Gaps in Palliative Care training affect service delivery

Dr. Rene Krause

A/Prof. Liz Gwyther

Dr. Linda Holding

Dr. Margie Venter

What is Palliative Care?

WHO Definition Palliative Care

Palliative care is an **approach** that improves the **quality of life** of patients and their **families** facing the problem 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 problems, **physical, psychosocial and spiritual**.

Why palliative care?

Improves quality of life and may prolong life

The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

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

Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A., Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H., Vicki A. Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N., Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H., J. Andrew Billings, M.D., and Thomas J. Lynch, M.D.

Brings value to the health system

Survey of dying patients proves value of palliative care specialists

By Tamsin Snow

A study that shows care by Marie Curie staff doubles the chance of terminally ill people being able to die at home will be used to lobby the government for investment in specialist end of life care.

The study of 60,000 patients found that more than three quarters of those cared for by the Marie Curie nursing service died at home and only 7.7 per cent died in hospital. In contrast, 34.9 per cent of those cared for by community nurses died at home and 41.6 per cent died in hospital.

The research, commissioned by the charity, also found that those cared for by its 2,000 nursing staff were less likely to use hospital care.

Hospital costs for people cared for by Marie Curie nurses were £1,140 per person, less than for the comparator group of 29,538 people cared for by community nurses.

Georgina Clue: 'Some clinicians think there is no other option but to die in hospital'

'Amazing' achievement

Although the figure excludes the cost of the charity nurses, Marie Curie community nursing and those in the charity's care was so marked.

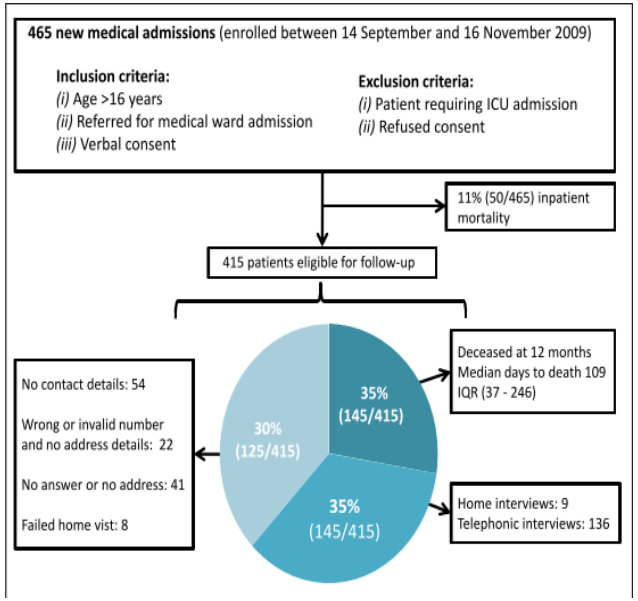
'This study proves for the first time the significant difference our nurses make. They specialise in end of life care and so are better able to meet the patients' and family needs, and anticipate and prevent crises that can lead to a hospital admission.'

Ms Munroe said the findings will be used to lobby the Department of Health

Marie Curie senior healthcare assistant Georgina Clue said: 'People do not know about our service. Even GPs and some district nurses do not know what resources they have in their area. It can be frustrating when professionals think that there is no other option but to die in hospital.'

A DH spokesperson said: 'We are making progress. This report adds to the evidence of what works best to

Huge need



Global and national PC development

Teaching and training of Palliative Care at UCT since 2001

May 2014

- WHA 67/19 resolution May 2014.

Apr. 2017

- The South African National policy framework and strategy was approved April 2017.

December 2017: **58** Medical doctors in South Africa with an M.Phil. (Palliative Medicine)

Sep. 2018

- Model for the Implementation of the PC Policy in the Western Cape September 2018:
  - "Dedicated Palliative Care Specialist in Tertiary and Rural Regional Hospitals"

health

Department:
Health
REPUBLIC OF SOUTH AFRICA

NATIONAL HEALTH INSURANCE FOR SOUTH AFRICA

TOWARDS UNIVERSAL HEALTH COVERAGE

Palliative Care is written into the NHI

- NHI is intended to move South Africa towards Universal Health Coverage (UHC) by ensuring that **the population** has access to quality health services and that it does not result in financial hardships for individuals and their families.
- **Progressive universalism:** All South Africans will have access to needed promotive, preventive, curative, rehabilitative and **palliative** health services that are of sufficient quality and are affordable, without exposing them to financial hardships.
- Across the continuum of care

