The need for Palliative Care in Oncology

World Cancer Congress
Oct 3, 2018

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Early Detection

Early Treatment

Prevention

1/3 Prevention

1/3 Treatment

1/3 Palliation

A call to action from the global cancer community

We, the global cancer community, call on governments, international governmental organizations, the international donor community, development agencies, professional organizations, the private sector and all civil society to take immediate steps to slow and ultimately reverse the growth in deaths from cancer, by committing to the targets set out below and providing resources and political backing for the priority actions needed to achieve them.
Cancer Care Continuum

Prevention and Risk Reduction:
- Tobacco control
- Diet
- Physical activity
- Sun and environmental exposures
- Alcohol use
- Chemoprevention
- Immunization

Screening:
- Age and gender specific screening
- Genetic testing

Diagnosis:
- Biopsy
- Pathology reporting
- Histological assessment
- Staging
- Biomarker assessment
- Molecular profiling

Treatment:
- Systemic therapy
- Surgery
- Radiation

Survivorship:
- Surveillance for recurrences
- Screening for related cancers
- Hereditary cancer predisposition/genetics

End-of-life Care:
- Implementation of advance care planning
- Hospice care
- Bereavement care

Survivorship:
- Care planning
- Palliative care
- Psychosocial support
- Prevention and management of long term and late effects
- Family caregiver support

Acute Care
Chronic Care
End-of-Life Care
Intentions of Treatment

Palliative vs Curative

Easy to say, but as oncologist, my role is as warrior against death. #endoflife discussions completely different role. @dmgorenstein

Hope you stay engaged in this chat. Oncology-Palliative partnership is critical. Look at ASCO and AAHPPM and
Survival Curve

% survival

Years

Normal Population

Disease
Cure

% survival

Years

Normal Population

Cure

Disease
Prolongation of Survival

% survival

Years

Disease

Normal Population

Cure

Prolongation of survival
Palliation

Normal Population

% survival

Disease

Years
Intentions of Treatment

Palliative vs Curative
Researchers assessed patients’ and their oncologists’ perceptions of prognosis using the Prognosis and Treatment Perception Perception Questionnaire at 1 month, at which time most patients had received laboratory results confirming their cancer type and stage. Results showed 90% of patients thought cure was somewhat or very likely, whereas 74% of oncologists said cure was unlikely or very unlikely ($P < .001$).

**ABSTRACT**

**BACKGROUND**
Chemotherapy for metastatic lung or colorectal cancer can prolong life by weeks or months and may provide palliation, but it is not curative.

**METHODS**
We studied 1193 patients participating in the Cancer Care Outcomes Research and Surveillance (CanCORS) study (a national, prospective, observational cohort study) who were alive 4 months after diagnosis and received chemotherapy for newly diagnosed metastatic (stage IV) lung or colorectal cancer. We sought to characterize the prevalence of the expectation that chemotherapy might be curative and to identify the clinical, sociodemographic, and health-system factors associated with this expectation. Data were obtained from a patient survey by professional interviewers in addition to a comprehensive review of medical records.

**RESULTS**
Overall, 69% of patients with lung cancer and 81% of those with colorectal cancer did not report understanding that chemotherapy was not at all likely to cure their cancer. In multivariable logistic regression, the risk of reporting inaccurate beliefs about chemotherapy was higher among patients with colorectal cancer, as compared with lung cancer ($P < .001$).
Curative, Life-Extending, and Palliative Chemotherapy: New Outcomes Need New Names

ALFRED I. NEUGUT, Holly G. Prigerson

a Department of Medicine and Herbert Irving Comprehensive Cancer Center, College of Physicians and Surgeons, and Department of Epidemiology, Mailman School of Public Health, Columbia University, New York, New York, USA; b Center for Research on End-of-life Care and the Department of Medicine, Weill Cornell School of Medicine, New York, New York, USA

Disclosures of potential conflicts of interest may be found at the end of this article.

Table 1. Chemotherapy terms, intent, and recommendations

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<td>Intent is cure; cure implies patient survival will not be restricted by his/her current cancer diagnosis</td>
<td>Retain, but apply as appropriate given operationalization of “cure” for the tumor that is being treated</td>
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Abbreviations: ABVD, doxorubicin/bleomycin/vinblastine/dacarbazine; BEP, bleomycin/etoposide/cisplatin; FOLFIRINOX, leucovorin/5-fluorouracil/irinotecan/oxaliplatin; FOLFOX, leucovorin/5-fluorouracil/oxaliplatin.
# Commentary

**Curative, Life-Extending, and Palliative Chemotherapy: New Outcomes Need New Names**

ALFRED I. NEUGUT,† HOLLY G. PRIGERSON†

†Department of Medicine and Herbert Irving Comprehensive Cancer Center, College of Physicians and Surgeons, and Department of Epidemiology, Mailman School of Public Health, Columbia University, New York, New York, USA; ‡Center for Research on End-of-life Care and the Department of Medicine, Weill Cornell School of Medicine, New York, New York, USA

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Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

Integration of Palliative Care Into Standard Oncology Care: American Society of Clinical Oncology Clinical Practice Guideline Update


ABSTRACT

Purpose
To provide evidence-based recommendations to oncology clinicians, patients, family and friend caregivers, and palliative care specialists to update the 2012 American Society of Clinical Oncology (ASCO) provisional clinical opinion (PCO) on the integration of palliative care into standard oncology care for all patients diagnosed with cancer.

