SOCRON/ASCO MULTIDISCILINARY CANCER MANAGEMENT COURSE

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Palliative care in Nigeria

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Outline

- **Hospice/Palliative care philosophy**
- **Nigeria cancer care policy**
- **Palliative care as part of the Nigerian cancer care policy**
- **Palliative care development in Nigeria**
- **Challenges**
- **The Future**

Palliative care / Hospice

- **Philosophy of holistic patient and family centred care encompassing physical, emotional, social and spiritual aspects through various settings .**
- **Origin from therapy with goal of relieving symptoms and improving quality of life without necessarily attempting to alter the course of the disease.**
- **“Hospes” Greek (Stranger), Hospitalis (friendly), “Hospitium” Latin (Warm feeling between guest and host)**
- **“Palliare” (Latin–to cloak) Palliate -mitigate, to alleviate, to lessen pain, to give temporary relief**

Palliative care

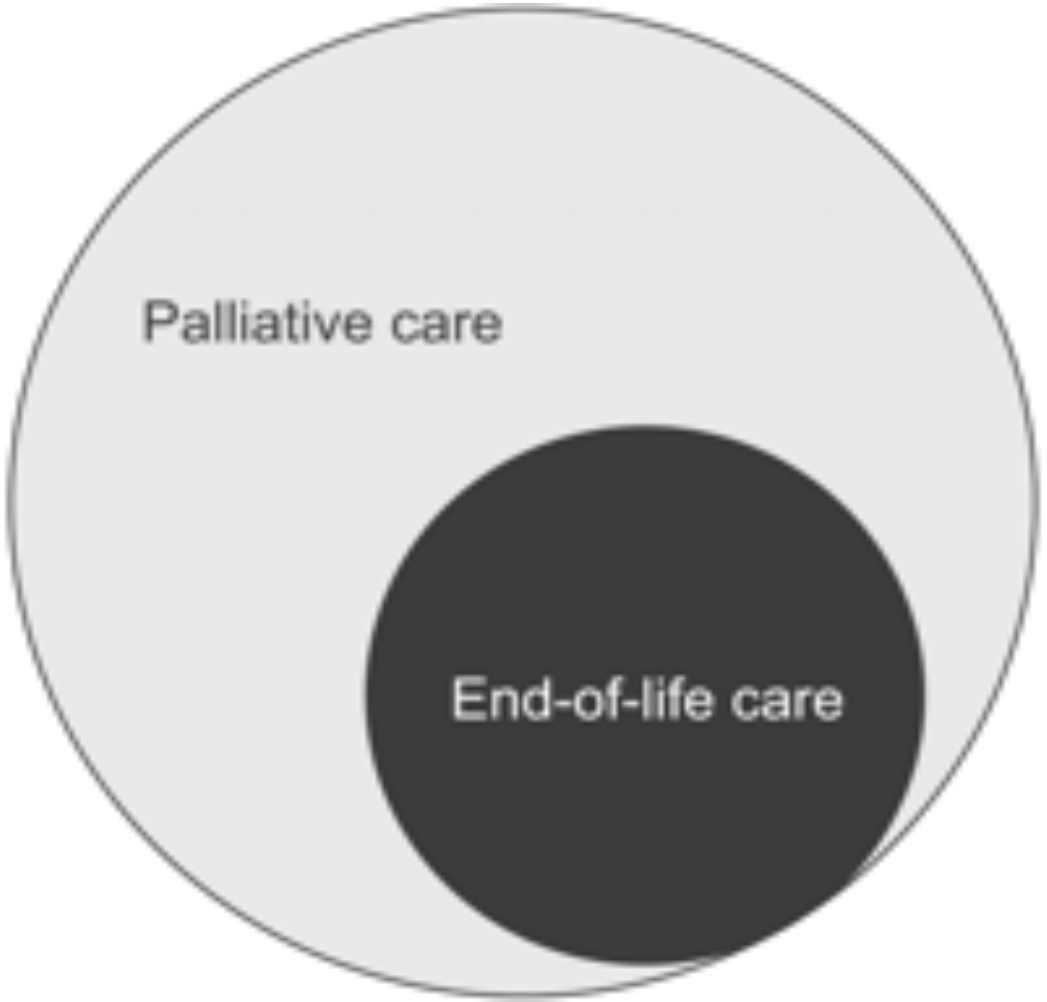
- **Recognises that death is a process rather than an event.**
- **For most people, this process is long and drawn out, requiring immense support from health care staff and family members**
- **Palliative medicine - specialty within the health care system with both service and academic components**

