INTEGRATING PALLIATIVE CARE TRAINING WITHIN ONCOLOGY CURRICULA IN INDIA

Dr Mhoira Leng
Palliative Care Unit Makerere University, Kampala
Cairdeas Palliative Care Trust, Scotland
IAHPC board
Global Health Academy, University of Edinburgh
Advisor Mehac
Palliative Care in Makerere/Mulago

Makerere Palliative Care Unit

‘We do this by delivering an integrated clinical service within the national referral hospital site in Uganda; carrying out research, training and capacity-building in collaboration with partners; and developing leaders in Palliative Care.’
Integrating oncology and PC

• ‘More than the cancer treatment it is the communication with the doctor that helps. Fear should be removed first. Earn the trust of the patient.’

Shri Ram Naik, Governor UP Address to AROICON2015 Lucknow.
Integrating PC within oncology

- Global priorities
- Integration and health system strengthening
- Indian scenario
- Transformational education
- Competencies for palliative care
Global health priorities

• Sustainable development goals
  • 17 SDGs and 169 targets to end extreme poverty, fight inequality and injustice, and protect our planet by 2030.
Global health priorities

- Chronic disease management

AGENDA 2030: TIME FOR ACTION ON NCDs

Working across sectors to improve health and NCDs

NCDs are now a universal priority. All governments must urgently take action if they are to meet these 2030 targets. Investing in efforts to reduce the global NCD burden will not only improve health outcomes, it will also accelerate progress on many other SDGs.
What are the global needs?

Multi-morbidity

Barnett K et al Lancet 2012

Slide from Prof Bruce Guthrie
Influencing health systems

- WHA resolution on palliative care
  - 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

June 2014
Influencing health systems

- WHA resolution on palliative care
  - focuses on health systems rather than specific diseases
  - urges palliative care integration into health worker training and education at all levels
  - advocates for universal coverage
  - highlights training needs inc. primary care, oncology, paediatrics, geriatrics and internal medicine
  - urges governments to fund palliative care
  - countries must report to WHO by 2016
Integrating palliative care

Palliative care is 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 of pain and other problems, physical, psychosocial and spiritual.

WHO 2002
Palliative care in India

- still less than 1% of 1.2 billion have access to pain relief
- significant disease burden
  - 30 lakh cancer cases
  - 11.5 lakhs new cases
  - 6 lakhs die each year
- 80% palliative care services in Kerala
- only 2 states with comprehensive policy
- few medical colleges teach palliative care
Palliative care in India

- New opportunities
  - MCI recognition and MD programme
  - NCD, cancer control and NHM
  - National and state training programmes
  - Strong national association IAPC
  - Amendment in Narcotics Act 2014
    - Easier access to oral morphine
  - Strong NGO models
  - WHO collaborating centres
    - Pallium India
    - PPCS Calicut
• How well are we integrating oncology and palliative care?
Integrating palliative care

- ‘my heart has become less heavy, I feel at peace, my pain is less

- ‘only when we came to palliative care was her pain relieved’
Tata Memorial Hospital, Mumbai

• Integrated PC within national cancer centre;
  • >12,000 patients treated since 1996
• Holistic care
  • including volunteer programme
  • IP/OP in TMC including paediatric programme (since 2002)
  • home care (since 1998), referral for hospice care at Shanti Avedna
• Active research programme
• Comprehensive education programme
  • 1st MD palliative care 2012
• Advocacy
  • Maharashtra state policy for palliative care 2013
MNJ, Hyderabad

- Integrated PC since 2008
- IP care including paediatrics
  - 10,000 review patients and 2,000 new patients per year
- Home care; ‘Life at your doorstep’
  - >6500 patients since 2008
- Rural outreach; Chevella Mandal Community Based Palliative Care Program
- Hospice and Institute of Palliative Medicine; Kumudini devi palliative care centre/ hospice
SGPGI and KGMC Lucknow

- 2007 joint palliative care project
  - with anaesthesiology, radiation and oncology and Pallium India supported by NCI and Cairdeas
  - KGMC and SGPGI
- ongoing development and collaboration
  - pain and palliative care
  - clinical service within radiation / oncology OP and IP
  - research and academic leadership
Setting up a palliative care clinic within a radiotherapy department: a model for developing countries. *Bansal M, Patel FD, Mohanti BK, Sharma SC*

*Support Care Cancer. 2003 Jun; 11(6):343-7*
AROI

- Wide remit including;
  - formulation policies, guidelines, teaching syllabi, assessment materials
  - uniform level and standard of excellence
  - coordination with MCI and other institutions
  - academic and research experience
  - forum for sharing and publication
    - AROICON
  - huge potential to formalise palliative care collaboration and training
Integrating PC and oncology

- European Society for Medical Oncology
  - "ESMO Designated Centre of Integrated Oncology and Palliative Care"
  - promote the integration of palliative care services into the existing national cancer care guidelines
  - encourage palliative care education and training for medical oncologists and other HCW
  - expand the cooperation worldwide in supporting and sustaining palliative care development
- 7 listed in India

http://www.esmo.org/
Transformative education

Professional practise
- doing
- experience
- knowledge
- feelings
- expectations
- assumptions
- attitudes
- beliefs
- values

D Fish and C Coles 1998

Leng M. Changing value, challenging practice; IJPC Jan 2011
Transformative education

- Global independent commission on the need to redesign professional health education
  - strengthens leadership and produces enlightened change agents
  - argues for institutional collaboration, shared learning and curricula design
  - need ‘to align the curriculum as an instrument of learning to achieve requisite competencies as the educational goal’

What palliative care competencies are needed for radiation oncology and haematology?
Tiers of palliative care competencies

• **Palliative care approach** – intended as a way to *integrate* palliative care methods and procedures in *general settings of care*

• **General palliative care** – intended for professionals *frequently involved with palliative care patients* or acting as a *resource person* for palliative care in their setting of care, but for whom palliative care is *not the main focus* of their clinical practice

• **Specialist palliative care** – intended for professionals *working solely in the field of palliative care* and whose main activity is devoted to dealing with *complex problems requiring specialised skills and competencies*
Competency based training

• Core constituents of palliative care

• What competencies are important for all practitioners, irrespective of their specific discipline?

