Developing Strategies to Improve Palliative Care in the World

2ND CONFERENCE ON HOSPICE AND PALLIATIVE CARE
IN DEVELOPING COUNTRIES

FRESNO, CALIFORNIA
SEPTEMBER 2009

LILIANA DE LIMA, MS, MHA
IAHPC EXECUTIVE DIRECTOR
Facts

- WHO estimates that more than 4 million cancer patients suffer needlessly in pain.
- The probability of being diagnosed with cancer is more than twice in developed countries, where 50% die of the disease.
- In developing countries, 80% of those diagnosed with cancer die of the disease.
- 95% of the resources to treat cancer are in developed countries.
Challenges in Developing Countries

- Poverty
- High incidence and mortality rates of cancer, AIDS and other chronic and infectious diseases
- Vast majority diagnosed at incurable stages
- Very few patients with advanced diseases have access to active care
- Poor communication among patients and family members: Emotional isolation
Problems with Current Health Financing

- Insufficient levels of health spending per capita ($13 per person per year)
- Proportion of health care spending is much lower than in high income countries (55% vs 71%)
- Private spending tends to be out of pocket rather than pre-paid
What is IAHPC?

- International Association for Hospice and Palliative Care
- Palliative Care organization with a worldwide approach
- Board of Directors: 22 members from 16 different countries
- Members from all regions of the World
- Programs and projects with the capability of making an impact at the local and national levels
- Focused on the professionalization of Palliative Care through policies, research and academic institutions
- Collaborates with existing organizations at the global, regional and local levels
Mission of IAHPC

Our Mission is to collaborate and work to improve the quality of life of patients with advanced life-threatening conditions and their families, by advancing hospice and palliative care programs, education, research, and favorable policies around the world.
We achieve this by:

- facilitating and providing palliative care education and training opportunities for care providers
- acting as an information resource for professionals, health care providers and policy makers
- developing collaborative strategies for hospice and palliative care providers, organizations, institutions and individuals
WHO Public Health Model
EDUCATIONAL PROGRAMS AND RESOURCES
# Education in PM: Survey

All medical schools in Canada (16); UK (30), and 129 randomly selected in the USA and Western Europe

<table>
<thead>
<tr>
<th>Countries/Region (%)</th>
<th>Mandatory Rotations (%)</th>
<th>Elective Rotations (%)</th>
<th>Educational Reading Material (%)</th>
<th>Academic Faculty Positions (% and Median)</th>
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<td>82</td>
<td>72</td>
<td>55 and 1</td>
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<tr>
<td>Canada</td>
<td>14</td>
<td>71</td>
<td>70</td>
<td>62 and 2</td>
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<tr>
<td>USA</td>
<td>11</td>
<td>62</td>
<td>59</td>
<td>14 and 1</td>
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<td>19</td>
<td>30</td>
<td>30</td>
<td>21 and 1</td>
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<td>p value</td>
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<td>0.014</td>
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</table>

Oneschuk, Hanson, Bruera - An International Survey of Undergraduate Medical Education in Palliative Medicine JPSM, 2000
### Number of Publications in Medline*

<table>
<thead>
<tr>
<th>Search String</th>
<th>Total N</th>
<th>Developing Countries N (%)</th>
<th>Africa N (%)</th>
<th>Asia N (%)</th>
<th>Eastern Europe N (%)</th>
<th>Latin America N (%)</th>
<th>Middle East N (%)</th>
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</thead>
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<tr>
<td>Hospice</td>
<td>6,264</td>
<td>32 (&lt;1)</td>
<td>41 (&lt;1)</td>
<td>155 (2)</td>
<td>41 (&lt;1)</td>
<td>2 (&lt;1)</td>
<td>17 (&lt;1)</td>
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<tr>
<td>Palliative Care</td>
<td>23,959</td>
<td>79 (&lt;1)</td>
<td>106 (&lt;1)</td>
<td>315 (1)</td>
<td>103 (&lt;1)</td>
<td>10 (&lt;1)</td>
<td>51 (&lt;1)</td>
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<tr>
<td>Supportive Care</td>
<td>7,327</td>
<td>150 (2)</td>
<td>96 (1)</td>
<td>205 (3)</td>
<td>26 (&lt;1)</td>
<td>12 (&lt;1)</td>
<td>40 (&lt;1)</td>
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<tr>
<td>EOL Care</td>
<td>16,971</td>
<td>327 (2)</td>
<td>185 (1)</td>
<td>446 (3)</td>
<td>120 (&lt;1)</td>
<td>57 (&lt;1)</td>
<td>37 (&lt;1)</td>
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<tr>
<td>TOTAL</td>
<td>54,521</td>
<td>588 (1)</td>
<td>428 (&lt;1)</td>
<td>1,121 (2)</td>
<td>290 (&lt;1)</td>
<td>81 (&lt;1)</td>
<td>145 (&lt;1)</td>
</tr>
</tbody>
</table>