Methods
ASCO convened an Expert Panel of members of the ASCO Ad Hoc Palliative Care Expert Panel to develop an update. The 2012 PCO was based on a review of a randomized controlled trial (RCT) by the National Cancer Institute Physicians Data Query and additional trials. The panel conducted an updated systematic review seeking randomized clinical trials, systematic reviews, and meta-analyses, as well as secondary analyses of RCTs in the 2012 PCO, published from March 2010 to January 2016.

Results
The guideline update reflects changes in evidence since the previous guideline. Nine RCTs, one quasiexperimental trial, and five secondary analyses from RCTs in the 2012 PCO on providing palliative care services to patients with cancer and/or their caregivers, including family caregivers, were found to inform the update.

Recommendations
Inpatients and outpatients with advanced cancer should receive dedicated palliative care services, early in the disease course, concurrent with active treatment. Referral of patients to interdisciplinary palliative care teams is optimal, and services may complement existing programs. Providers may refer family and friend caregivers of patients with early or advanced cancer to palliative care services.

J Clin Oncol 35:96-112. © 2016 by American Society of Clinical Oncology
The ESMO **Clinical Practice Guidelines** (CPG) are intended to provide the user with a set of recommendations for the best standards of cancer care, based on the findings of **evidence-based medicine**.

**Latest enhanced and revised set of guidelines**

Supportive and palliative care are areas of **high importance in oncology** and ESMO published Clinical Practice Guidelines on the management of a variety of issues: Constipation in advanced cancer, Delirium in Adult Cancer Patients, Diarrhoea in adult cancer patients, Management of anaemia and iron deficiency in patients with cancer, Management of infusion reactions to systemic anticancer therapy, Management of toxicities from immunotherapy, Management of febrile neutropaenia, MASCC and ESMO consensus guidelines for the prevention of chemotherapy and radiotherapy-induced nausea and vomiting, Treatment of dyspnoea in advanced cancer patients, Central venous access in oncology, Management of oral and gastrointestinal mucosal injury, Management of refractory symptoms at the end of life and the use of palliative sedation, Advanced care planning in palliative care, Bone health in cancer patients, Cancer, fertility and pregnancy, Management of chemotherapy extravasation, Cardiovascular toxicity induced by chemotherapy, targeted agents and radiotherapy, Management of cancer pain, Management of venous thromboembolism in cancer patients.
Palliative Care in the Global Setting: ASCO Resource-Stratified Practice Guideline

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Sudip Shrestha
Sarah Temin
Zipporah V. Ali
Rumalie A. Corvera
Henry D. Ddungu
Liliana De Lima
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Frank L. Lu
Daniela Moshou
Christina Puchalski
Carole Seigel
Olaitan Soyannwo
James F. Cleary

Purpose The purpose of this new resource-stratified guideline is to provide expert guidance to clinicians and policymakers on implementing palliative care of patients with cancer and their caregivers in resource-constrained settings and is intended to complement the Integration of Palliative Care Into Standard Oncology Care: American Society of Clinical Oncology Clinical Practice Guideline Update of 2016.

Methods ASCO convened a multidisciplinary, multinational panel of experts in medical oncology, family medicine, radiation oncology, hematology/oncology, palliative and/or hospice care, pain and/or symptom management, patient advocacy, public health, and health economics. Guideline development involved a systematic literature review, a modified ADAPTE process, and a formal consensus-based process with the Expert Panel and additional experts (consensus ratings group).

Results The systematic review included 48 full-text publications regarding palliative care in resource-constrained settings, along with cost-effectiveness analyses; the evidence for many clinical questions was limited. These provided indirect evidence to inform the formal consensus process, which resulted in agreement of ≥75% (by consensus ratings group including Expert Panel).

Recommendations The recommendations help define the models of care, staffing requirements, and roles and training needs of team members in a variety of resource settings for palliative care. Recommendations also outline the standards for provision of psychosocial support, spiritual care, and opioid analgesics, which can be particularly challenging and often overlooked in resource-constrained settings. Additional information is available at www.asco.org/resource-stratified-guidelines.

Recommendations It is the view of ASCO that health care providers and health care system decision makers should be guided by the recommendations for the highest stratum of resources available. The guideline is intended to complement but not replace local guidelines.
## ASCO Guideline Panel Members

<table>
<thead>
<tr>
<th>Name (and designation)</th>
<th>Affiliation/Institution</th>
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<tbody>
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</tr>
<tr>
<td>Sarah Temin, Staff, Health Research Methodologist</td>
<td>American Society of Clinical Oncology, Alexandria, VA</td>
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Clinical Questions

The clinical practice guideline addresses seven overarching questions:

(1) Who should provide palliative care in the absence of specialized palliative care physicians and what is the minimum training necessary to meet the palliative care needs of the community (whether by an oncologist or other clinicians/providers)?

(2) What is the most effective model of palliative care delivery?

(3) When is best to involve a palliative care team in cancer care?

(4) What is the role of the nurse in palliative care assessment, pain and symptom control, and prescriptions (opioid prescriptions)?

(5) At what level of health care (health centers, dispensary, hospitals) should oral opioids be available?

(6) What is the place of spiritual care in palliative care?

(7) What are the roles of social workers/counselors in palliative care?
Summary of Recommendations

CLINICAL QUESTION 1
What is the most effective model of palliative care delivery?

