

Experiences & Attitudes of Palliative Care Nurses Caring for Patients with Chronic Disease

Debbie White
Nurse Practitioner Palliative Care
Hastings Macleay

The Project

- HETI Rural Research Capacity Building Program
- Encourages novice researchers within rural settings to complete a project
- Over 22 months and well supported
 - Face to face
 - Mentor
 - Teleconferences
 - Backfill

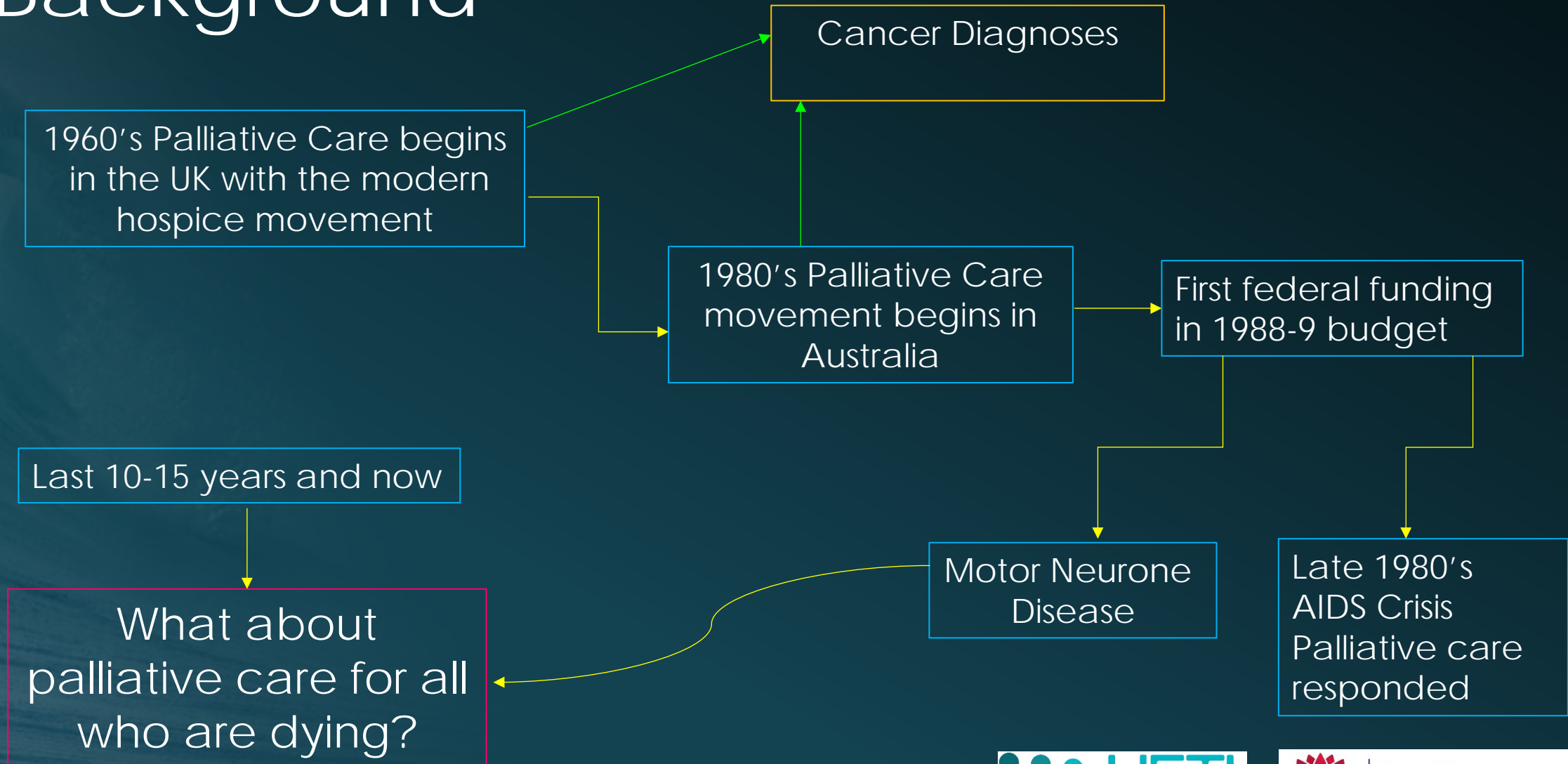


Two things before starting....