Palliative care - WHO

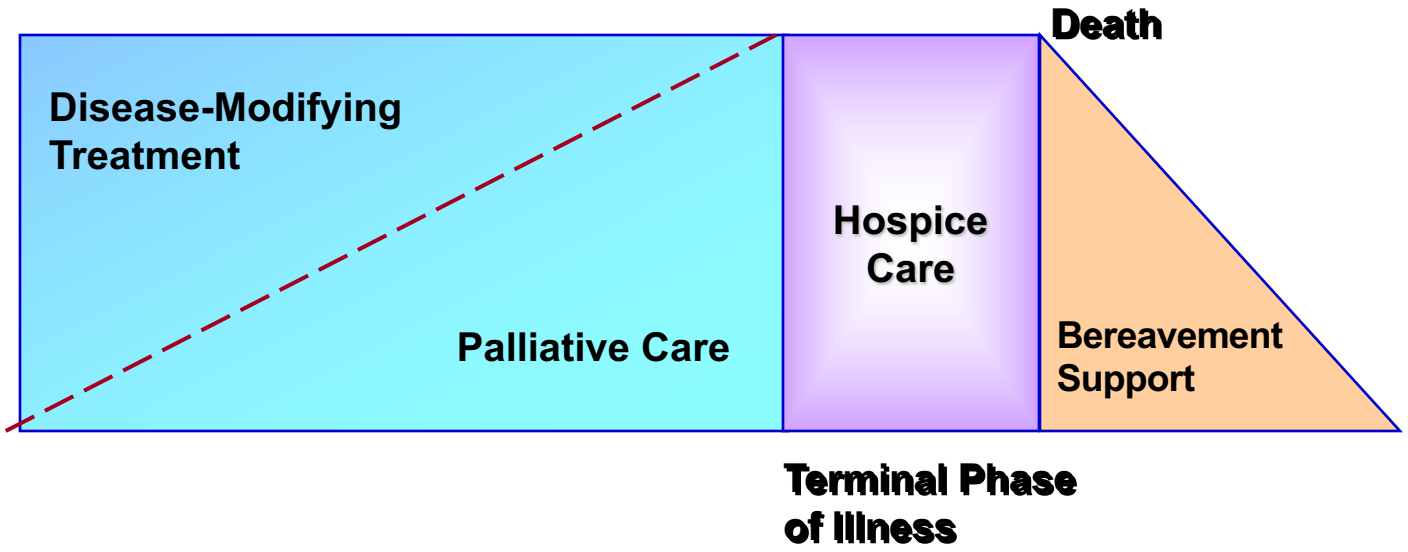
- **An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other symptoms , physical, psychosocial and spiritual.**
- **Can be provided at all levels of health care (tertiary, secondary, primary) in hospital, on outpatient basis, hospice, or in the comfort of the patient's home.**

Palliative Care

- **NOT just “terminal care” OR “end-of-life-care”**
- **Does Not Say ‘There is nothing else we can do” OR “DAMA”**
- **“You matter because you are you, and you matter until the last moment of your life. We will do all we can, not only to help you die peacefully, but also to live until you die – Dame Cecily Saunders” (1918 - 2005)**


Palliative care
End-of-life care

Continuum of care



NCP, 2009

Integrating palliative care into the trajectory of cancer care

David Hui and Eduardo Bruera Nat Rev Clin Oncol. 2016 Mar; 13(3): 159–171.

integrating palliative care early in the disease trajectory can result in improvements in quality of life, symptom control, patient and caregiver satisfaction, quality of end-of-life care, survival, and costs of care

key domains - *symptom management, psychosocial care, communication, decision-making, and end-of-life care*

health-care systems and institutions need to tailor integration based on their resources, size, and the level of primary palliative care available.