Recommendation 1.0 General: There should be a coordinated system where the palliative care needs of patients and families are identified and met at all levels, in collaboration with the team providing oncology care. The health care system should have trained personnel who are licensed to prescribe, deliver, and dispense opioids at all levels. Distance communication should be instituted at the national or regional level through oncology centers (or other tertiary care centers) to support those providing oncology care to patients in lower resource areas. (Type: Formal consensus; Not Rated)

Recommendation 1.1 Basic (Primary Health Care): Palliative care needs should be addressed in the community or at the primary health care center. These needs may be addressed by primary healthcare providers, nurses, community health workers, volunteers, and/or clinical officers. (Type: Evidence based and formal consensus; Evidence quality: Intermediate; Strength of recommendation: Moderate)
Summary of Recommendations

**Recommendation 1.2 Limited (District):** In addition to provision of palliative care in the community and at primary health care centers, outpatient palliative care services should be established. When a counselor is not available, psychosocial and spiritual needs may be addressed by team members trained in basic palliative care. (Type: Formal consensus; Evidence quality: Intermediate; Strength of recommendation: Moderate)

**Recommendation 1.3 Enhanced (Regional):** In addition to the community-based and outpatient palliative care services available at the limited level, inpatient consultation services should be available to hospitalized patients with palliative care needs. Consultation services should be provided by an interdisciplinary team including (but not limited to) a physician, nurse, counselor, and pharmacist. Mental health and spiritual services may be added to the team when possible. (Type: Formal consensus; Evidence quality: Intermediate; Strength of recommendation: Strong)

**Recommendation 1.4 Maximal (National):** In addition to the palliative care services available at the enhanced level, dedicated inpatient palliative care beds should be established, staffed with trained professionals. No oncology center, hospice, or palliative care facility should exist without a well-developed palliative care team, with its different specialties. (Type: Formal consensus; Not Rated)
Over the wall!

Standard Medical Care  Hospice
Palliative Care

Standard Medical Care

Hospice

Bereavement
Modern Model

Focus of Care

Traditional Care

Palliative Care

Hospice

Diagnosis
Symptom Burden
6-Month Prognosis
Death

Time →

Campbell TC et al Semin Intervent Radiol 2007
Accelerating the implementation of the World Health Assembly Resolutions on palliative care

Designing and executing national programmes for the implementation of the World Health Assembly Resolution on palliative care in Africa

Dr Emmanuel Luyirika
African Palliative Care Association
Roles and responsibilities in the 2014 WHA Palliative Care Resolution

These fall on:

• WHO member states
• Training and Education institutions
• Civil Society and patients’ organisations
• The WHO through its Director General
• Other international agencies such as UNICEF, INCB
• Care givers in general
Roles of members states

1. To develop, strengthen and implement, where appropriate, **palliative care policies** to support the comprehensive strengthening of health systems to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels, with emphasis on **primary care, community and home-based care**, and **universal coverage schemes**;

2. To ensure adequate domestic **funding** and allocation of human resources, as appropriate, for palliative care initiatives, including development and implementation of palliative care policies, education and training, and quality improvement initiatives, and support the availability and appropriate use of essential medicines, including controlled medicines for symptom management
Roles of members states

3. To provide basic support, including through multisectoral partnerships, to families, community volunteers and other individuals acting as caregivers, under the supervision of trained professionals, as appropriate.
Roles of members states

4. include palliative care as an **integral component** of the ongoing **education and training** offered to care providers according to the following principles:

- **basic training** and continuing education on **PC** integrated in all undergraduate **medical & nursing** professional education, in-service training of caregivers

- **intermediate** training offered to all health care workers working with patients with **life-threatening illnesses**, such as in **oncology, infectious diseases, paediatrics**, geriatrics and internal medicine;

- **specialist** palliative care training to prepare health care professionals who manage integrated care for patients
Roles of members states

5. to assess domestic palliative care needs, including pain management medication requirements, and promote collaborative action to ensure adequate supply of essential medicines in palliative care, avoiding shortages

6. to review and revise national and local legislation and policies for controlled medicines, with reference to WHO policy guidance, on improving access to and rational use of pain management medicines, in line with the United Nations international drug control conventions
Roles of members states

7. to **update**, as appropriate, **national essential medicines lists**, in the light of the recent addition of sections on **pain** and **palliative care medicines** to the WHO Model List of Essential Medicines and the WHO Model List of **Essential Medicines for Children**;

8. to foster **partnerships** between **governments** and civil **society**, including **patients’ organizations**, to support, as appropriate, the provision of services for patients requiring palliative care;

9. to **implement and monitor** palliative care actions included in WHO’s global action plan for the prevention and control of NCDs 2013–2020;
Roles of Civil society

• The resolution recognises the role already played by NGOs

• The resolution encourages partnership between governments and civil society organisations to support service provision in palliative care
The first African Health Ministers’ session on palliative care

- The momentum of African ministers of health to support the resolution started at the inaugural African ministers of health session on palliative care in South Africa in 2013 by APCA, HPCA-SA and MoH South Africa which attracted 92 delegates from 23 countries.

- The main outcome from the Ministers of Health session was the adoption of a “Consensus statement for palliative care integration into health systems in Africa: ‘Palliative Care for Africa’.

- Inspiration from this session and the consensus statement were used by African Governments and APCA in advocacy leading to the passing of the historical 2014 World Health Assembly resolution on palliative care.
The second African Health Ministers’ session on palliative care

- The Second African Ministers of Health in 2016 in Kampala, Uganda co-hosted by APCA, WHPCA and Uganda’s Minister of Health, Hon. Jane Ruth Aceng and opened by the Ugandan Prime Minister Dr Ruhakana Rugunda

- The session focused on state obligations in implementing the 2014 WHA Palliative Care resolution and attracted 163 delegates from 48 countries.

- The main outcome was adoption of a Consensus statement “The Kampala Declaration 2016.” that focused on implementing the 2014 WHA Resolution and adoption of appropriate technologies.

- The Kampala Declaration was presented by the Ugandan Health Minister at the African Health Ministers’ meeting at the African Union which took place soon after the session.

