Building Global Palliative Care Building a Coalition for Advocacy

Canadian Hospice Palliative Care Association
Worldwide Palliative Care Alliance

UICC Conference, Montreal, Canada, August 28, 2012
Sharon Baxter

Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs

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Outline

- How can coalitions expand our work?
- Two case studies
  - Quality End-of-life Care Coalition of Canada
  - Worldwide Palliative Care Alliance
- Call to action

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How can coalitions expand our work?

- Coalitions expand our reach and include partners that might not otherwise be included in our cause
- Show that what you are asking for has a wide interest and isn't self serving to one group = show wide benefit
- But you need to find the common denominator

Forming the Quality End-of-life Care Coalition of Canada (QELCCC)

- 28 groups from diverse backgrounds over the need to have better access to hospice palliative care
- CHPCA hosted this meeting in 2000 and continues as secretariat to the coalition
- The Blueprint for Action: 2000 – 2010 sets the stage.
- New strategy included committees:
  - Advocacy
  - Caregiver issues
  - Communication
  - Education
  - Research (mostly Knowledge Translation)

QELCCC Mission

The right of every Canadian to
die with dignity, free of pain,
surrounded by loved ones,
in a setting of their choice

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- ALS Society of Canada
- Alzheimer Society of Canada
- Canadian AIDS Society
- Canadian Association of the Deaf
- Canadian Association of Occupational Therapists
- Canadian Association for Spiritual Care
- Canadian Association of Social Workers
- Canadian Breast Cancer Network
- Canadian Cancer Society
- Canadian Cancer Action Network
- The College of Family Physicians of Canada
- Canadian Healthcare Association
- Canadian Home Care Association
- Canadian Hospice Palliative Care Association
- Canadian Lung Association
- Canadian Medical Association
- Canadian Nurses Association
- Canadian Pharmacists Association
- Canadian Society of Palliative Care Physicians
- Canadian Society of Respiratory Therapist
- Canadian Working Group on HIV and Rehabilitation
- Catholic Health Alliance of Canada
- Childhood Cancer Canada
- The GlaxoSmithKline Foundation
- Heart and Stroke Foundation of Canada
- Huntington Society of Canada
- Kidney Foundation of Canada
- Long Term Care Planning Network
- Mental Health Commission of Canada
- National Initiative for Care of the Elderly
- Ovarian Cancer Canada
- Saint Elizabeth Health Care
- VON Canada
- The Pallium Foundation
- Canadian Arthritis Patients Alliance
- Canadian Caregiver Coalition
- Canadian Virtual Hospice
- Long Term Care Planning Network

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QELCCC Cancer groups

- Five national Cancer groups –
  - Canadian Breast Cancer Network
  - Canadian Cancer Society
  - Canadian Cancer Action Network
  - Ovarian Cancer Canada
  - Childhood Cancer Canada
- Disease specific groups
- Professional group
- Home care groups
- Faith based groups
- Seniors groups
- Mental health groups

Leadership in Hospice Palliative Care

Advocacy for policy change...

- Quality End-of-Life Care Coalition of Canada (30+ members)
  - *Blueprint for Action: 2010 – 2020* – released January 28/10

Changing the dialogue about death & dying...

- Advance Care Planning in Canada
  - leading change and encouraging Canadians to engage in the process

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QELCCC Advocacy moving forward

- Identifying the key issues – expansion of programs and funding – four main recommendations
- Multi-level voices are more powerful – joined the Federal, Provincial and local groups together with clear messages
- Making the case – evidence
  - National Fact Sheet on Hospice Palliative Care
  - Integrating research outcomes/findings
  - Quality of Life and Economic arguments made

Advocacy successes

Education

- CHPCA project - Educating Future Physicians on Palliative and end-of-life care (EFFPEC) Project in all 17 medical schools – undergraduate & postgraduate medical training (2008) What about oncology?
- Nursing Competencies and now curriculum (2011)
- Social Work Competencies (2010)
- Canadian Society for Palliative Care Physicians work towards a Palliative Care Specialty (ongoing)

Education

- National Home Support training manual
- First Nations Home Support training manual (2009)
- National Volunteer training manual (2012)
- Involved many QELCCC Members – common ground

Advocacy successes

Caregiver Issues

- Canadian government announces Compassionate Care Benefit – 8 weeks paid leave (2004)

Research

- 16.5 million dollars in HPC research from CIHR finished (2009) but research continues in other ways
- New focus on Knowledge Translation – influencing policy and clinical practice

Advance Care Planning

Speak Up
Start the conversation about end-of-life care

- National initiative brings together NGO, Professional groups, Canadian Bar Association and others
- National Framework – broad consultation

  www.AdvanceCarePlanning.ca
- Speak Up: Start the conversation about end of life care campaign launched April 12th, 2011
- If we can't talk about death and dying then let's talk about how we want to live our lives till the end….
- Developed a repository of over 500 tools

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CHPCA's Champion's Council

Leaders in industry lead the Life Blanket Campaign. Working on Caring Companies.