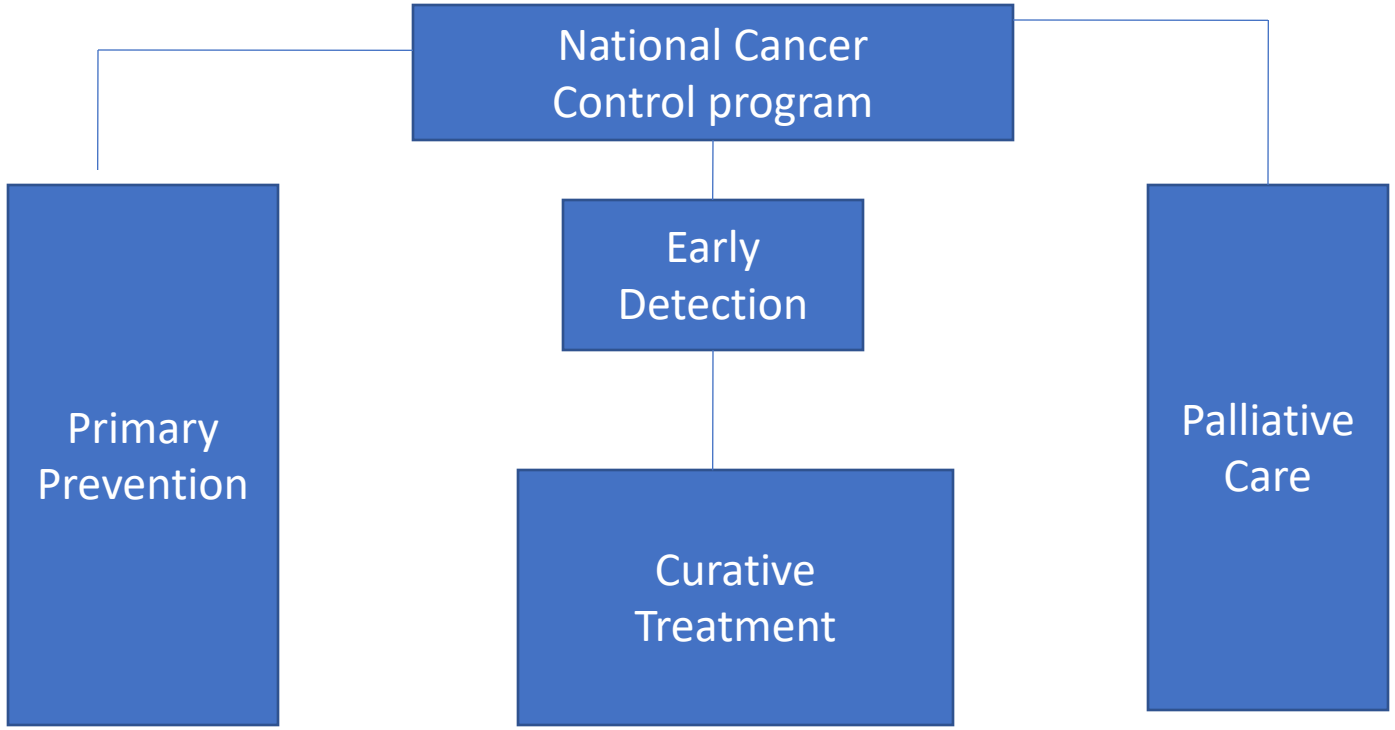
Palliative care service – status in sub- Saharan Africa (including Nigeria)

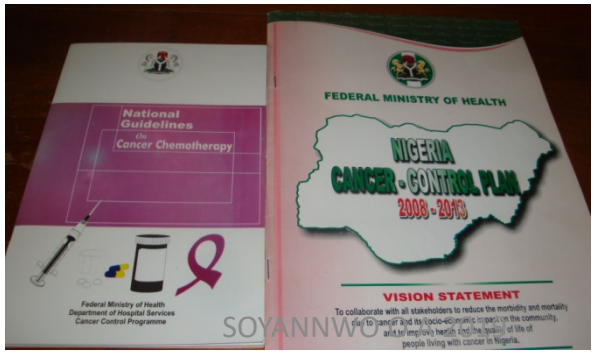
- **Less than 5% of people in need currently receive palliative care**
- **Most of the countries in SSA just practice the hospital and home-based care model of service provision – built around trained health professionals, family care givers and community-based volunteers.**
- **Such circumscribed coverage does not address all the components of the WHO enhanced public health model - care across all health settings (hospital, clinic, home, nursing home, rehabilitation centres, community programmes and hospices) -**