- The session resulted into accelerated implementation of national level palliative care programmes in several African countries including Kenya, Uganda, Togo, The Gambia, Liberia, Sudan, Botswana and South Africa, among others.

- The session was sponsored by the True Colours Trust
Follow up to the second ministers of health palliative care session

• Following the 2016 ministers’ session and the conference, APCA engaged the session sponsor – the True Colours Trust now funding an 18 months project in three countries – Liberia, The Gambia and Togo.

• The project involved in-depth country situational analysis, formal partnership with ministries of health based on agreements/MoUs, technical assistance has been provided by APCA to address their needs and priorities.

• A commitment for sustainability of the national programme and outcomes of the project was obtained by APCA from the Ministries at the start of the project.
The third African Ministers of Health Palliative Care Session 17th Sept 2019

• The 3rd session is to be co-hosted by the Minister of Health of Rwanda in Kigali in September 2019

• Aims to engage countries on importance of palliative care and pain relief and financing it as part of the essential package for universal health coverage.

• The session is to inspire African Governments to ensure inclusion of palliative care and pain relief in UHC schemes

• It will build the momentum of African Governments towards the inclusion of palliative care and pain relief in the deliberations and outcome document from the UN high-level meeting on UHC in 2019.

• Sponsorship of this session is still open to willing partners
SAVE THE DATE!

Palliative Care and Universal Health Coverage
6th International African Palliative Care Conference
17-20 SEPTEMBER 2019
Kigali, RWANDA

HOSTED BY
African Palliative Care Association and the Ministry of Health of the Republic of Rwanda

conference2019@africanpalliative.org
www.africanpalliativecare.org Tel +256 393 264978
Acknowledgements

The True Colours Trust
OSF
OSIEA
OSISA
Treat the Pain/American Cancer Society
African Union
WHO
IAEA-PACT
UICC
HPCA-SA and other national associations
WHPCA
IAHPC
Ministries of Health of South Africa and Uganda
Thank you

Contact details: emmanuel.luyirika@africanpalliativecare.org
www.africanpalliativecare.org
FROM NO PALLIATIVE CARE TO A NATIONAL SUSTAINABLE PALLIATIVE CARE PROGRAM: EXPERIENCES FROM A LOW-AND-MIDDLE INCOME COUNTRY (TOGO)

Kokou Nouwame Alinon, Msc, Ph.D
MASHAV & UICC Alumnus Fellow; Humphrey Fellow 2018-2019
Focal Point of Palliative at the Ministry of Health and Social Protection
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Geographic characteristics & location

- Area: 56,000 square kilometers
- Population: 7,500,000 habitants
- Pop < 15: 42%
- Currency: Francs CFA
- National language: French
- Local languages: Ewe, Kabye
- Tropical climate
- Capital: Lomé
Health System: Three-Level Health Pyramid

I - Central Level
➢ Cabinet of the Ministry (National Health Policy)
➢ 3 National Hospitals (3 CHU)
➢ 1 National Reference Laboratory (INH)
➢ 1 CNTS, 1 CNA0 et 1 hôpital psychiatrique.

II- Intermediate or Regional Level (Implementation of Health Policy) and National Guidelines
➢ 6 Regional Health offices (DRS)
➢ 6 Regional Hospital (CHR)
➢ 1 CRTS & 1 CRAO

III- Peripheral Level (Health Policy Operationalization)
➢ 44 Health district offices,
➢ 44 district Hospitals
➢ Health Centers (USP)
Governance and Policy towards the integration of Palliative Care (PC) in the Health System

- First African Ministers of Health Session in 2013 on PC
- Second Session of the African Ministers of Health on PC (Uganda 2016)
- Engagement for the implementation of the 2014 WHA Resolution on PC
- Full-time staff for PC within the National NCD program.
- Inclusion of PC in the Health Sector Strategic Plan (HSSP) and in the National Development Plan for NCDs (2017-2022)
- Partnership with APCA, HAU and MdM Switzerland.
Palliative Care Project in Togo through the Partnership with APCA

❖ **Project title**
- Implementation of the World Health Assembly resolution on PC in Togo

❖ **Main Objectives of the project**
- To establish national level priorities for the integration of PC in the Health System.
- To support the implementation of key priorities in Togo through a formal partnership with the Ministry of Health and Social Protection.
- To produce the oral liquid morphine and integrate it into the National Essential Medicines List
# Project’s Stakeholders

<table>
<thead>
<tr>
<th>Stakeholders</th>
<th>Image</th>
</tr>
</thead>
<tbody>
<tr>
<td>MSPS - NCD</td>
<td><img src="image1.png" alt="Image of MSPS - NCD stakeholders" /></td>
</tr>
<tr>
<td>WHO</td>
<td><img src="image2.png" alt="Image of WHO stakeholders" /></td>
</tr>
<tr>
<td>CHU SO</td>
<td><img src="image3.png" alt="Image of CHU SO stakeholders" /></td>
</tr>
<tr>
<td>CAMEG-PHARMACY-CNAD</td>
<td><img src="image4.png" alt="Image of CAMEG-PHARMACY-CNAD stakeholders" /></td>
</tr>
<tr>
<td>PRIVATE HOSPITAL</td>
<td><img src="image5.png" alt="Image of PRIVATE HOSPITAL stakeholders" /></td>
</tr>
<tr>
<td>LOCAL NGOs &amp; PC ASSOCIATIONS</td>
<td><img src="image6.png" alt="Image of LOCAL NGOs &amp; PC ASSOCIATIONS stakeholders" /></td>
</tr>
</tbody>
</table>
Indicators for measuring the integration of Palliative Care in Togo’s Health System (1)

- Integration of PC in the Health Sector Strategic Plan (HSSP) and the National Development Plan for NCDs (2017-2022)
- Existence of a functional multidisciplinary and multi-sectoral Palliative Care task force through APC’s project
- Existence of a full-time staff for PC within the National NCD program.
- Existence of PC Associations and NGO
- Existence of Population-Based Cancer registry desk
Indicators for measuring the integration of Palliative Care in Togo’s Health System (2)

- 6 Regional Hospitals, 2 Private Hospitals and 3 National level Hospitals’ management teams were sensibilized on PC.