- Russell Williams, CEO, RxD (chair)
- The Honorable Sharon Carstairs (retired)
- Paul Lucas, former CEO, GlaxoSmithKline
- The Honorable Michael MacDonald
- Kathryn Butler-Malette, Head of HR, House of Commons
- Dr. Balfour Mount, HPC Pioneer
- Michael Sangster, VP, Telus
- Bill Greenhalgh, CEO, Human Resources Professionals Association

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Making a Difference

- Caring communities – more than health
- Integrated programs within health
- Acute care, home based care, long term care, residential hospice and care for those marginalized by society
- Pushing out the four recommendations in the Blueprint for Action – Day on the Hill
- 3 million dollar 3 year national initiative entitled "*The Way Forward: moving towards community-integrated hospice palliative care*"

Coalition challenges

- Losing control of our message as others jump on board – this can be a good thing
- Canadians don't understand the difference between hospice, palliative care, end-of-life care, supportive care and many other terms – we need to move forward and take the lead

Worldwide Palliative Care Alliance

- Our role on the international stage – Worldwide Palliative Care Alliance (WPCA)
- Goals of the WPCA:
  - Access to hospice palliative care worldwide
  - Access to pain and symptom management worldwide

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About the WPCA

- Officially registered in the UK in 2008
- Board of Trustees from every region of the world
- Regional associations at the table i.e. APCA, EAPC, others
- Over 200 national associations, national professional groups, affiliates and friends
- Partners and allied groups on the Advocacy Committee
- Lots of informal/formal alliances on specific issues

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WPCA Advocacy Agenda 2012

- Non Communicable Disease Strategy (NCDS) indicators/Global Monitoring Framework on Non-Communicable Diseases – World Health Organization (WHO)
- World Health Assembly (WHA) inclusion on agenda
- UNAIDS – inclusion of palliative care in care and support
  - Social Protection and Care and Support Working group

WPCA Advocacy Agenda 2012

- WPCA partners with the WHO and OSI work on TB
- WHO and WPCA – to publish the World Atlas in fall 2012
- Conferences
  - International AIDS Conference 2012 – Washington
  - Union of International Cancer Control - Montreal

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WPCA Advocacy Agenda 2012

- Inside alliance/coalition strategy
- Moving international bodies to include palliative care
- Supporting alliance members to be able to do the work they need to do
- World Hospice Palliative Care Day – October 13th, 2012
- Launch of ehospice October 2nd, 2012

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World hospice & palliative care day

13 October 2012

49 days 05h:40m:18s

- Welcome
- About World Day
- News Archive
- Get Involved
- Materials
- Voices for Hospices
- Share Your Story
- Discussion forum
- Events
- Messages of Support
- PR & Press
- Reports
- Partners