1. The research is not yet completed
2. The approach is phenomenological not IPA



Background



Hockley, J (1997) Saunders C (2001) Hunt RW & Maddocks I (1997)

The tip of the iceberg...



In NSW, 60% of people who die from malignant disease receive specialist palliative care services



A similar number of people die from chronic disease each year and yet only 10% of these patients receive specialist palliative care



Inequity

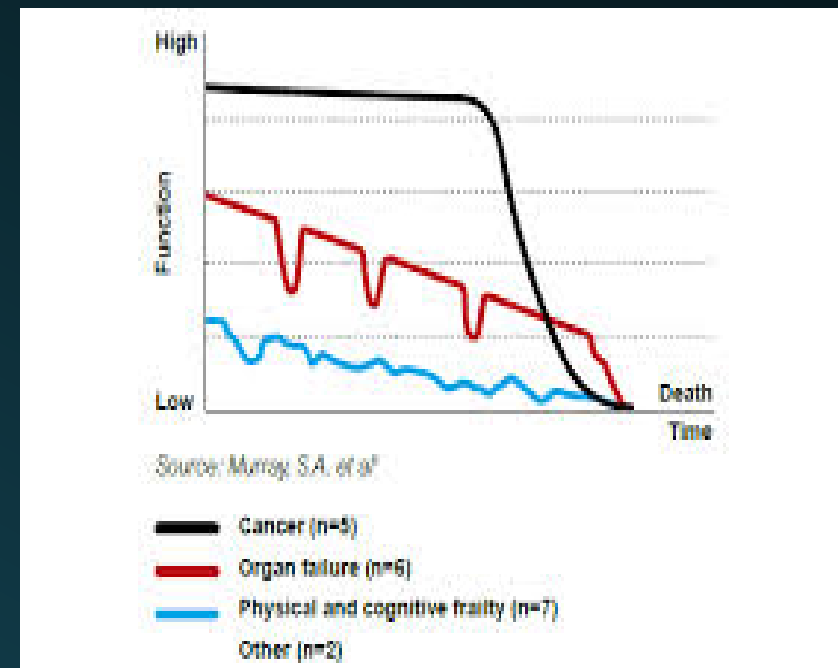
Palliative care services have been responsive

Life-limiting, non-malignant chronic disease

- Non cancer
- Progressive disease
- Death is the expected outcome as a direct result of the illness or disease
- Includes but not limited to end stage respiratory, cardiac, renal, hepatic and neurological conditions
- 1 in 5 Australians affected by multiple chronic diseases (AIHW <http://www.aihw.gov.au/chronic-diseases/>)

From the literature we know.....

- Illness trajectories are different
 - Longer & less predictable (Murray SA 2005 & 2009)
- Increased symptom burden (Murtagh et al)
- Multiple co-morbidities
- Discussion about this interface & recognition of need
- Take up by PCT's is variable (Gibbs 2006)
- Little about experiences & attitudes
- Lack of understanding by other services about palliative care (Selman et al 2007)



Thinking about this....

What might we need to help us do this?

How do we transition from caring for people with malignancy to people with non-malignant conditions?

Are the principles of symptom control for malignancy transferrable to non-malignancy?

Aim

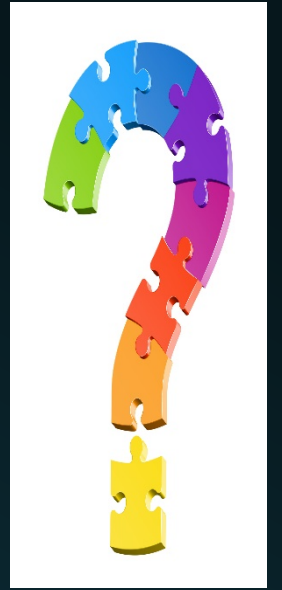


To discover the experiences palliative care nurses were having in caring for this patient group

To understand how they felt about caring for this patient group

The Question

“What are the experiences and attitudes of community specialist palliative care nurses on the Mid North Coast of NSW in caring for patients with life limiting, non-malignant chronic disease?”