Cancer care Policy - Nigeria

- **In Nigeria, cancer control/care - one of the signature projects and although the Federal Government has been deploying resources into making it a national priority, the current situation is still poor**
- **20 member multidisciplinary National consultative committee on cancer control inaugurated October 2006 with sub committee on 'Palliative care including pain control' (Goal 10 in 2008 – 2013 Cancer Control Plan). Recently re-inaugurated.**
- **Since 2016, some commitment to upgrade eight of the tertiary health institutions as centers of excellence for cancer care with specific focus on research, clinical service, prevention and rehabilitative services.**

Collaboration with FMOH - National Cancer Control Program





Palliative care as part of Cancer Plan Strategies

- **10A Establish facilities for quality and continued care of patients living with cancer**

Proposed activities:

*** 10A.1 establish hospital and community based palliative care and hospices in all the geopolitical zones of the country.**

*** 10.A.2 Increase the number of professionally trained healthcare professionals who specialize in palliative care and pain control**

*** 10.A.3 Provide continuing education training on appropriate pain management /control services**

- **10.B Sustain advocacy to lift ban on importation of narcotic analgesics**

Positive Actions - FMOH

- **Short term observership educational programme at M D Anderson cancer Centre, Houston, USA (2009)**
- **2010 - two-week training for forty six (46) health Professionals from seventeen (17) health institutions in 13 States and the 6 geopolitical zones of the country in collaboration with Hospice Africa Uganda, CPCN and UCH.**
- **Over 100 health professionals sponsored for 5 weeks Health professionals course (Palliative care Initiators course) in Uganda since 2007.**
- **3 year (2012 -2014) partnership agreement with the Global Access to Pain Relief Initiative (GAPRI)**
- **Since 2015 ACS "Treat Pain"/Pain Free hospital project (4 -15 tertiary hospitals)**
- **Increased Opioid availability/accessibility/monitoring efforts**
- **Morphine powder reconstitution (by pharmacists in tertiary hospitals) to oral morphine at low cost**

Oral Morphine - FMOH, GAPRI, ACS

- **Drug forecasting**
- **Supplier identification and negotiation**
- **Procurement**
- **Supporting Infrastucture upgrades**
- **Communication of availability**

Megan O'Brien, Faith Mwangi-Powell, Isaac F Adewole, Olaitan Soyannwo, Jacinto Amandua, Elizabeth Ogaja, Mary Okpeseyi, Zipporah Ali, Rose Kiwanuka, Anne Merriman.. *Lancet Oncol* 2013; 14: e176–82,

- **Facilitation of approvals**
- **Empowering 8 zonal reconstitution centres**
- **Ensuring Cancer/HIV Guidelines**
- **Training of health professionals**
- **Coordination with NGOs, PEPFAR and NACA**

Palliative care Service development - historical

- **First effort – Hospice Nigeria, Lagos (1991)/Advocacy by Anne Merriman founder Hospice Africa, Uganda**
- **In 1996, The "Ibadan cancer pain group" commenced**

vigorous advocacy to government for opioid availability, pain and palliative care awareness, education and service development. Society for Study of Pain inaugurated in 1998

- **Opioids became available in 2003**
- **2005 – Centre for palliative care Nigeria (an NGO) registered to support the palliative care initiative, education and service development**
- **2007 – Hospice Africa UK/Anne Merriman support to establish structured Hospital/Home based care service at the University College Hospital, Ibadan**

From the Archives

1998 Pioneers at Inaugural conference – for pain relief

2008 – HPCAN exco at Ibadan - working towards palliative care for all

Growth

- **Immense growth since then and several palliative care centres and trained health professionals in more than 28 States**
- **At a cancer workshop, Dr Merriman convened a meeting for inauguration of Hospice and Palliative Care Association of Nigeria (HPCAN) in National Hospital, Abuja on 18th of January 2007.**
- **Annual conferences since then and 12th Conference for Makurdi by July 2019. Previous meetings held in Oyo, Kaduna, Anambra, Kwara, Rivers, Osun, Ogun, Benue and Abia States.**
- **Currently, Eleven (11) organizations listed for Nigeria on https://hospicecare.com/global-directory-of-providers-organizations/search/?idcountry=21**

- **Services (mixed) in 3ry hospitals led by anaesthetists, oncologists, family physicians - Include:**

Centre for Palliative Care, Nigeria, Ibadan: UCH Hospice and Palliative care Dept; Palliative Care Department, Federal Medical Centre, Abeokuta; ABUTH, Zaria Palliative Care Centrre, UNTH Enugu, UITH Ilorin etc