Living to the end - palliative care for an ageing population

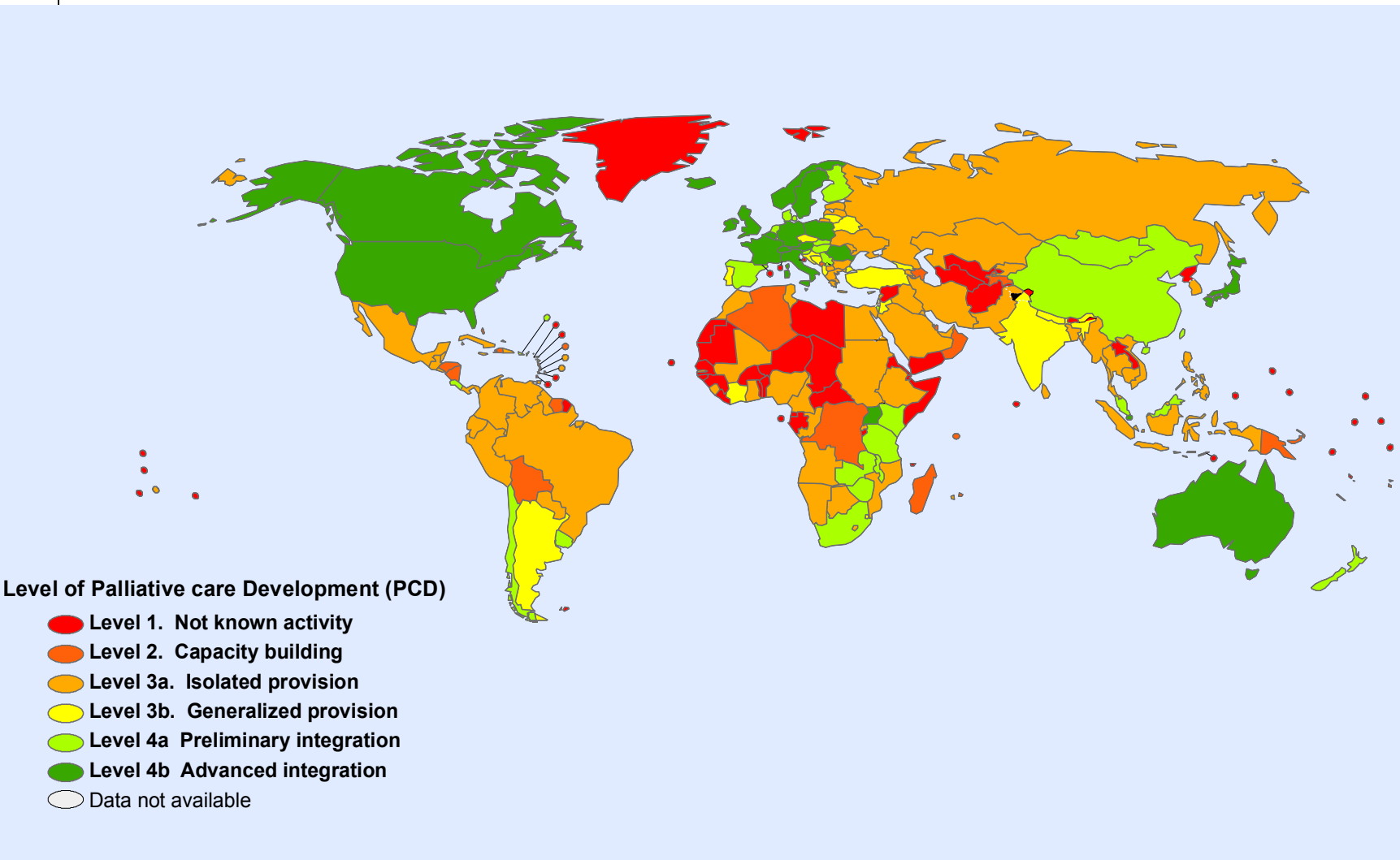
Latest News

- Registration now open for 2012
- See what happened in India
- Read people's stories from World Day
- Congratulations and evaluation
- 42% of countries have no palliative care services
- More news stories...

Latest Events

- World Palliative Care Day 2012 - Luxembourg
- Sacred Music by St. Paul Choral Society - Valetta, Malta
- Okuyamba Fest - South Bend, Indiana, USA
- "Redefining Hope" Ground Breaking Ceremony - Brantford, Ontario
- Palliative Care Center - Esfahan, Iran
- More events

WPCA Palliative Care Development
All levels (n = 234)