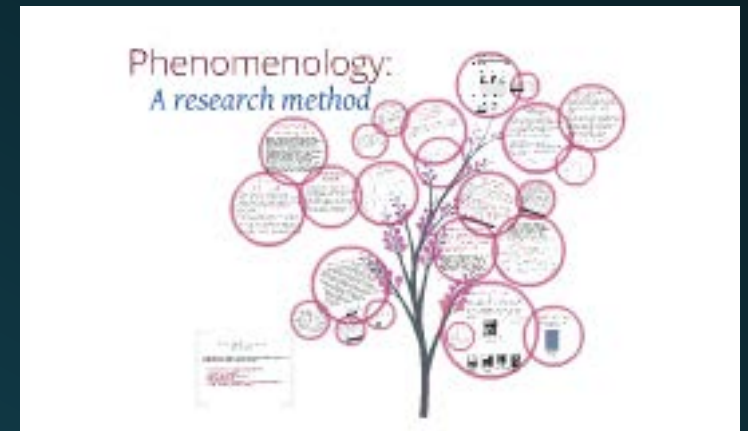


Methodology: A Qualitative Approach

- Goal – to gain an understanding of the lived experience

➔ phenomenology

- Ethics and SSA approval



Flood A (2010), Connolly LM (2010), Creswell JW (2013)

Method

- Target population: Community palliative care nurses working in specialist teams in the MNC LHD
- Semi-structured interviews, transcribed
- Analysis: Coding the data to identify emergent themes
- Interpretation of the themes

(Sandelowski, 1995)

Mid North Coast LHD



- Population: 208,331 (2012)
- Palliative Care Teams
 - Coffs Harbour
 - Macksville
 - Kempsey
 - Port Macquarie
- 1.0 fte Palliative Care Specialist (Coffs)
- 21 Palliative Care Nurses (14.6 fte) (including CNC, CNS2, CNS1, RN)

Sample

- 21 nurses invited
- 16 respondents (1 unable to attend)
- Number to interview 15
- Of the 4 teams, 1 team (2) declined because 99% of their workload is malignancy
- Palliative Care Experience: Range 1.5 – 25 years
Average 8.8 years
- 60% (n=9) post grad qualification / working towards
- All female

Results to date.....

- Interviewed 15 participants
- Coded 10 interviews so far
- Qualitative process – identifying themes from the coding



The first point...

All 15 participants saw caring for patients with life limiting non-malignant chronic disease as part of palliative care service provision

"....palliative care for all, everybody absolutely has the right to palliative care and that's for whatever reason, because we all die in the end. So I think it's a good thing and it's to me probably a good thing that we've had more referrals that people are acknowledging that someone needs referral to palliative care because they're reaching their end. So yeah, I think that that's great. Whoever, whatever the reason is, if people feel that they are heading towards the end and there might be issues that they need help with....."

PCN128

Diagnoses Cared For

Respiratory: COPD, Pulmonary Hypertension

Heart Failure

Frailty

Dementia

Liver Failure

Renal Failure

Neurological: MND, MS

AIDS

Emerging Sub Themes

Carers

Benefit, support, reassurance

"I think because it's a chronic illness they deteriorate over a long - many years,They're in and out of hospital a lot over that time.....The carers - I suppose they just go along as if this is normal. It's just normal life." PCN132

"I think that the carers themselves actually really say they benefit from palliative care being involved." PCN129

Emerging Sub Themes

Communication

Conversations about dying, Advance Care Directives

Nurses themselves, treating teams, patients & families

"So each of them understood what her plans were should there be an event that compromised her life; you know, if she arrested at some time, that each of them were aware of what her wishes were." PCN123

"Predicting end of life and having end of life conversations are definitely a lot harder with the chronic patient group." PCN124