*Including authors/subjects from developing and developed countries
Searched February 10th, 2005
Traveling Fellowships

For individuals invited to teach in developing countries for extended periods of time

Since 1998, IAHPC has sponsored 52 individuals who have spent time teaching hospice and palliative care in Argentina, Cambodia, Cameroon, China, Colombia, Cuba, Ghana, India, Kenya, Kyrgyzstan, Malaysia, Mongolia, Papua New Guinea, Philippines, Pakistan, Russia, Saint Lucia, Swaziland, Thailand, Uganda and Vietnam.

Dr. Vivek Khemka teaching seminars in India in 2005
IAHPC Traveling Fellowship Program

Terry Magee, RN in Ghana - invited by the Ghana Cancer Society
Traveling Scholarship Program

To support individuals from developing countries to attend seminars, training sessions, meetings and congresses.

Since 1998, IAHPC has sponsored 106 scholars from Afghanistan, Argentina, Bulgaria, Brazil, Cambodia, Chile, Colombia, Cuba, DR of Congo, Egypt, Georgia, Guatemala, Hungary, India, Korea, Lebanon, Lithuania, Malaysia, Mexico, Moldova, Nepal, Nigeria, Peru, Poland, Romania, Russia, Saudi Arabia, Serbia, South Africa, Sudan, Tanzania, Uganda, Ukraine, Uruguay, Vietnam, Yugoslavia, and Zimbabwe.

EAPC Congress, Aachen 2005
Traveling Scholars from Romania and Colombia
Faculty Development Program

- To support faculty palliative care positions in developing countries
- Full time position MD or RN in a developing country for 4 years
- Completed:
  - Municipalidad de Rosario (Rosario, Argentina)
- In progress
  - Ocean Road Cancer Institute (Dar es Salaam, Tanzania)
  - Sichuan University, (Chengdu, China)
  - Universidad Catolica (Santiago, Chile)

Dr. Jinxiang Li at the Palliative Care unit in Sichuan University in Chengdu, China
IAHPC Clearing House Program

More than 4 tons of books and journals were sent during 2005-07 to more than 400 programs in developing countries.
www.hospicecare.com

> 800 pages of information
>10,000 visits per day from all over the world

- HON Principles
- IAHPC Programs: Guidelines and Applications
- Bookshop/Video Shop/Publications
- International and National Newsletters
- International Directory (more than 800 listings)
- Calendar of Events and Meetings

Resources:
- Policy and Advocacy
- Assessment and Research Tools
- Educational Resources
- Treatment Guidelines
- Administrative and Financial Tools
International Association for Hospice & Palliative Care
Promoting Hospice & Palliative Care Worldwide

Quick Links
- Global Palliative Care
- Publications
- Palliative Care Books
- Events & Meetings
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or 1-938-321-9846

Ion Code
We comply with the HONcode standard
for health trustworthy information
Health on the Net Foundation
Accreditation: Verify here

Global Palliative Care
medications, consumption of opioids, service providers and educational programs
Enter Here

Imagine a world in which every person in need, has access to hospice and palliative care
Help us make this a reality
Donate to Hospice Care

Pallipedia
The IAHPC Palliative Care online dictionary project
Enter Here
Welcome to Pallipedia
The Free Online Palliative Care Dictionary

What do you want to do?
Learn more about Pallipedia Click Here
Search for a term or concept? Click Here
Submit a term or concept to Pallipedia Click Here

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P

P-value
Pain
Palliative care
Palliative medicine
Pamidronate disodium
Paramedical staff
Paresthesia
Paroxetine hydrochloride
Patient and family centered care
Patient
Patient-centred care
Patients' rights
Payment
Pediatric palliative care
Peer review
Per-diem charge / fee / payment
Peripheral neuropathy
Petrolatum-mineral oil-lanolin-ceresin ointment
Pharmacokinetics
Phenobarbital
Phlebitis
Physical dependence
Physician-assisted suicide
Piroxicam
Pain

1. An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.

See: breakthrough pain, episodic pain, incident pain, total pain


2. "Pain is what the patient says hurts."


