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Palliative Care Nursing in Poorly Resourced Nations
The Challenges of Making a difference in Ways that Inspire
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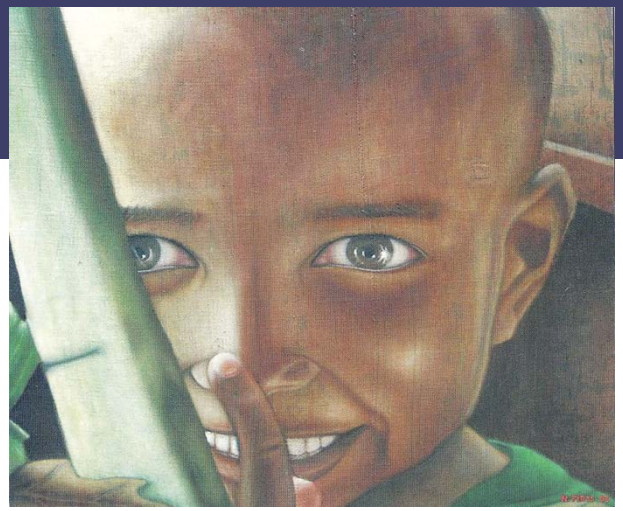
Joan Ryan
Palliative Care Clinical Nurse Consultant
Royal Prince Alfred Hospital
Sydney, Australia

Dr Frank Brennan
Renal Supportive Care and Palliative Care Specialist
Calvary and St George Hospital
Sydney, Australia



Palliative Care as a Human Right.

Human beings are mortal…how we die is a matter of universal concern…

the quality of the dying and the level of suffering varies around the world…

Frank Brennan 2015

- There are huge discrepancies in palliative care development worldwide, resulting in very different experiences of care provision

(Harding and Higgison,2005: Lynch, et al, 2011)

- Interrelated and essential elements: availability, accessibility, acceptability, and quality… (Frank Brennan 2015)

- What does it mean to mentor in Palliative Care nursing within the context of such diversity involving relationships, cognition, culture, spirituality, religion, language, community and so much more

- *Are we fit for the future globally ?*
- *How can we make a difference beyond teaching of facts*
- *How may we engage at grass roots ?*

Palliative Care in Asian Pacific Region

In response to global deficits advocacy by international bodies include many;

- Human Rights Watch
- The Open Society Institute (OSI)
- Worldwide Palliative Care Alliance
- International Association of Hospice and Palliative Care (IAHPC)
- World Health Organisations (WHO)
- International Narcotics Control Board
- Non government Organisations
- Asian Pacific Hospice and Palliative Care Network (APHN)
- Australian Palliative Link International (APLI)
- Lien Foundation for Palliative Care, Singapore.
- Non government organisations
- ehospice International(Regional, national and international collaboration)
- Global core competencies and education clinical practice European Association of Palliative Care (EAPC)
- Shanthi Foundation , Sri Lanka.
- International Children's Palliative Care Network

End of life Nursing Education Consortium ELNEC.

Judith A Paice, APHC, Bangkok, Thailand, 2013

Education Program adapted to over 70 countries

- Train the trainer programs
- Various modules interchangeable
- Clinical competencies

Challenging the paradigm of care
Creating experience and knowledge
Fostering a nursing presence
Expert attention to the body
Relief of symptoms
End of life as a spiritual expertise