- 25 Health Care workers in CHU SO received 5 day of training on PC through APC’s project.

- 25 Policy makers sensibilized on PC through APC’s project.

- 60 Health Care workers have been oriented to Paediatrics PC through a 2 day conference and one day training.
Indicators for measuring the integration of Palliative Care in Togo’s Health System (2)

- 8 Health Care workers trained on PC through a 6 weeks course in HAU
- 8 Health Care workers trained through a 2 weeks course by a team from Korea
- 3 Hospitals with established PC services following the partnership with APCA, HAU and MdM Switzerland
- Allocation of a budget for the procurement of the morphine powder.
PC Activities with APCA
PC Activities with MdM
Activities currently in process on Palliative Care (PC) (1)

- Country national situation analysis documented
- Country reports on estimation of need for PC
- Introduction of PC in curricula of medical, nursing and other professionals
- Capacity building of CHU SO Hospital to become a center of excellence for PC (Pediatrics & Adult) for others hospital
- Integration of morphine in the National Essential Medicines List
- Definition of National Level Indicators for regular data collection on PC
Activities currently in process on Palliative Care (PC) (2)

- National guideline for best practices in Peadiatrics & Adult PC
- Support to PC Associations and NGOs to improve their services
- Nation Program of PC that includes all diseases requiring
- Securing production site for morphine reconstitution
- Peadiatrics & Adult PC unities and Mobile team for home care in CHU SO Hospital
- New project on Peadiatrics PC with MdM
Conclusion

❖ Many challenges to deal with:
➢ Low funding for PC
➢ Physicians' fear of morphine products prescription
➢ Weakness of the Health System (No Radiotherapy and other facilities for cancer patients)
❖ But, Very strong political will for the integration of PC in the Health System

Dr Kokou Nouwame Alinon. E-mail: alinonkokou@gmail.com/kokou.alinon@emory.edu
A new approach to palliative care

Ednин Hamzah
Hospis Malaysia
In 10 mins

• Perception of palliative care
• Communication by palliative care services
• Changing the conversations
Malaysia’s achievement in UHC is defined as ensuring that all people can use the promotive, preventative, curative, rehabilitative and palliative care health services they need, of sufficient quality to be effective, whilst also ensuring that all people have the access to all services and do not incur financial hardship to pay for them.
Implementing WHA palliative care resolution

• Governments may develop palliative care friendly policies and guidelines
• Improve access to medicines and pain relief
• Adequate funding for palliative care
• Caring for children

but
EXTRA! EXTRA!
READ ALL ABOUT IT!
FAKE NEWS!
Fake News on Palliative Care

- Giving up
- Only when dying
- Only when doctors cannot do anything else
- Only for poor patients
- If you tell them, they will give up
- Morphine is addictive
It's hospice care

It's palliative care

It's supportive care

It's the care of the terminally ill

It's the end of life care folks!

It's BEST supportive care
How does it feel to be a patient?
The medical team
Who decides?
Family and relatives
Healthcare in the community
Healthcare systems
When illness progress
End of life issues
Palliative Care Needs Assessment

Malaysia

- Palliative Care needs analysis
- Public survey about palliative care
- Mapping of community palliative care service with a suggestion to ‘standards’
Public awareness

• 90% not aware
• 60% wanted care at home
• 75% expected to care for another family member
• 90% had not prepared / thought of advance care plans
• 75% fear of upsetting their families
Palliative Care is about the messaging

• Those touched by palliative care become advocates
• Those that don’t are fearful
• Patients / public complain about the palliative care messaging
  – Terminal care
  – Dying
  – Grief and bereavement
IF IT IS ESTIMATED THAT EVERY YEAR, 30,000* PEOPLE ARE IN NEED OF PALLIATIVE CARE, WHO IS TREATING THEM?

Palliative care is a holistic form of care that addresses the physical and mental well-being of patients and families facing problems associated with life-limiting illnesses. These illnesses include cancer, HIV/AIDS, organ failure or degenerative neurological disorders. Hospis Malaysia is a key palliative care provider. Our vision is to provide the highest quality of palliative care so as to provide relief from, and prevent pain and suffering associated with progressive and life-limiting illnesses.

OUR SERVICES INCLUDE:

- Patient Services
- Training, Education & Research
- Public Awareness & Advocacy

HOW WE SPEND OUR MONEY

- Patient services 62%
- Education, Training & Research 23%
- Public Awareness & Advocacy 9%
- Administration 6%

However, we cannot do this alone. Hospis Malaysia relies almost entirely on charitable contributions from the public to continue our mission to help families and individuals achieve support, hope and promote quality of life.

Donate to us at hospismalaysia.org/donate

* Source: Dr Lim, Richard. “More palliative care specialists needed”. The New Straits Times [Kuala Lumpur], 12 April 2015
A hunt for awareness

Spreading awareness about the need for better palliative care

People should have better access to palliative care

The Little Stars in our midst

The documentary Little Stars: Accomplishing the Extraordinary in the Face of Serious Illness aims to put children's palliative care on the global media and public health agenda.