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Submit a Term or Concept

When submitting a term or concept to Pallipedia, please take note of the following criteria:

- Contributions must be related to the field of Palliative Care.
- Contributions must provide timely and valuable information to the development and understanding of Palliative Care.
- The official language of Pallipedia is English. Suggested terms or concepts may be in languages other than English if no translation is available for such word. However, all contributions must be in English.
- Generic names for products and medications should be used. The use of commercial names may be used only if it is absolutely necessary. In such case, all the commercial names of products from the same class should be mentioned. Publicity for a particular product, device or medication is forbidden.
- Personal views/opinions will not be accepted.
- Contributions must include appropriate references. Appropriate references include peer reviewed journals, technical reports, books, and websites. Abstracts as references will not be accepted. All references will be checked and verified by the reviewers. Submissions based on references from peer reviewed journals are preferred and will go through a faster review process than those using other sources as references.

Instructions for citing publications:

- Journal Article:
  Authors, Article Title, Journal Title, Date of Publication, Volume, Issue, (Pagination).
- Journal Article on the Internet:
  Authors, Article Title, Journal Title, Type of Medium (Internet), Date of Publication, Date of Citation, Volume, Issue, (Pagination), Link
- Scientific and Technical Report:
  Authors, Title, Place of Publication, Publisher, Date of Publication, Total Number of Pages, Report Number.
- Book:
  Authors, Title, Edition, Place of Publication, Publisher, Date of Publication, (Pagination).
- Book on the Internet:
  Authors, Title, Type of Medium (Internet), Place of Publication, Publisher, Date of Publication, Date of Citation, Link
- Website:
  Name of Organization/Institution, Title of the page, Type of Medium (Internet), Date of Citation, Link

NOTE: IAHPC reserves the right to include, review or decline a contribution submitted to Pallipedia.

Please fill in the form below to submit a term or concept to Pallipedia.
Please fill in the form below to submit a term or concept to Pallipedia

* = Required

* Term or Concept:

* Definition:

* Reference: - Select type -

* Please submit complete reference information in the space provided:

* Your Name:

* Your Email:

* Verification Code: VVVV

Enter code here:

Submit
Publications IAHPC Press

- Free Monthly Electronic Newsletter
- IAHPC Palliative Care Manual
- Guias de Cuidados Paliativos IAHPC/PAHO (in Spanish)
- Palliative Care in the Developing World: Principles and Practice
- Getting Started Guidelines
Dear Liliana:

I have some personal reservations on giving recommendations for malaria “palliative treatment”, as there is no documented evidence of its effectiveness. As you are very well aware, malaria is an acute and fatal disease which needs rapid treatment with highly effective drugs.

Trying to make recommendations for places where there is no effective curative treatment is extreme challenging and for me also questionable on ethical grounds.

Dr. Andrea Bosman  
WHO Malaria Department  
World Health Organization  
20 Avenue Appia  
1211 Geneva 27, Switzerland
Getting Started:
Guidelines and Suggestions for those Starting a Hospice/Palliative Care Service
2nd Edition

Derek Doyle
IAHPC Press
Currículo de Enfermería para un Programa de Postgrado en Cuidados Paliativos

2009
MEDICATIONS
Facts

- In 2006, Western Europe and North America together accounted for 89 per cent of global consumption of morphine.
- 80 per cent of the world population lives in developing countries and consumes only 6 % of the morphine distributed worldwide.
- More than 50 countries in the world still do not have any opioids available.
- Opioids are not available in rural areas and in home care in most of the countries in the world.