Palliative Care

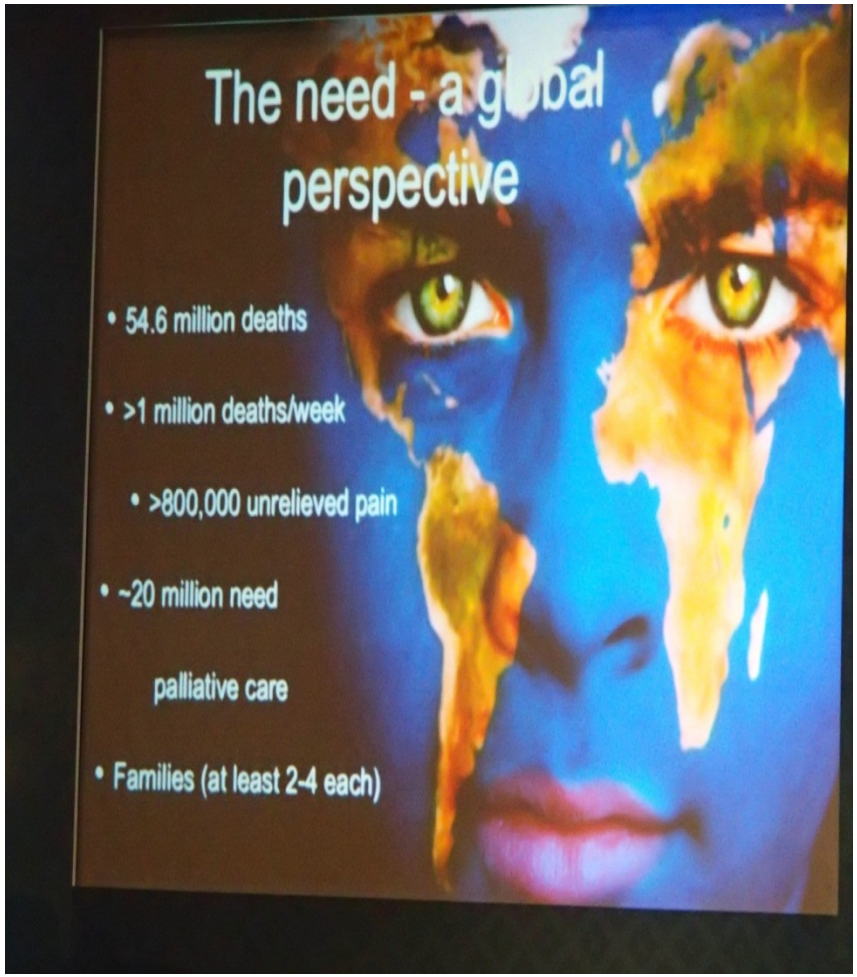
World Health Organisation and International Narcotics Control Board recommend that all countries have a national palliative care program

WHO recommendations for the creation of Palliative Care in Low Resourced Countries.

- Assess palliative care needs, gaps and barriers
- Develop palliative care guidelines to establish uniform standards of care
- Remove barriers to essential palliative care medicines, modifying national narcotic control policies to facilitate access to essential pain control drugs
- **Improve pre-service and in-service palliative care education, training and certification**
- Scale up home, and hospital based palliative care services

Global perspective…
the need for urgent action to reduce suffering

- Each year 58 million people die around the world
- 35 million will die from chronic life limiting illness
- It is estimated that over 100 million people would benefit from Palliative Care
- 78% of adults requiring Palliative Care live in low and middle resourced countries
- Vast majority of the world's population does not have access to Palliative Care or adequate pain control
- 75 nations still have no hospice or palliative care provision
- 83% of the worlds morphine consumption for medical purposes is used by 7 countries
- Palliative Care is an emerging and often unknown discipline



APHC Bangkok, 2013

International Narcotics Board Annual Report 2009
Palliative care as a Human Right 2015

Context within the Asian Pacific Region?

- Death often occurs prematurely
- Palliative Care is an emerging often unknown discipline
- Serious illnesses often without professional involvement
- Significant unmet gaps with competing health needs
- Pain management often not a priority
- Access to Availability of essential medications inconsistent
- Large populations with limited resources and competing health care needs
- Late presentations with limited treatment options
- Diversity...political, historical, social, civil, language, religion, spiritual, literacy
- Bereavement issues often traumatic with multiple losses
- Repeated stories of patients being sent home to die without medications

Aim

- To identify common themes to the success and challenges of providing end of life education to nurses in poorly resourced nations.

Do we really make a difference ?