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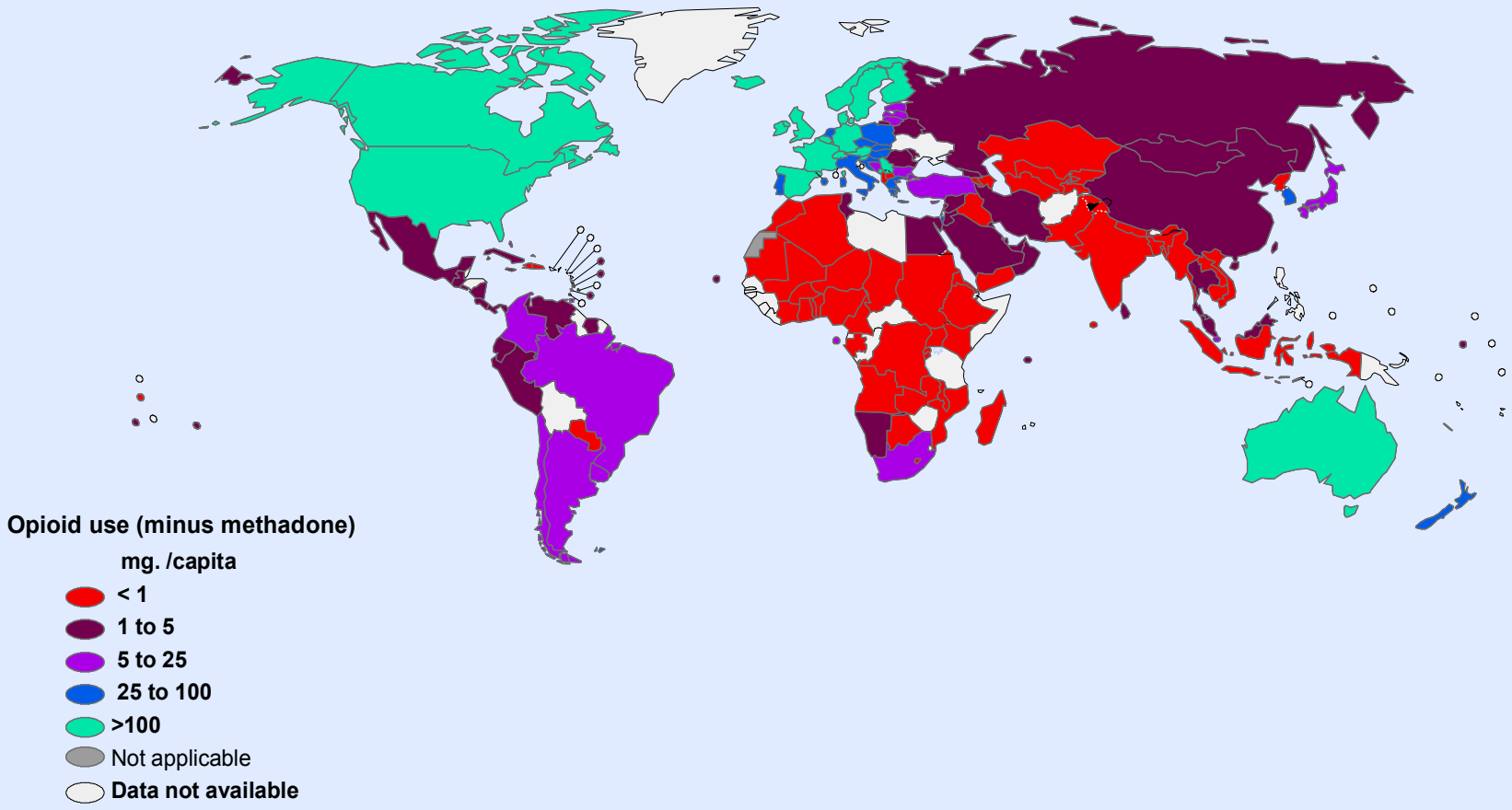
Worldwide Opioid use in mg per capita (minus methadone use) (Both Sexes: 2008)



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ehospice Palliative care news, views and inspiration from around the world

What is ehospice?

- Daily international news app and website
- Platform: Web, Tablet, Mobile
- Delivered by regional and national hospice and palliative care organisations worldwide via separate editions
- Audience: anyone with a professional or personal interest in hospice, palliative and end of life care
- Change the way we learn about what is going on on our own doorstep and on the other side of the world
- The ultimate goal being to improve patient care

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Editions

- Africa – African Palliative Care Association
- Australia – Palliative Care Australia
- Canada – Canadian Hospice Palliative Care Association
- India – Indian Palliative Care Association
- International – Worldwide Palliative Care Alliance
- International children's – International Children's Palliative Care Network
- Kenya – Kenya Hospices and Palliative Care Association
- South Africa – Hospice Palliative Care Association of South Africa
- US – National Hospice and Palliative Care Organization
- UK – Help the Hospices

Others are in the pipeline…

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What you will find on ehospice

ehospice
Palliative care news, views and inspiration from around the world

- Latest palliative care news, commentary and analysis
- Intelligence and examples of good practice/innovation
- Feature articles and ‘thought pieces’
- Details of:
  - current research findings
  - developments in clinical practice
  - funding, scholarship and research opportunities
  - policy developments
- Coverage of major meetings and conferences
- Updates from organizations within the palliative care field

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What you will find on ehospice

ehospice Palliative care news, views and inspiration from around the world

- Inspirational stories ('Be inspired' button)
- Photo/image galleries and videos
- Jobs and events listings
- Directory of hospice and palliative care worldwide via interactive globe
- In short, access to the expertise and experience of the global hospice and palliative care community

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How can ehospice benefit you?

ehospice Palliative care news, views and inspiration from around the world

- Once place where you can access all the latest hospice, palliative and end of life care news
- Great opportunity to circulate your own news and information to a local, national and even global audience
- Share expertise and knowledge with colleagues throughout your country and around the world
- Highlight the exceptional work you do to funders
- Raise your profile nationally and internationally
- Advocate and advocacy campaigns

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Call to Action

- Coalitions work - Get involved!
- Decide on what needs to change
- Decide on who are the decision makers that needs to be influenced
- Align with interested partners – common goals
- Develop your key messages – stick to the script
- Get on side and SPEAK UP!

Be proud to be an advocate!

www.chpca.org
www.advancecareplanning.ca
www.thewpca.org

Thank you

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