Emerging Sub Themes

Collaboration

Relationship, 'ownership of the patient', varied in areas

"It was also difficult if the patient stabilised as is the nature of chronic care, it was difficult to refer them back to the chronic care team." PCN 131

"So the relationship between the patient and the chronic care team ceased and then it became a relationship between the patient and the palliative care team." PCN130

Emerging Sub Themes

Disease Trajectory

Longer, variable, impact for service, patients and carers

"..chronic illness tends to be the same for a long time, then something goes wrong. We fix that and on they go for another length of time" PCN 125

"These people tend to be more long-term people and I think - our problem once they got onto palliative care books in that we could not discharge them." PCN 123

Emerging Sub Themes

Dying with a Chronic Disease, patient perspectives

Resilience, longevity, sudden death

".....they don't really see themselves as dying. It's more a hiccup, I suppose, when they do have to go into hospital.....because they've had such a long period of time, they approach it differently, I think, a little bit than someone with a malignancy. That's more a certainty..."
PCN126

"But they become so used to that adversity if you like that their expectations are really quite low if you were to compare them to ours. So their expectations and what they want from life are not a lot and so they plod along and they keep plodding along." PCN125

Other emerging sub themes

- Impact on practice for teams
- Referral to and from Palliative Care
- Resources & Support
- Service Issues
- Symptom Control

And

Paediatrics !

What Next?

- Complete the coding
- Establish the themes
- Interpret the themes to make meaning relevant to the question and current evidence

Understanding the Lived Experience

- Inform about the needs of palliative care nurses to care for this patient group
- Highlight some of the challenges and opportunities in caring for this patient group
- Illustrate the palliative care nurses professional perspective
- Help develop models of care and collaborative team approaches to care

References

Hockley, J., (1997) *The evolution of the hospice approach*. In *New Themes in Palliative Care*. D. Clark, J. Hockley, and S. Ahmedzai. Editors Open University Press Buckingham UK

Saunders, C. (2001) *The Evolution of Palliative Care* Journal of the Royal Society of Medicine 94(9): pp430-432

Hunt, R.W. & Maddocks, I. (1997) *Terminal care in South Australia*. In *New Themes in Palliative Care*. D. Clark, J. Hockley, and S. Ahmedzai. Editors Open University Press Buckingham UK

Addington-Hall, J. (1998) *Reaching Out: specialist palliative care for adults with non- malignant disease*. National Council for Hospices and Specialist Palliative Care Services

NSW Ministry of Health (2012) *The NSW Government Plan to Increase Access to Palliative Care 2012-16*. Ministry of Health, Sydney.

Wallwork, L. (2000) *Palliative care in non-malignant disease: a pragmatic response*. International Journal of Palliative Nursing 6(4):pp186-191

AIHW Chronic Diseases <http://www.aihw.gov.au/chronic-diseases/>

Murray, SA. (2005) *Illness trajectories and palliative care*. BMJ 330(7498): pp1007-1011

Murray, SA. (2009) *Illness trajectories and stages*. In: *Palliative Medicine* D. Walsh et al Editors Saunders Elsevier; Philadelphia

Murtagh, F.E.M., Preston, W. & Higginson, I.J. (2004) *Patterns of Dying: palliative care for non-malignant disease*. Clinical Medicine 4: pp39-44.

References

Gibbs LME, Khatri AK, Gibbs JSR. (2006) Survey of Specialist Palliative Care and Heart Failure. Palliative Medicine Vol 20

Selman L, Harding R, Beynon T, Hodson F, Hazeldine C, Coady E, Gibbs LME and Higginson I. (2007) Palliative Medicine Vol 21 No 5 pp 385-390

Flood A. (2010) Understanding Phenomenology Nurse Researcher 17(2) pp 7-15

Connolly LM (2010) What is Phenomenology MEDSURG Nursing 19(2) pp 127-128

Creswell JW (2013) Qualitative Inquiry & Research Design: Choosing Among Five Approaches Third Ed California SAGE

Sandelowski M (1995) Qualitative Analysis: What It Is and How to Begin. Research in Nursing & Health 18, 371-375