

Advocacy for Improved Access to Internationally Controlled Essential Medicines



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Outline

- Introduction: define terms and goals
- Legal/Normative framework: paradigm shift
- UN Organisations
- Agenda 2030
- Recent Progress

Advocacy

- To speak *for*- “voc” from the Latin
 - ❖ patients, families, colleagues
- And to speak *to*
 - ❖ policymakers, opinion leaders, colleagues
- To persuade them to take positive action

The Advocacy *Pallium*

- Multi-lateral conventions/international law
- Published evidence and research
 - ❖ e.g., Lancet Commission Report 2017
- INCB “narcotics” consumption reports
- Bioethical principles

Internationally Controlled PC Medicines

Downloaded from <http://jhp.bmj.com> on March 19, 2014 - Published by group.bmj.com

Cover story

Key concepts in palliative care: the IAHPIC list of essential medicines in palliative care

Liliana De Lima

Background This paper describes the process of developing a list of essential medicines in palliative care based on a consensus of experts.

Method Phase I: guiding principles and identifying the most prevalent symptoms in palliative care. Phase II: identifying the medications used to treat the symptoms, developing an initial list of medicines with a survey of 40 physicians, and implementing a Delphi survey. 112 physicians and pharmacologists were invited to rate the safety and efficacy of each medication. Phase III: representatives of 28 pain and palliative care organisations were invited to a meeting. 26 accepted (93% RR). Participants were split into groups and received the results of the Delphi survey. Groups were instructed to raise the discussions on medications for which at least 50% of the respondents rated both safe and effective (score of 7 or above).

Results 21 symptoms were identified as the most common in palliative care. 120 medications were recommended to treat these symptoms. 71 participants (65% RR) responded to the Delphi survey. A final list with 53 medications was approved as the International Association for Hospice and Palliative Care (IAHPC) essential medicines list for palliative care. There was no consensus among respondents in recommending medications as safe and effective for bone pain, dry mouth, sweating, fatigue or hiccups.

Conclusion Additional research is needed to identify safe and effective medications to treat these symptoms. The IAHPC will soon be implementing a project to update the list of essential medicines in palliative care to reflect these new findings.

Introduction

According to the WHO, essential medicines are those that satisfy the primary health care needs of the population.¹ The concept was introduced by the WHO in 1977 with the recommendation that essential medicines be selected on the basis of their clinical prevalence, evidence on efficacy and safety, and comparison with other medicines. Essential medicines are considered to be available, so that the content of functioning health systems at all times in adequate amounts, in the appropriate dosage forms, with a sound quality and at a price the individual and the community can afford.

To advance application of the concept, the WHO has also developed a model list of essential medicines, which is updated every 2 years. The concept and the model list are presented to countries as expert guidelines which they can use to develop

their own essential medicines policies and lists.

Scope of the problem

According to data from the WHO, in spite of major progress, a large part of the world's population still has little or no access to essential medicines. This is due to economic, socio-cultural, and political factors, particularly among the poor, and no one dares to national consensus.²

A major problem is the lack of access to pain relief. Morphine (immediate and sustained release oral and injectable) is included in the current WHO model list in the analgesic section.³ However, several reports from the United Nations, the WHO, the International Narcotics Control Board and other organisations have indicated that opioid analgesia is not readily available, particularly in developing countries.⁴⁻⁶ In many countries, opioid use is prohibited or restricted by national laws and a controlled by substance laws, regardless of the patient's needs.⁷ Recently, many organisations, individually, academic centres, advocacy groups and pain and palliative care

organisations have been working towards improving access to all medications needed to treat the most common symptoms in palliative care, not just pain.⁸⁻¹⁴

Process and results

The concept of essential medicines can also be applied to palliative care, and under the banner of the WHO Cancer Control Programme requested support from the International Association for Hospice and Palliative Care (IAHPC) to develop a list of essential medicines for palliative care. In response, the IAHPC formed a working group (WG) which included board members of the IAHPC and national leaders. The WG developed a plan of action and a list of essential medicines in palliative care (list) by following these steps:

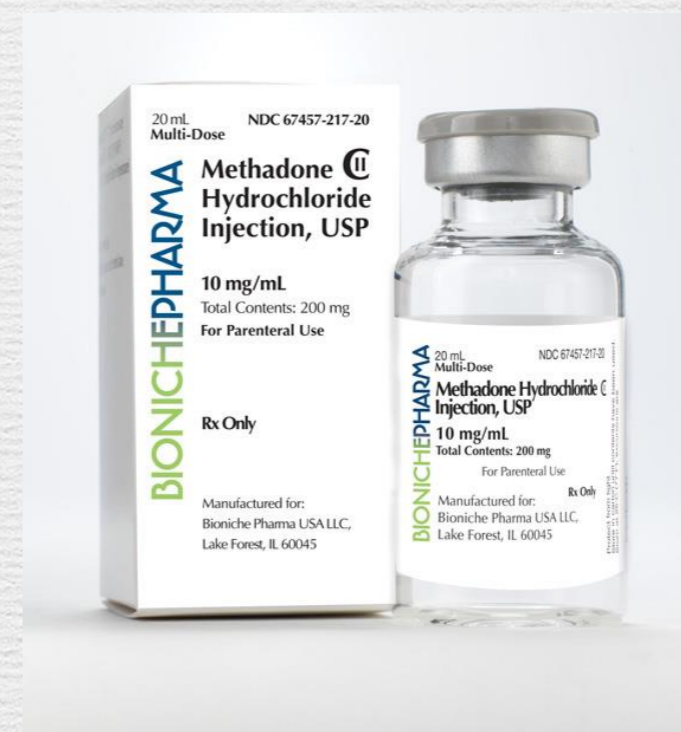
Guiding principles

The following set of principles were also adopted to guide the process:

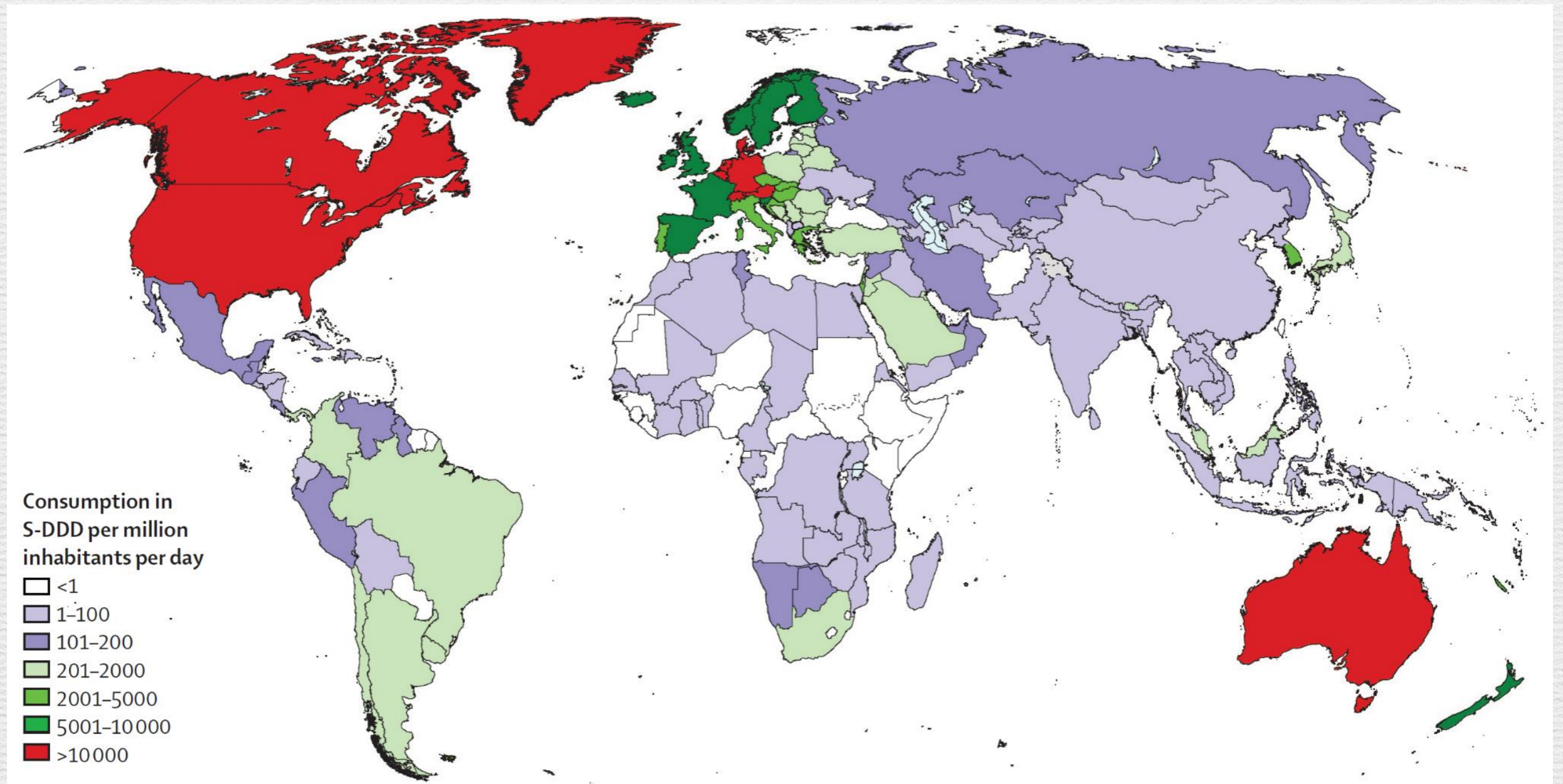
- ▶ The list was developed by palliative care workers from around the world with a commitment to provide palliative care to



WHO Model List



The Clinical Abyss



5.7 billion people (>75% global population)
low to no access

The Epistemic Abyss

- **Opioids carry > century of legal and cultural stigma**
- Many countries have pre-palliative care era regulations
 - ❖ Criminalise legitimate medical use
- Uneducated workforce (including policymakers)

INCB Report 2015

Around **5.5 billion** people still have limited or no access to medicines containing narcotic drugs, such as codeine or morphine, leaving **75 per cent** of the world population without access to proper pain relief treatment.