National Steering Committee for Palliative Care

- Policy Task Team – NPFSPC, referral policy, clinical guidelines
- Funding task team – NO BUDGET
- Support for families & health care workers – Position paper
- Education and Training – sub-groups addressing different disciplines
- Drug availability task team (addresses 3 of the WHA recommendations & tasked to include nurse-prescribing of pain management medicines)
- Vulnerable populations – plan to develop position statements
- Ethics task team – Position paper and palliative care SOP

"Despite abundant evidence of the efficacy of life-saving interventions, there is little understanding of how to deliver those interventions effectively."

Palliative Care is a complex intervention

- Not well understood by society
- Complexities in identifying patients in the African context
- Interdisciplinary work
- Bio-psychosocial and spiritual care
- Emotive topic
- Many aspects are still poorly defined for the South Africa setting
- Mainly practiced outside the formal health care setting
- Multiple well described barriers

Competencies required to deliver palliative care

Ten core palliative care competencies as identified by the EAPC

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
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

Core competencies in palliative care: an EAPC White Paper on palliative care education – part 1

Levels of Palliative Care Expertise	Skills of Health Care Workers	Level of Health Service Delivery
Palliative Care Approach (All health care workers)	A Palliative care approach can be offered by any cadre of health care worker (HCW) at all levels of the health system. The palliative care approach should be included in all pre-service and in-service trainings. The undergraduate curricula of health professionals should include the palliative care approach. Most patients will have needs that can be adequately met by HCWs with this level of skill.	Community Primary care clinics Community Health Centres District hospitals Regional Hospitals Tertiary Hospitals (Non-Palliative Care Specialists)
General Palliative Care (Nurses, doctors, allied health)	General palliative care may be offered by HCWs who are not full time palliative care practitioners but have a higher level of training in palliative care (such as a postgraduate diploma or family physicians with appropriate training in palliative care).	Community Health Centres District hospitals Regional Hospitals
Specialist Palliative Care (Nurses doctors, allied health)	Specialist palliative care services are provided by full time palliative care specialists with relevant specialist postgraduate training in palliative care. (Master's level or a specialist qualification in the future) These HCWs will care for patients with complex or high intensity needs at a tertiary level.	Specialist Hospitals

Basic Palliative Care

A suggestion for the split for the percentages of the topics within the syllabus is presented below:

Basics of Palliative Care 5%	Pain and symptom management 50%	Psychosocial and spiritual aspects 20%	Ethical and legal issues 5%	Communication 15%	Teamwork and self-reflection 5%

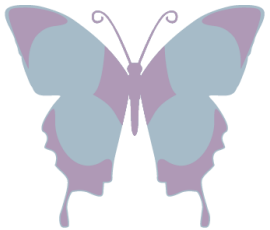
40 hours

Available courses

HPCA-UCT 40 hour online course / face to face	University of Stellenbosch 40 hour online course

Undergraduate PC training SA: 2013 Survey

INSTITUTIONS*	UCT	WITS	MEDUNSA	SU (2017)	UFS
Hours	42	26.5	20	6/30	0
Practical experience	✓	✓	✓	✓ ✗	✓
PC trained educator	✓	✓	✗	✓	✗
Department	Family Medicine	Wits Centre for PC	Practice of Medicine	CHPE Fam Med	Int Med/ Surgery
Years of training	2,3,4,6	3,4,5,6	3,6	2,3	3,4,5
Summative assessment	✓	✓	✓	✓	✓
Teaching methods	Blended	Blended	Blended	Blended	UKN



*Non-respondents: UKZN/ UP/ Walter Sisulu University

AE Fourie & L Gwyther, 2015

Undergraduate PC training SA: 2019 Survey

Institutions	UCT	Wits	FS	KZN	SU
Hours	41 + 6	40	12	30 +6	32
PC trained educator	√	√	√	√	√
Department	Family Medicine and internal medicine	O&G and surgery	medical ethics and doctor in the community	Paeds	Stand alone module
Years taught	2,3,4,6	3,4,5,6	1,3,5	4,5,6	2,3

Where should we be teaching basic palliative care?