Palliative care more effective with national standards

The following principles guide the provision of palliative care services, as well as other health-care services: evidence-based care, patient and family centered care, interdisciplinary care, comprehensive care, and community-based care.

Importance of palliative care training in healthcare education

By Dr. Chong Lee Ai

Need for a holistic approach to medical education

Palliative care must be integrated into the education and training of healthcare professionals in order to ensure that all healthcare providers have the necessary skills and knowledge to provide quality palliative care services. This includes medical students, nurses, pharmacists, and other allied health professionals.

There is a lack of national palliative care professionals in the country. Malaysia needs to be a leader in organizing regular palliative care courses and seminars.
Patient/Family Advocates
TESTIMONIALS

Raja Kumar

Raja Kumar is an affable, friendly man who can chat with a room full of strangers easily. A proud husband and father, he used to immerse himself in hands-on hobbies like photography. A skilled Tabla player, he used to play the classical Indian drum at his local church in Brickfields every Sunday. Religion and spirituality play a significant role in his life.

In 2010, Raja Kumar was diagnosed with multiple myeloma, a type of cancer that affects the blood. He is doing his best to remain upbeat and cheerful and to get as much enjoyment as he can with his family and friends.

Raja Kumar recalls the time he first learnt of his diagnosis as terrifying, “I didn’t want to be admitted to a hospital ward full of cancer patients, I wasn’t prepared to identify myself as one.” At the time, the disease had affected his spinal cord. This hampered his ability to walk, and he was confined to bed rest.
Patient testimonials at palliativecare.my
CELEBRITY MESSAGES

Sheila Majid believes that individual choice is essential for those facing life-limiting illnesses.

Elaine Daly believes that governments should invest more in palliative care.

Hans Isaac believes that the more people know about palliative care, the more people will benefit from it.

Melinda Looi believes that it’s important for patients with life-limiting illnesses to talk about their treatment options.

SHEILA MAJID
View More

ELAINE DALY
View More

HANS ISAAC
View More

MELINDA LOOI
View More
What do people think?
Reflection

• The care is the same, the messaging is positive
• Improved acceptability in community
• More positive association
Speak Up
there's an elephant in the room

www.speakup.com.my
#speakupforpalliativecare
Conclusion

• A death defining approach may not always be culturally acceptable
• Positive messages is associated with hope and empowers patients and families
• Will assist governments in implementing palliative care resolutions
Increasing Access to Controlled Drugs while Preventing Diversion, Misuse and Abuse: Global Vision

Elizabth.mattfeld@unodc.org
What does success look like?
The International Drug Control Conventions

Single Convention on Narcotic Drugs of 1961 as amended by the 1972 Protocol

Convention on Psychotropic Substances of 1971

United Nations Convention against Illicit Traffic in Narcotic Drugs and Psychotropic Substances of 1988
The International Drug Control Conventions

Protecting the health of people from the dangerous effects of drugs is **NOT** in conflict with promoting the medical and scientific use of controlled drugs.
“Foundation Documents”

INCB

2010 Report of the International Narcotics Control Board on the Availability of Internationally Controlled Drugs: Ensuring Adequate Access for Medical and Scientific Purposes

2015 Report of the International Narcotics Control Board on the Availability of International Controlled Drugs: Ensuring Adequate Access for Medical and Scientific Purposes: Indispensable, adequately available and not unduly restricted
Ensuring balance in national policies on controlled substances: Guidance for availability and accessibility of controlled medicines
“Foundation Documents”

UNODC
2011 Ensuring Availability of Controlled Medications for the Relief of Pain and Preventing Diversion and Abuse
“Foundation Documents”

UNODC
Technical Guidance: Increasing access and Availability of Controlled medicines

Advanced Draft 2018
“High-Level Political Documents”

Political Declaration and Plan of Action 2009

Outcome Document of the 2016 UNGASS
Global Data

Access imbalance for the world’s population

5.5 billion (83%): low or non-existent access

250 million (4%): moderate access

460 million (7%): adequate access

430 million (6%): insufficient data

WHO, 2011
Global Data

Disparity in the global consumption or access to pain medication

- Canada and US with 812 and 749 ME/mg/cap
- Nigeria and Myanmar with 0.014 and 0.015 ME/mg/cap

High income countries: 17 per cent of population account 92% of medical morphine

Half of the countries reporting to INCB in 2011 consumed less than 1 mg of morphine per person
UNODC-WHO-UICC Joint Global Program

UNODC

WHO

UICC

Legislation and policies

Community Awareness

Build capacity of healthcare workforce
UNODC-WHO-UICC Joint Global Program

- Global Advocacy and Partnerships
- National Strategic Planning
- National Policy and Guidelines
- Data and research
UNODC-WHO-UICC Joint Global Program

Healthcare workforce

Vulnerable Population
Patient Centered
Positive Environment
Prevent diversion

Systems

Responsive supply chain
Economic Structures
Integrated Systems
Consistent policies
UNODC-WHO-UICC Joint Global Program

Establishing technical guidance on increasing access to, and availability of controlled drugs for medical purposes:
Key areas of focus

Expert Group Meeting – September 2017
3 Core Areas

- Systems Integration
- Supply Chain Management
- Education and Awareness
Economic Structure

Data and research

Consistent Messaging

Prevent Diversion, Non-medical use

Patient Centered Care

Data and research → Economic Structure → Consistent Messaging → Prevent Diversion, Non-medical use → Patient Centered Care → Economic Structure
Economic Structure

Data and research

Consistent Messaging

Prevent Diversion, Non-medical use

Education and Awareness

Supply Chain Management

Patient Centered Care

Systems Integration
Core Areas and Cross-Cutting Themes

Foundation Actions

Enhancing Actions
Core Area:  Education and Awareness

Foundation Actions

- Train healthcare workforce
- Minimum understanding of both health and regulatory
- Compulsory – evaluate pain
- Mandatory continuing education
- Community level capacity building
Core Area: Education and Awareness

