish one website that highlights how individuals, organizations, or countries attempt to get their message out about what it is we do in hospice/palliative care.

Website Of The Month - Canadian Hospice Palliative Care Association

<http://www.chpca.net/>

CHPCA is the national voice for Hospice Palliative Care in Canada. Advancing and advocating for quality end-of-life/hospice palliative care in Canada, its work includes public policy, public education and awareness. Established in 1991, its volunteer Board of Directors is composed of hospice palliative care workers and volunteers from Canadian provinces and territories as well as members-at-large.

<http://www.chpca.net/>

Until next month!

Anne Laidlaw
IAHPC Webmaster

Letters to the editor!

William Farr, PhD, MD

Newsletter Editor

May be submitted at: billfar@hospicecare.com

****Thanks to all contributors to this issue.****

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