- **Palliative care for HIV/AIDS patients mostly embedded within national HIV/AIDS programs but patients with difficult to manage pain referred**

Emerging Palliative Care Departments – 28 States

Others – Community based

Available on-line

- **Hospices (Adults and children)**
- **Elderly care homes**
- **Home care services**
- **Nursing home services**
- **Health care home services (hire home care professionals)**

CPCN/UCH COLLABORATION - PALLIATIVE CARE DEPARTMENT

- **Volunteer group from 1996**
- **UCH day care centre (commissioned 2007)**
- **Hospital ward Consultation**
- **Daily clinic/Telephone follow up**
- **Weekly oncology counseling clinic**
- **Home based care service**
- **sensitization @ other clinics**
- **Bereavement visits**
- **Day care forum**
- **Training, research**
- **Other activities –**

Staff day out

Memorial Service

World Hospice day

Clinical Placement at the Dept.

	2017	2018
Medical student (600 level)	154	121
Nurse Tutor	25	8
M.Sc Clinical Psychology	17	19
M. Sc Nursing students	15	3
Physiotherapy(500 level)		29
MSc Family &Repr.Health	2	2
BNSc (Nursing) UI		34
Foreign Medical professionals	1	4

Cancer cases Jan – Dec 2013 (Soyannwo et al)

Diagnosis	N	%
Breast carcinoma	29	23.9
Gastrointestinal cancers	24	19.8
Prostatic carcinoma	17	14.0
Cervical carcinoma	14	11.6
Other gynae-oncological carcinoma	12	9.9
Head/neck cancers	12	9.9
Blood cancers	4	3.3
Lung cancers	4	3.3
Other urological cancers	3	2.5
Osteosarcoma	2	1.7
Peripheral nerve sheath tumor	1	0.8
Total	121	100.0

Palliative care issues identified (UCH adult cancer patients – 2015)

Palliative care issues	Number of patients	% (n =121)
Psychosocial + Pain	79	65.3
Psychosocial + spiritual + Pain	53	43.8
Spiritual + Pain	37	30.6
Unconscious	12	9.9

PAIN : 89/121 (73.6%) - UCH Palliative care Patients (2015)

Number of pain site (s)

Number of pain site(s)	N	%
1	70	79
2	12	13
>3	7	8
Total	89	100

Pain score (NRS)

Pain score	N	%
1-3	0	0
4-7	62	70
8-10	27	30
Total	89	100

But still ----- Patient story

- **43 year old civil servant, married with 3 children (15 -20years) presented in 2012 with lump in R breast and was offered mastectomy.**
- **Defaulted and she told her husband (a pastor) she didn't want surgery since lump was painless**
- **Came back in 2015 August with low back pain. Offered radiotherapy following bone scan.**
- **Afraid of complications of the therapy & Preferred prayers**
- **June 2017 - severe low back pain, Very ill looking , swollen L upper limb, cough and difficulty in breathing.**
- ****Referred to Palliative care.**
- **Very sad and wished she had had met palliative care team earlier on.**

HOLISTIC PALLIATIVE CARE (Physical, emotional, social, spiritual) NECESSARY

Problems/priorities vary between family, patients and health professionals

- **Patients – Anxiety about disease and the future, anger, denial, unrelieved pain, inconvenience of hospitals, taking medications, poor mobility, fear of dying, loneliness**
- **Family – Financial concerns, loss of income, home disruptions, emotional turmoil**
- **Health professionals – investigations and results, planning for interventions - chemo, radiotherapy, surgery, dialysis, monitoring charts.**

Oncologist referral to the palliative care consult team (PCCT) in the early stages of a patient's disease opens the door to address not only EOL issues but also pain relief, physical problems, and psychosocial issues patients and their caregivers face and is now considered standard of care.