- Everyone gets basic training
- Non-traditional partners engaged
- Standard national curricula
- Professional associations
- Sector specific advocacy
- Credentialing for experts
- Address stigma
- Ethics training
- Mentoring and Peer programs
- Role of Faith

Enhancing Actions
Cross-Cutting Theme: Messaging

Foundation Actions

- Review legislation and policy
- Sector reports
- Engage non-traditional partners
- Use non-traditional strategies of engagement
Cross-Cutting Theme: Messaging

- Inclusive approach – all patients, all healthcare workers
- Create common language in policy and practice
- Palliative care technical experts train policy makers and vice versa

Enhancing Actions
Cure sometimes, treat often, comfort always.

Hippocrates
Accelerating the implementation of the World Health Assembly Resolutions on palliative care and cancer: A National Perspective

Mawuli Gyakobo PhD, FWACP, FGCP
Ghana College of Physicians and Surgeons &
University of Cape Coast, Ghana
2018 Population: 29,624,068

Male: 50.9%
Female: 49.1%

GDP Per Capita: $4,700 (est. 2017)

D/P = 1 : 11,494
N/P = 1 : 1,510
M/P = 1 : 6,599

HIV/AIDS Adult Prev. Rate: 1.7% (2017 est)
Palliative care situation in Ghana

- Baseline survey (2015) of regional teams: 13 teams inequitably distributed
- Presently >50 teams and facilities in palliative care
- Increasing by 2 a month
Scaling up palliative care and pain management -- national

Short term
- National policy
- Continuing Medical Education

Long term
- Amalgamation into curricula of health training institutions
Short term / 1

- Hospital Team-Based GHS led approach
  - One time workshop
  - Interdisciplinary team from each region
  - Externally funded
  - @200 health staff trained from all 10 regions

- Weakness:
  - Team attrition over years from transfers
Short term / 2

- Hospital-Based approach (PFHI project)
  - Experimented in two hospitals in 2 geographical zones
  - Hospital management involved -- ownership
  - Staff champion coordinating activities
  - Patterned along project lines and fully funded
  - One year mentorship

- Weakness
  - Sustainability once project was over
  - No oversight responsibility from the apex of health care
Short term / 3

- Hospital-Wide Apex Health Authority Driven approach
  - Led by the GCPS in partnership with the GHS
  - Accredited by the MDC - 14 credit points
  - Training based in facilities
  - Part sponsored with facility contribution
  - Electronic platform for continuing mentorship
  - Mentorship for 1 year
  - Monthly submissions of data to monitor progress
  - Facilities trained >50
  - Health staff trained >1,169
Trend of Opioid Consumption, ME/grams

Opioid Consumption, ME/grams

October 2017: 5.94
November 2017: 28.04
December 2017: 21.02
January 2018: 57.13
February 2018: 58.01
March 2018: 66.13
April 2018: 84.17
May 2018: 70.80
June 2018: 67.85
Opioid consumption trend by formulation

- Injection Fentanyl 50mcg/1ml (2ml)
- Injection Morphine 10mg/1ml (1ml)
- Injection Pethidine 50mg/1ml (2ml)
- Injection Tramadol 50mg/1ml (2ml)
Average Hospital Pain Scores (2018)
Long term

- Integration into routine health care delivery
  - Reportable indices in national data base/software -- DHIMS
- Curriculum of Health Training Institutions
  - Private and Public
  - Undergraduate and post graduate programmes (GCPS & GCNM)
    - Nursing Training Colleges - Certificates & HND
    - Nursing Schools (Colleges of Health Sciences) - Undergraduate
    - Medical Schools (Colleges of Health Sciences) - Undergraduate
    - Professional Bodies in Health Training - GCPS, GCNM: Postgraduate
Inter-sectorial Collaboration/1

Academia and Research

Health Services

Government - Political Environment

Private Endeavour, Industry and NGOs

The Nation

The Tramadol crisis
The Tramadol Crisis - UCCH / 1

Injection Morphine 10mg/1ml
Injection Pethidine 50mg/ml (2ml)
Injection Tramadol 50mg/ml (2ml)
Syrup Morphine 10mg/5ml (100ml)
Tablet Dihydrocodeine 30mg
Capsule Tramadol 100mg
Capsule Tramadol 50mg
Inter-sectorial Collaboration/3
Quantification of Opioid Medicines and Estimation of Psychotropic Substances and Precursors: The Nigerian Story
## Consumption of opioid medicines in Nigeria

<table>
<thead>
<tr>
<th>S. No.</th>
<th>Drug substance</th>
<th>Estimated annual consumption (kg)</th>
<th>Estimated consumption with 10% mark up (kg)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Codeine + Pholcodeine</td>
<td>3834.2973</td>
<td>4217.7270</td>
</tr>
<tr>
<td>2</td>
<td>Dextromethorphan</td>
<td>726.7511</td>
<td>799.4262</td>
</tr>
<tr>
<td>3</td>
<td>Dihydrocodeine</td>
<td>2113.4494</td>
<td>2324.7943</td>
</tr>
<tr>
<td>4</td>
<td>Fentanyl Citrate Injection</td>
<td>0.0996</td>
<td>0.1096</td>
</tr>
<tr>
<td>5</td>
<td>Methadone Suspension</td>
<td>0.1680</td>
<td>0.1848</td>
</tr>
<tr>
<td>6</td>
<td>Morphine Injection</td>
<td>2.7809</td>
<td>3.0590</td>
</tr>
<tr>
<td>7</td>
<td>Morphine Syrup</td>
<td>104.2664</td>
<td>114.6930</td>
</tr>
<tr>
<td>8</td>
<td>Morphine Tablet</td>
<td>6.3868</td>
<td>7.0254</td>
</tr>
<tr>
<td>9</td>
<td>Pethidine</td>
<td>167.9705</td>
<td>184.7675</td>
</tr>
<tr>
<td>10</td>
<td>Tramadol</td>
<td>12074.9225</td>
<td>13282.4147</td>
</tr>
</tbody>
</table>

**Total Consumption, ME= 7,170.52kg**
INCB estimates and estimated consumption from survey

Except for codeine, methadone and pholcodeine, the estimated annual consumption of opioid medicines were consistently higher than INCB estimates.