To understand the nature of Palliative Care

Ethos of Palliative Care as the starting post

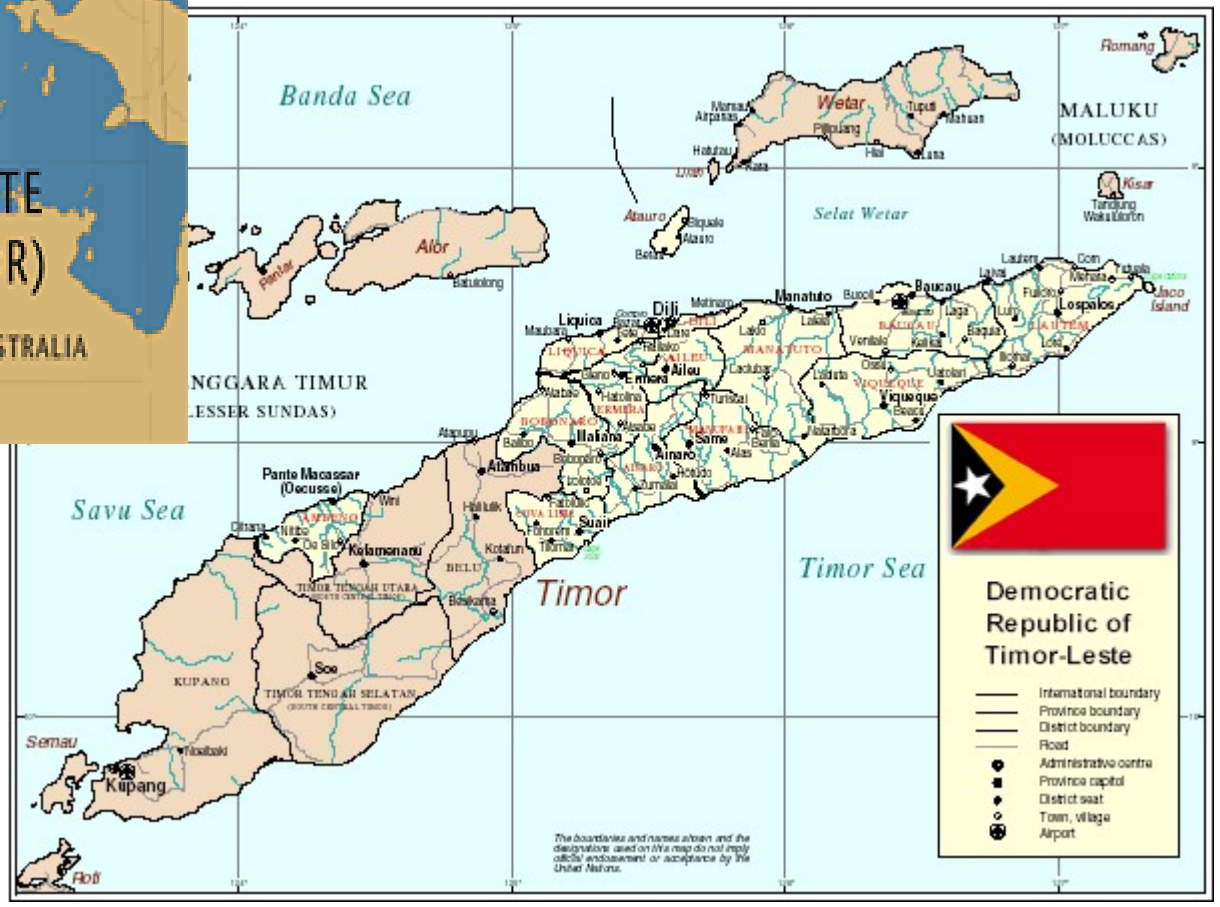
- Effective Palliative Care rests on a sound ethical foundation of on going conversations with patient and family within the context of values, preferences, diversity and measured and considered responses
- Maturing discipline
- Care tailored to the individual needs
- Foundation for achievable goals
- All aspects of physical, psychosocial, and spiritual dimensions of care
- Promotion of quality care supported by research, quality and education
- Highest regard for quality of life and death as a natural life event

(WHO definition of Palliative Care)

Methods

- Evaluation of 10 facilitated face to face teaching sessions using interpreters when possible.
  - 2 formal two day workshops
  - 8 informal sessions
  - 5 rural region in clinics
  - 5 hospital based
- Asian Pacific region of Malaysia, Nauru and Timor-Leste …(Sri Lanka and India)
- Semi-structured face to face interviews during communication skills workshops using both verbal and written responses, (excluding Timor Leste)
- Informal discussions with nurses post workshop (less formal)
- Official reports and documentation on each visit.
- Transcribed data reviewed and analysed thematically

Timor Leste…newly independent nation



Diversity

- 16 distinct language groups
- National language is Portuguese and Tetum (35 dialects)
- 40% live below the poverty line
- 70% population are under 30. (Mean age 18)
- Rebuilding and regrowth competing international interest
- Faith based outreach centres

Access to services
hindered by weather, transport,
terrain and costs with 70%
rural population

Republic of Nauru.