INCB, Press Release #4 p 11, March 2008
 모르핀
MORPHINE
ISSUETIME
11:30 TO 12:30
2PM TO 2:45
Global Consumption of Morphine
mg/capita, 2003

Source: International Narcotics Control Board, United Nations "Demographic Yearbook"
By: Pain & Policy Studies Group, University of Wisconsin/WHO Collaborating Center, 2005
* 2001 Reporting Data

The global mean is calculated by adding the individual mg/capita statistics for all countries and then dividing by the number of countries.
2006 Global Consumption of Morphine

Sources: International Narcotics Control Board; United Nations population data
By: Pain & Policy Studies Group, University of Wisconsin/WHO Collaborating Center, 2009
Opioids are Expensive

- Comparative study
- 15 analgesic therapies, 12 countries
- Monthly Morphine ED
- 3 street pharmacies
- Number of therapies ≥33% than the monthly GNP per capita:
  - 4% in developed countries
  - 51% in developing countries

De Lima L, Sweeney C, Palmer JL, Bruera E. JPPCP Vol 3 (2), 2004
IAHPC List of Essential Medicines in Palliative Care

• Includes 33 Medications
• 14 are already included in the WHO Model List
• © by IAHPC
• Medications indicated to treat the most common symptoms occurring in palliative care – not underlying conditions
• No consensus: bone pain, dry mouth, fatigue, hiccups, and sweating
• Available in www.hospicecare.com
ADVOCACY
A moral imperative:  
Joint Declaration and Statement of Commitment

- Coordinated by the IAHPC and the WPCA
- More than 400 organizations and 4,000 individuals have signed
- Aim is to work on 7 areas: Recognition of palliative care and pain treatment as human rights, ensuring access to palliative care services, education, and eliminating barriers in opioids for pain treatment.
- Signatures collected until the EAPC Congress in May 2009
- To sign: www.hospicecare.com
Individuals who have signed the Joint Declaration

To learn more about this initiative and the organizations coordinating this effort, click here.

To go the IAHP homepage click here.

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<thead>
<tr>
<th>ID</th>
<th>First Name</th>
<th>Last Name</th>
<th>City</th>
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<td>Mattoo</td>
<td>Oklahoma City</td>
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<td>Moscow</td>
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<td>Ana Maria</td>
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<td>Patel</td>
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<td>Cardenas-Turanzas, MD., Dr PH</td>
<td>Houston, TX</td>
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<td>New York</td>
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</table>
June 12, 2009

Her Excellency Mrs. Sahsa Akhalaia-Kodzody,
Permanent Representative of Russia to the United Nations at Vienna,
Chairperson of the 52nd Session of the Commission on Narcotic Drugs
Embassy of the Republic of Russia,
Gussing 13-14,
1030 Vienna,
Austria

Dear Excellency,

We are writing this letter as President and Executive Director of the International Association for Hospice and Palliative Care (IAPPC) on behalf of our Board of Directors, our members and the millions of patients with life-limiting conditions around the world.

The role of hospice and palliative care is to improve the quality of life of patients and their families facing the problems associated with life-limiting illnesses 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.

We urge the UN General Assembly Special Session on Drugs, starting March 11, 2009, to address the lack of access to opioid medications, which leaves millions of people worldwide suffering from severe but manageable pain.

In particular, we urge you to support our campaign calling on member states to provide the availability and accessibility of controlled medications, particularly the WHO Model List of Essential Medicines. The 1961 Convention on Narcotic Drugs notes that these medications are indispensable for the relief of pain and suffering, establishing a balance between preventing abuse while ensuring their availability for medical purposes. However, many member states have implemented strict laws and policies that target drug abuse, ignoring these obligations to ensure legitimate access to pain relief medicines.

As a result, the World Health Organization estimates that tens of millions of people worldwide suffer from severe pain without access to adequate treatment, including severe pain in cancer patients and 1 million end-stage AIDS patients.

Yours Sincerely,

[Signature]

President

[Name]

[Position]

[Address]
Safeguarding public health

Date 2nd September 2009
Dear Colleague,

Updated advice on non-prescription medicines containing codeine or dicyclomine (TIC)

Issue

New warnings and tighter controls on the sales of over-the-counter (OTC) medicines containing codeine or DHC are being introduced to minimise the risk of overuse and addiction to these medicines in line with recent advice from the Commission on Human Medicines (CHM).

Action required

Current stock can be sold through, but pharmacists are asked to support these public health measures by:

- recommending codeine or DHC containing products appropriately for moderate pain in accordance with revised indications within the OTC analgesic range;
- giving key safety messages regarding short term use and avoidance of the risk of addiction by taking for no more than 3 days as recommended;
- noting that packs of more than 32 effervescent form are for dispensing use only.