Key: Negative indicates excess of INCB estimates over national consumption.
Percentage representation of opioid medicines

- Codeine: 16.168%
- Dihydrocodeine: 9.803%
- Fentanyl: 0.127%
- Methadone: 0.001%
- Morphine: 1.601%
- Pethidine: 0.318%
- Pholcodeine: 0.004%
- Tranadol: 71.978%
Percentage contribution of Tramadol formulations

Dose limit=400 mg/day
Percentage contribution of Codeine formulations

- Pholcodeine Syrup 2mg/5ml in 100ml: 0.026
- Codeine Tablet 8mg: 2.400
- Codeine Tablet 30mg: 0.302
- Codeine Tablet 100mg: 0.210
- Codeine Syrup 7.5mg/5ml in 100ml: 0.262
- Codeine Syrup 5.7mg/5ml in 100ml: 21.106
- Codeine Syrup 25mg/5ml in 100ml: 0.673
- Codeine Syrup 10.95mg/5ml in 100ml: 75.021

Percentage %

0 10 20 30 40 50 60 70 80
Distribution of opioid medicines among facilities

Graph showing the consumption of Tramadol, Codeine, Morphine Injection, and Morphine Syrup among different types of facilities: Community Pharmacy, Primary, Secondary, Tertiary. Consumption values range from 0 to 8000 Kg.
Distribution of opioid medicines among facilities / 2

![Graph showing the distribution of opioid medicines among facilities](image-url)

- **Tramadol Tablet 100mg**: 74.71%
- **Tramadol Injection 50mg/ml in 2ml**: 81.93%
- **Tramadol Capsule 50mg**: 86.71%
- **Tramadol Capsule 100mg**: 59.84%
- **Morphine Tablet 10mg**: 95.01%
- **Dihydrocodeine Tablet 30mg**: 89.33%
- **Codeine Tablet 8mg**: 52.91%
- **Codeine Syrup 10.95mg/5ml in 100ml**: 91.15%
### Consumption of precursor drugs in Nigeria / 1

<table>
<thead>
<tr>
<th>S. No.</th>
<th>Drug substance</th>
<th>Estimated annual consumption (kg)</th>
<th>Estimated consumption with 10% mark up (kg)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Ephedrine</td>
<td>701.3493</td>
<td>771.4843</td>
</tr>
<tr>
<td>2</td>
<td>Ergometrine</td>
<td>59.7525</td>
<td>65.7277</td>
</tr>
<tr>
<td>3</td>
<td>Ergotamine</td>
<td>23.0106</td>
<td>25.3117</td>
</tr>
<tr>
<td>4</td>
<td>Pseudoephedrine</td>
<td>4996.7454</td>
<td>5496.4199</td>
</tr>
</tbody>
</table>
INCB estimate for ephedrine and pseudoephedrine far outstripped the estimated annual consumption for Nigeria.

Key: Negative indicates excess of INCB estimates over national consumption.
Formulations of Precursor - Pseudoephedrine

- Pseudoephedrine Tablet 5mg
- Pseudoephedrine Tablet 60mg
- Pseudoephedrine Tablet 30mg
- Pseudoephedrine Syrup 15mg/5ml in 100ml
- Pseudoephedrine Syrup 30mg/5ml in 100ml
- Pseudoephedrine Syrup 30mg/5ml in 50ml
- Pseudoephedrine Syrup 30mg/5ml in 100ml
- Pseudoephedrine Syrup 15mg/5ml in 50ml
- Pseudoephedrine Syrup 6mg/ml in 100ml
- Pseudoephedrine Syrup 9.38mg/ml in 15ml
- Pseudoephedrine Tablet 5mg
Formulations of Precursor -- Ephedrine

- Ephedrine Tablet 22mg
- Ephedrine Injection 30mg/ml in 1ml
- Ephedrine Tablet 30mg
- Ephedrine Tablet 11mg
- Ephedrine Syrup 6mg/5ml in 100ml
- Ephedrine Syrup 3mg/5ml in 100ml
- Ephedrine Tablet 5mg
- Ephedrine Tablet 16mg
- Ephedrine Syrup 7.2mg/5ml in 100ml

Consumption, Kg
Dispensing Outlets for Precursors / 1

Graph showing consumption of Ephedrine, Ergometrine, and Ergotamine across different types of facilities: Community Pharmacy, Primary, Secondary, Tertiary. The graph indicates a significant consumption of Ephedrine at the Community Pharmacy, with a decrease in consumption as the type of facility progresses from Community Pharmacy to Tertiary.
Dispensing Outlets for Precursors / 2

Consumption, Kg

- Ephedrine
- Ergometrine
- Ergotamine
- Pseudoephedrine

Type of facility
- Community Pharmacy
- Primary
- Secondary
- Tertiary
Appreciation

Thank you
Mawuli Gyakobo