• Autonomy
• Dignity
• Relationship between patient and healthcare professionals
• Quality of life

• Position towards life and death
• Communication
• Public education
• Multiprofessional approach
• Grief and bereavement

Gamondi C al European journal of palliative care, 2013; 20(2)
Competency based training

10 core competencies for PC

1. Apply the core constituents of palliative care in the setting where patients and families are based
2. Enhance physical comfort throughout patients’ disease trajectories
3. Meet patients’ psychological needs
4. Meet patients’ social needs
5. Meet patients’ spiritual needs
6. Respond to the needs of family carers in relation to short, medium and long-term patient care goals

Gamondi C at al European journal of palliative care, 2013; 20(2)
Competency based training

10 core competencies for PC

• 7. Respond to the challenges of clinical and ethical decision-making in palliative care
• 8. Practise comprehensive care co-ordination and interdisciplinary teamwork across all settings where palliative care is offered
• 9. Develop interpersonal and communication skills appropriate to palliative care
• 10. Practise self-awareness and undergo continuing professional development

Gamondi C et al European journal of palliative care, 2013; 20(2)
Competency based training

• Assessment
  • formative / summative
  • knowledge, skills, attitudes, values
  • need stronger evidence base
    • systematic review of indicators
    • medical knowledge/skills, perceptions of knowledge/ skills, confidence in palliative care skills, attitudes/opinions towards palliative care, and experience in palliative care delivery.
    • multiple appraisal approaches, combined in a strategy of triangulation

What indicators are measured by tools designed to address palliative care competence among ‘generalist’ palliative care providers
Competency based training

- Undergraduate
  - handful of medical and nursing colleges integrating palliative care
  - agreed framework developed by panel of experts led by WHOCC; Pallium India
  - submitted to MCI and INC
  - www.palliumindia.org/resources/curricula/

Sub: Submission of palliative care modules for consideration of incorporation into Undergraduate Nursing Curriculum

Ref: 1. National strategy for palliative care declared by Ministry of Health & FW of Government of India
    2. Public Interest Litigation (PIL) WP (C) 76/2007 pending before Supreme Court of India
Competency based training

- Undergraduate
  - implementation elsewhere eg UK, EAPC, Makerere
- Curriculum Toolkit developed
  - Integrate Project, Global Health Academy UoE
- http://integratepc.org/

Gibbons et al. Incorporating palliative care into undergraduate curricula: lessons for the UK and abroad
Medical education 43(8):776-83 2009
Integrating PC within oncology

• e-learning
• E-cancer
  http://ecancer.org/
• children’s palliative care
  • ICPCN
  http://www.icpcn.org/
Integrating PC within oncology

• ‘it is imperative to develop instructional frameworks to address deficiencies in the teaching of communication skills and palliative care in hematology-oncology fellowship programs so that more oncologists emerge from their training competent to address the nontechnical aspects of patient care’.

• ‘medical oncologists should take care not to over delegate palliative care to other individuals. Such a strategy would deprive us of the opportunity to participate in the richest dimensions of the care of our patients’.

M.A. Hoffman et al JCO Aug 1, 2012:2802
Transformative education

MD radiation oncology

- 9.1.3. Ensure effective training in palliative care at least in all oncology post graduate programs including practical exposure and inclusion in the examination process.
- 9.2.5. One month rotation in palliative care for oncology postgraduate residents in RCCs/Palliative Care Centres/Regional Training Centres
  - ?competencies
  - ?assessment
  - ?models and capacity for training
Values based change

• 'The palliative care training has made a huge impact; I now see the patient as a person and not a disease, I don't avoid difficult conversations, I don't order unnecessary investigations, I see them as part of a family, I do holistic care. It was not like that before.' MMed doctor Makerere.
Values based change

- As a link nurse (oncology) I have come to know that patients are individuals with different problems, so I handle them at the individual level. Also the concept of team work has made me get very close to the palliative care team so we work hand in hand. Patients have become ours not theirs.
Integrating oncology and PC; realities

• **Barriers and influences**
  • Professional factors
    • previous exposure /experience / training
    • lack of guidelines / peer opinion
    • pressure of time
    • insufficient evidence base
    • aggressive treatment plans
  • Personal factors
    • ‘giving up’ / ‘there is nothing we can do’
    • ‘learned helplessness’ compassion fatigue
    • expectations / communication
Integrating oncology and PC; realities

- **Barriers and influences**
- Systems factors
  - availability / models of care
  - challenges in accessing oral morphine
- Patient and family factors
  - expectations / communication
  - poverty
  - rurality
Integrating PC within oncology

• Way forward
Integrating oncology and PC; realities

Suggest

• Agreed competencies and guidelines
• Training and clinical modelling
  • undergraduate
  • postgraduate
  • positions to lead PC medical colleges, RCC, cancer centres, NCD programmes
• Develop and evaluate models of care
  • based on need and across continuum of care
  • innovative and creative, cost effective
  • joint with community / NGO
• Registration / legal issues cf ESMO

Public and policy involvement; mobilise resources
Integrating oncology and PC

- ‘people need from their doctors...to be valued, listened to, cared for, loved.’

J. Patient with colorectal cancer in Valdivia, Chile