Background – reason for change

The CHM’s predecessor, the Committee on Safety of Medicines (CSM), considered the risk of addiction to codeine and DHC containing OTCs in 2000. At that time warnings were added to product information and packs sizes were reduced, by voluntary agreement, to 32 with any pack sizes above 32 (namely the effervescent forms) labelled as “dispensing only”. Feedback from patient groups has indicated that the existing warnings of the risks of addiction and overdose headache have not proved effective. Also, analysis of sales data has shown that pharmacists appear to be selling more packs of 100 effervescent paracetamol and codeine products since the reduction in pack size of the other forms.

CHM has now further strengthened its advice to recommend that:

- the warnings on the labels and leaflets of medicines containing codeine or DHC should be further clarified and strengthened;
- large packs of effervescent tablets should be restricted to 32, and
- the existing advertising self regulatory code should be strengthened in line with the new warnings.

Products affected

All OTC solid dose medicines containing codeine or DHC including brands, generics and effervescent forms.

Details

Indications

All indications related to colds, flu, coughs and sore throats, and references to minor painful conditions will be removed. The remaining list of indications will be for the short term treatment of acute, moderate pain which is not relieved by paracetamol, ibuprofen or aspirin alone.

Patient Information Leaflets (PIL) and Labels

The PIL and Labels will state that the products are for short term use only (up to three days) for the treatment of moderate, acute pain, and that the products can cause addiction or overdose headache if used continuously for more than three days. In particular, the following warning will be positioned clearly and prominently on the front of the pack:

‘Can cause addiction. For three days use only’

The PIL will also carry information about the warning signs of addiction, i.e. if the medicine is needed for longer periods and in higher doses than recommended, and if stopping the medicine makes you feel unwell but you feel better when you start taking it again.

This action is being taken in parallel with the Department of Health’s review of policy on addiction to prescription and OTC medicines.

Pack size

All packs greater than 32 of codeine or DHC containing OTC medicines, including effervescent formulations, will no longer be available as P products.

Advertising

The advertising and promotion code of practice for manufacturers and retailers will be updated to reflect the new indications and warnings, and to remove references to painkilling power and strength. Also, all advertisements will include the statement ‘Can cause addiction. For three days use only’.

Timing

Changes to Marketing Authorisations will be completed by 31st December 2009 and all products with the updated information will be on pharmacy shelves 3 – 6 months later. Existing packs of greater than 32 effervescent tablets and marked for dispensing purposes only should be supplied only in accordance with RPSGB guidance.

Further information

For further information on this advice please refer to our website (http://www.mhra.gov.uk) or contact the MHRA Information Centre by email (info@mhra.gsi.gov.uk) or by telephone (020 7061 2000). Visit www.yellowcard.gov.uk for an online Yellow card report.

Yours faithfully,

Shirley Norton
Deputy Director, Vigilance and Risk Management of Medicines
Medicines and Healthcare products Regulatory Agency

MHRA
New warnings and tighter controls on the sale of OTC medicines containing codeine...and reduce the risk of misuse and addiction.

Giving key safety messages regarding short term use and avoidance of the risk of addiction by taking no more than 3 days as recommended...

The PIL and labels will state that products are for short term use for the treatment of moderate acute pain, and that the products can cause addiction if used continuously for more than 3 days. In particular, the following warning will be positioned clearly and prominently on the front of the pack:

“Can cause addiction. For three day use only.”
Partnerships and Collaboration

- **WHO**: Essential Medicines in PC, Cancer Technical Group, Education initiatives in PC, Expert Committee on Drug Dependence
- **Worldwide Palliative Care Alliance**: World Day, Advocacy group
- **European Association for Palliative Care**: Task Force Development of PC in Europe, Support to EAPC Congress
- **UICC**: World Cancer Congress: Palliative Care Seminar
  - GAPRI Project
- **Latin American Association for Palliative Care**: Distance learning course in PC, Nursing Manual
- **SECPAL**: Training for Latin American PC workers
- **PPSG – WHO CC**: (Madison, Wisconsin) International Fellows in Policy Studies
So how can You help?

- By Joining IAHPC as a member
- By joining those who are willing to spend time teaching in a developing country
- By donating to IAHPC
- By helping us identify potential donors
- By spreading the word
www.hospicecare.com

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