- Population less than 10,000 plus 1,000 refugee
- 12 tribes population
- Isolated no public transport
- Decaying health infrastructure
- Stark landscape from phosphorous mining boom
- Enviromental impact of mining
- One hospital .
- No community services
- No Palliative Care Health Professionals
- Limited Palliative Care Plan

Nauru

- Chronic diseases
- Limited opioids irregular supply
- Australia and New Zealand links
- Workforce issues
- Socio economics issues
- Predominately Christian

Comments to morphine…

Why give morphine to an old dying man when we may need it for others who may have an accident'

Hospis Malaysia

Established 1991

- Palliative Care vision and mission statements and peak body for Palliative Care in Malaysia
- Home care program/ day hospital/ volunteers/ in patient
- Palliative Care Foundation Education at medical, nursing and allied health
- University and teaching hospital program
- Public Awareness program
- International collaboration and networking and research

'Being cared for should not have to be requested or a privilege but a human right'

Palliative Approach to Palliative Education

- Interactive four module approach based on ABC Introductory Palliative Care Nursing Program, Central Sydney Health District with adaptations
- Approaching Palliative Care
- Communication workshop
- Pain and symptom assessment and management
- Bereavement
- Specifically requested topis areas of recognised need

Limitations were immediate

- *Recruitment of nurses to partake in discussions challenging and dependent upon building trust*
- *Reported discomfort discussing death and dying*
- *Medical hierarchy*
- *Verbal and written communication challenging*
- *Limited data due to the overall diversity*
- *Limited resources. Opportunistic encounters*
- *No palliative care trained nursing professional (except Malaysia)*
- *Dearth of trained nurses in leadership roles*
- *Multiple languages*
- *No official response*

Avoidance

- **No one talks about death …many felt that they could not change anything and discussions were negative**
- *''We do not like to talk about death as it is a private thing for family and it may bring bad luck'*
- *'We know what to do when people die as it is just all normal to us'*
- *'Why do you want to talk about it…I cannot say the words to this old woman'*

Avoidance of diagnosis/ prognosis complex issue for nurses

- *'we would never tell a patient they are dying ever…why ! The doctors do not even tell them and we would never do it*

Place of death … a community affair

Overwhelming desire to die at home

The concept of going to hospital to die alien…you need to be in the village

- *Many people go to hospital and never come back*
- *We do no have money to get to the hospitals*
- *A death hospital would be strange for us …why would you go there… bad for the spirit…*
- *Sometimes the treatment is so expensive …only the wealthy ones can live longer so we take them home*

Strong sense of the inevitability of death

- *He is an old man who needs to be at home with his family at the end of his life… he knows the way…we have no means to travel*
- *Many of my family have died so it is not to be feared as god will take care now…*
- *I feel sad when people die but that is just life and we keep them safe.*
- *We have to worry about feeding our family not about those preparing to die.*
- *Hospitals are for accidents not a place for death.*
- **Multiple bereavements and missing family…**

'We do not know what happened to them'

Palliative care has given me confidence but my family think it is strange

What care is

- Many expressed confusion about the concept of care and what that meant especially nurse initiated…

'We make sure the charts are done and let the doctors do the rest'

'We just follow the orders as best we can'

'We do not touch the person as they are too sick'

- The concept of general comfort nursing care challenging.

' If people are in pain often the healers come to see them as pain is part of dying and people know there time is near

Strengths

- *Some of the challenges are some of the strength*
- *Strong sense of family and community*
- *Strong spiritual ethos and sense of ritual*
- *Emergence of nursing and medical schools*
- *International interest in education and support*
- *Role models and clinical leadership in the Asian Pacific Region*
- *Sensitisation of Palliative Care in understanding the scope of what maybe possible*

Creating expertise and knowledge in their own characteristic way

- *Education happens at multiple levels, no one fit*
- *Step by step approach honouring diversity*
- *Multiple origins embracing a sensitive approach*
- *Mentoring with bed side role modelling*
- *Resist the urge to fix everything*
- *Culture as the bearer of wisdom*
- *Fostering local champions and clinical supervision*
- *Context is critical*

Sharing of stories

Inspiring hope to make a difference

Renewing through collaborative strengthening

Mentoring…about context
Simply teaching ?? Learning facts??

Set what you need to think about beforehand

Dialogue what happens during the teaching

Closure how you finish off.

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- Nurses of Malaysia, Timor Leste and Republic of Nauru