- All undergraduates medical curriculums
- All undergraduate nursing curriculums.
- All undergraduate social worker curriculums
- Ensure medical officers, PN and social workers are being upskilled

Intermediate Palliative care

Provided by **primary care professionals** and **specialists** treating patients with life-threatening diseases who have good basic palliative care skills and knowledge. Should be made available to professionals who are **involved more frequently** in palliative care, such as **oncologists, geriatric specialists, and family physicians** but **do not provide palliative care as their main source** of work. Depending on the discipline, may be taught at an undergraduate or postgraduate level or through continuing professional development.

Post Graduate Diploma in Palliative Medicine

- 1 year full time blended learning program at UCT
- Average of 20 students per year
- General course and a pediatric specific course.

Oncology curriculum

College approval

- One year program
- 12 modules (2-4h / month)
- Summative assessment through anonymised evaluation forms, pre and post-module MCQ's and monthly discussions

Curriculum outline

- Communication 40%
- Symptoms 30%
- Legal, self care, spiritual 30%
- Blended learning consisting of on-line educational material, video's, PowerPoint presentations with voice-over, skills lab usage and face-to-face discussions.

Learning methods

- Blended learning
- Contact sessions monthly(1-2 hours)
- Facilitators support

CANSA
Cancer Association of South Africa
Research • Educate • Support

Family Medicine registrar training (UCT)

- Palliative Medicine is assessed in College exams
- 6 weeks clinical rotation in hospice, hospital palliative care and oncology.

Proposed Specialist training

Domain 1	Palliative Care Principles
Domain 2	Physical Care
Domain 3	Psycho-social care
Domain 4	Communication
Domain 5	Culture and spirituality
Domain 6	Ethics, human rights and legal aspects of Palliative Care
Domain 7	Collaborative care
Domain 8	Research
Domain 9	Leadership, governance, and advocacy

Proposed structure of training

Hospital PC service delivering Palliative medicine across all services in the hospital	**950 hours**
Accredited Hospice with an inpatient unit	950 hours
Depending on base speciality the following rotations can be as chosen as electives to ensure comprehensive exposure:	
Primary Health Care delivering PC	475 hours
Oncology	475 hours
Paediatric Palliative Care	475 hours
HIV and TB clinics	475 hours
Emergency Medicine (hospital level) delivering PC	475 hours
Internal Medicine	475 hours

M.Phil. (Palliative Medicine)

- 2 year research based degree
- Interdisciplinary
- Advanced PC skills taught

PALPRAC

The Association of Palliative Care Practitioners of South Africa

Established in May 2017, 70 clinicians from state, hospice and private.

Goals:

Peer-support (many work in isolation)

- clinical/ethical
- connecting to resources
- establishing services

Linking patients in need to providers via website: www.palprac.org

Engage widely to create economically sustainable services

Recognition of palliative care as (sub)specialty

Education/advocacy

Gaps in training

- Not taught in all undergraduate curriculums
- No bespoke curriculum for Physicians, Emergency Medicine specialist and Geriatricians.
- No intermediate level training nor specialist training beyond the Western Cape
- No clinical specialist training (funding)

Standard Treatment Guidelines and Essential Medicines List for South Africa

Primary Healthcare Level
2018 Edition

Stage 5 or ESRD or eGFR < 15 or on dialysis	» Kidney failure requiring renal replacement therapy » End Stage Renal Disease (ESRD)	» Refer for consideration of renal replacement therapy, i.e. dialysis or transplant if uraemia present.	ON RRT: » Monthly testing of Hb. » 3 monthly clinical assessment. » 3 monthly testing of urea, calcium, creatinine, PTH, potassium, HIV phosphate, and Hepatitis B.