Challenges

- **Late referral of patients.**
- **Late acceptance of diagnosis by patients/carers**
- **Non availability of wide range of pain management options (including opioids)**
- **Financial constraints**
- **Knowing when to stop particular life prolonging interventions (blood transfusion, chemo)**
- **Health professionals poor knowledge about use of Opioids analgesics especially oral Morphine**
- **Fear of Opioids (Morphine)**
- **Lack of national guidelines**
- **Irregular supply of opioid analgesics**

Future plan

- **More Advocacy – government policy required (palliative care for all – desk in FMOH/States with adequate budget**
- **More Education – Patients, public, policy makers, health/allied professionals- Not just certificate level!**
- **Clinical training/skills acquisition**
- **Integration into curricula of all health professionals**
- **More Palliative Care services (3ry, 2ry, 1ry levels) - Units/Hospices**
- **Training of Volunteers/Carers**
- **Research**
- **Collaboration with NGOs and FBOs to establish stand alone hospices**

Address Barriers to Quality Palliative care

- **Failure to acknowledge the limits of medicine**
- **Lack of training for healthcare providers**
- **Lack of knowledge of the public**
- **Hospice/palliative care services are poorly understood**
- **Bureaucratic processes**
- **Lack of access to opioids and ‘opiophobia’**
- **Denial of death**

World Health Assembly resolution

SIXTY-SEVENTH WORLD HEALTH ASSEMBLY
WHA67.19

Agenda item 15.5 24 May 2014

Strengthening of palliative care as a component of comprehensive care throughout the life course

Urges member states And, where applicable, regional economic integration organizations to --------

(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 supporting the availability and appropriate use of essential medicines, including controlled medicines for symptom management;

(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;

**(4) To aim to include palliative care as an integral component of the ongoing education and training offered to care providers, in accordance with their roles and responsibilities,

Palliative Care in the Global Setting: ASCO Resource-Stratified Practice guidelines 2018

Recommendations- General, Basic Level, Limited, Enhanced

- **Palliative care Models**
- **Training**
- **Workforce Knowledge and Skills**
- **Nurse role in pain management**
- **Spiritual care**
- **Social work/councelling**
- **Opioid availability**
- **Cost implications**

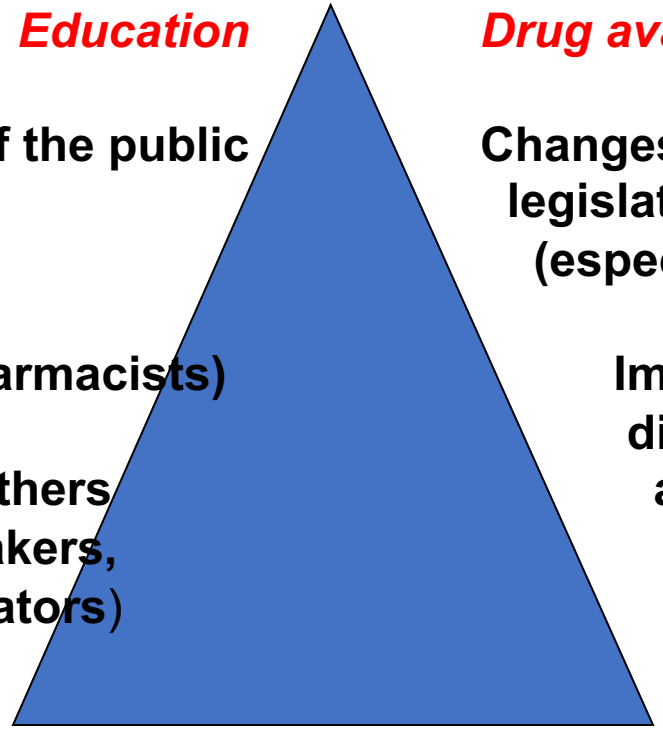
Guidelines for Palliative Care in oncology

- **The American Society for Clinical Oncology (ASCO) recommends considering the combination of palliative care with standard oncology care early in the course of treatment for patients with metastatic cancer and/or a high symptom burden**
- **For newly diagnosed patients with advanced cancer, the Expert Panel suggests early palliative care involvement within 8 weeks after diagnosis**
- **Inpatients and outpatients with advanced cancer should receive dedicated palliative care services early in the disease course concurrent with active treatment.**

ASCO recommendations on delivery of palliative care

- **For patients with cancer who have high symptom burden and/or unmet physical or psychosocial needs, outpatient cancer care programs should provide and use dedicated resources (palliative care clinicians) to deliver palliative care services to complement existing program tools.**
- **For patients with early or advanced cancer who will be receiving care from family caregivers in the outpatient setting, providers (eg, nurses, social workers) may initiate caregiver-tailored palliative care support, which could include telephone coaching, education, referrals, and face-to-face meetings.**
- **Telephone support may be offered for family caregivers who may live in rural areas or are unable to travel to the clinic.**