Around **92 per cent** of morphine used worldwide is consumed in countries in which only 17 per cent of the world population lives: primarily the United States of America, Canada, Western Europe, Australia and New Zealand.

Inadequate access contradicts the notion of article 25 of the Universal Declaration of Human Rights,³ including the right to medical care, which also encompasses palliative care.

Basic Advocacy Agenda

Greater availability, affordability, and accessibility, acceptability of internationally controlled medicines

- Training/certification of healthcare professionals
Inclusion of CM in Essential Medicines Lists
- Rebalance unduly restrictive regulatory frameworks
- Universal Health Coverage

Advocates re-present

- People (patients, families, colleagues)
- Facts about public health:
 - ❖ epidemiology, PC availability, opioid availability
- A Vision:
 - ❖ Communities free of avoidable suffering

Legal/Normative Framework

- Single Convention on Narcotic Drugs
- UN Human Rights Treaties/Conventions
- WHO Constitution/WHA Resolutions
- Sustainable Development Goals — Agenda 2030
- Inter-American Convention on Rights of OP

International Drug Control Paradigm Shift

- From supply control strategies
- Repression: imprisonment, crop eradication, stigmatisation
- Main government actors: Interior and Narcotics Control



To Public Health Approach

- Human rights based/person centred care
- Treatment, prevention, harm reduction
- Improved access to controlled medicines
- Multi-stakeholder collaborations including civil society

2030 Agenda for Sustainable Development



How can PC contribute to SDGs?

- **Addresses population ageing and health**
- **Addresses global burden of NCDs**
- **Absence of PC particularly affects women (Gender)**
 - ❖ **as patients, family caregivers, nurses**
 - ❖ **breast, cervical cancer largest killers**

Target 3.8

- Universal health coverage (protection from catastrophic costs)
- Access to quality essential health-care services, and
- Access to safe, effective, quality and affordable essential medicines and vaccines for all
- Developing PC Indicator with WHO staff now

UN Implementing Agencies

- **UN General Assembly**
(New York)
- **Commission on Narcotic Drugs**
(Vienna)
- **Human Rights Council**
(Geneva)
- **World Health Organisation**
(Geneva)
 - IAHPC in official relations
- **Open Ended Working Group on Ageing** (New York)



Human Rights Council

- Human Rights Council (Geneva)
- Special Rapporteurs/ Independent Experts
- Social Forum
- Universal Periodic Review
- Treaty bodies



Advocacy ethos

- Patient and family at center of concern
- Collaboration and partnership
- Mutual Respect



Palliative Care Virtues

- Courage (to face life-limiting illness together)
- Friendship (*agape* — prioritise good of the other)
- Honesty (*parhessia*) — truth-telling
- Magnanimity — generosity
- Economy of grace

Recent Progress I

- Statements of Human Rights Experts
 - Special Rapporteur for Health, D.Puras
 - Independent Expert on Rights of Older Persons, Rosita Kornfeld Matte
 - Chair of Committee on Rights of Persons with Disabilities

Recent Progress II

- World Health Assembly Resolution on Palliative Care, 2014
- OAS Convention Rights of Older Persons, 2015
- UNGASS on Drugs GA Resolution, 2016
- HRC Resolution on IE Mandate, 2016
- Kampala Declaration, 2016
- Montevideo Declaration 2017
- WHO General Program of Work 2018

Inter-American Convention

- Ratified by Argentina, Bolivia, Brazil, Chile, Costa Rica, Uruguay
- “States Parties shall take steps to ensure that public and private institutions offer older persons access without discrimination to comprehensive care, including palliative care; avoid isolation; appropriately manage problems related to the fear of death of the terminally ill and pain”

OEWGA9

- UN Headquarters July 2018
- Will consider long-term and palliative care
- Series of guiding questions out now

UNGASS 2019

Governments and Civil Society Must Report on Progress:

- **Review** domestic legislation, regulatory, administrative mechanisms
- **Simplify and streamline** distribution processes and regulations
- **Address** issues related to the *affordability* of controlled meds
- **Expand** distribution networks to rural areas
- **Promote** capacity-building and workforce training,

Civil Society Role

- IAHPC Advocacy Hub
 - Foster global provider leadership network
 - Nurture relationships with policymakers
 - Health, Narcotics/Regulatory, Foreign Affairs, Education, Development, Finance

“Never doubt that a small group of thoughtful, committed citizens can change the world; Indeed, it's the only thing that ever has.” Margaret Mead