CHAPTER 22: MEDICINES USED IN PALLIATIVE CARE

22.1 Gastrointestinal conditions
- 22.1.1 Constipation
- 22.1.2 Diarrhoea
- 22.1.3 Nausea and vomiting

22.2 Neuropsychiatric conditions
- 22.2.1 Anxiety
- 22.2.2 Delirium
- 22.2.3 Depression

22.3 Pain
- 22.3.1 Chronic cancer pain

22.4 Respiratory conditions
- 22.4.1 Dyspnoea

22.5 Pressure ulcers/sores

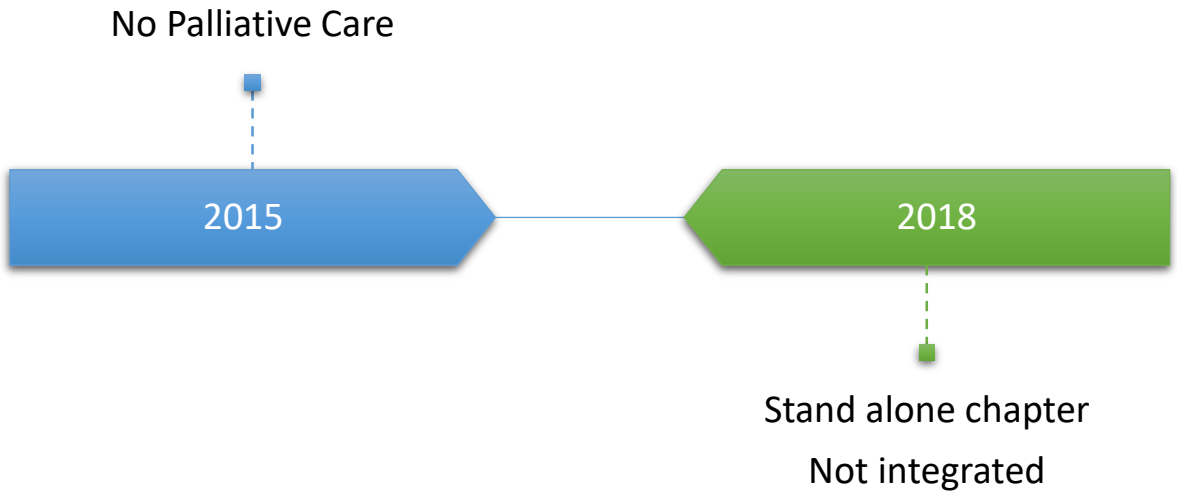
22.6 End of life care

REFERRAL

» All cases of suspected chronic kidney disease stages 3–5 for assessment and planning.
» All children.
» All cases of CKD with:
  – haematuria
  – significant proteinuria with urine protein creatinine ratio of > 0.1 g/mmol
  – eGFR < 60 mL/min for initial assessment and planning
  – eGFR < 30 mL/min
» Uncontrolled hypertension/fluid overload.
» CKD associated with hyperlipidaemia.
» No reduction of proteinuria with ACE-inhibitor therapy.
» If ACE-inhibitors are contra-indicated.
» If ACE-inhibitors are not tolerated.

Patients who might qualify for dialysis and transplantation or who have complications should be referred early to ensure improved outcome and survival on dialysis, i.e. as soon as eGFR drops < 30 mL/min, or as soon as diagnosis is made/suspected.

Standard Treatment Guidelines and Essential Medicine List for South Africa



Current status quo in EOL care is a lose-lose-lose

Patients	Approximately **60%** of all patients with access to insured health benefits in South Africa die in intensive care units. Yet about **70%** of people would prefer to die at home*
Providers	Current contract mechanisms & benefit design do not incentivise value-based care, team-based care or home- based care resulting in disillusioned doctors, fragmentation of care & funding frustrations
Funders	• Huge costs for medical schemes in last year of life • Ethical dilemmas for the cessation of funding for non-beneficial care

*Dying Matters NatCen Survey 2009. Available from URL:https://www.dyingmatters.org/page/key-facts

Medical Aids

- Prescribed Minimum Benefits –
  - current wording refers to cover for last 2 weeks of life only. Clinically inappropriate to prognosticate
  - Wording change proposed over 2 years ago, not yet actioned by Council for Medical Schemes
- Most schemes pay for hospice services, but not always from the hospital cover
- Limited cover for home nursing, usually paid from out of hospital benefits

Conclusions

- Assistance from the HPCSA to ensure palliative care is taught across all curriculums (basic, intermediate and on specialist level)
- Assistance from the HPCSA to support the development of Palliative Medicine as a sub-speciality
- Standard setting of palliative care practices
  - Hospitals
  - Clinics
  - Intermediate Care facilities
  - Hospices