WHO Model for PC



Education

Of the public

Of health care professionals (doctors, nurses, pharmacists)

Of others (health care policy-makers, administrators, drug regulators)

Drug availability

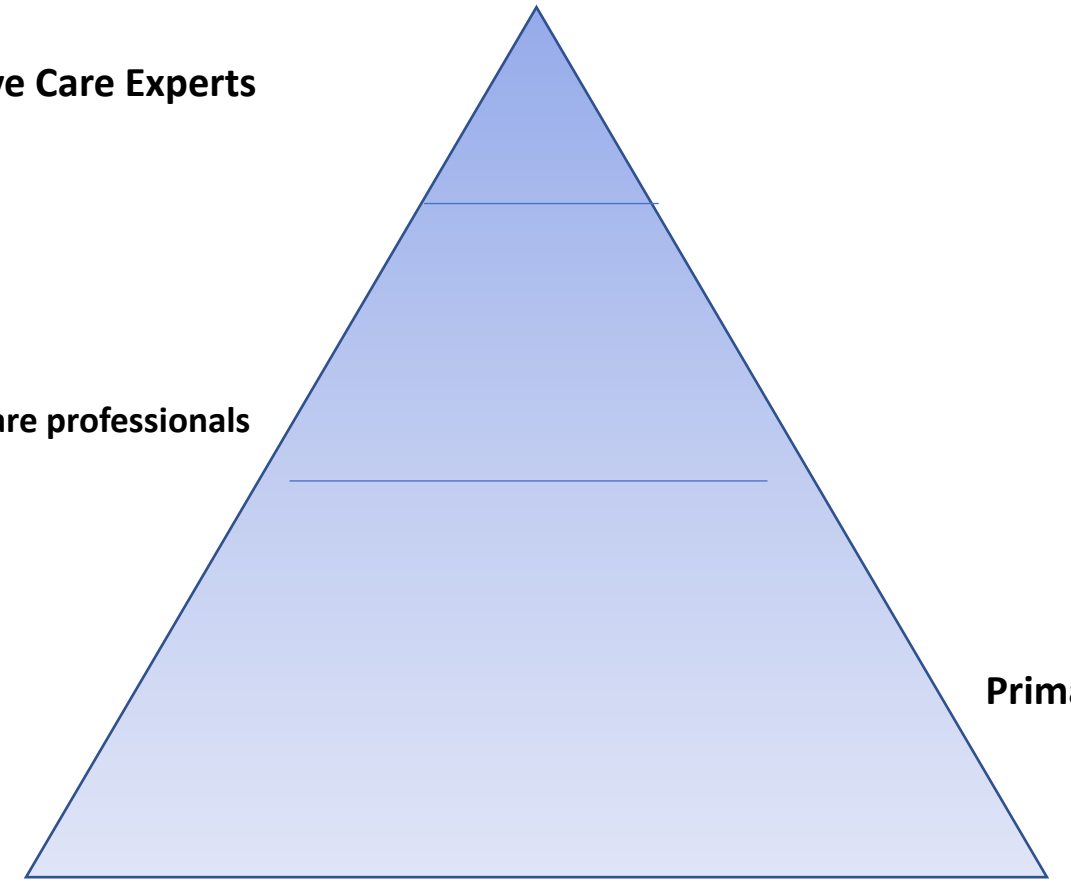
Changes in health care regulations/ legislation to improve drug availability (especially of opioids)

Improvements in prescribing, distributing, dispensing and administration of drugs

Government Policy

National and state policy emphasising the need to alleviate chronic cancer pain

WHO- Possible to have Palliative Care for All !



relies on the community in care-giving and support throughout illness period.

Conclusion

- **Palliative care offers a support system to help patients live as actively as possible until death =“ Best Supportive Oncology Care”**
- **Collaboration and strategic partnerships are required to achieve quality models of care and linkages**
- **Without government national integration policy, most palliative care services will be provided by individuals, non-governmental, faith, or community-based organizations with no in-built sustainability.**
- **Effective government policy and support are essential to provide palliative care for all in need at various settings**

Living and dying in pain –

It doesn't have to happen

- Theme 2016 World Hospice and Palliative care day

THANK YOU