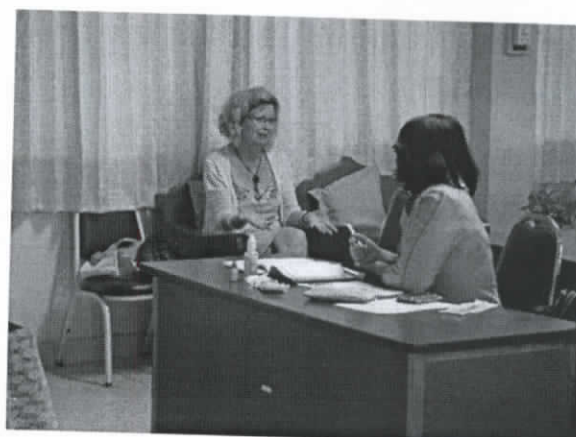


4.1-7-4

การพัฒนาศักยภาพด้านการวิจัยและจริยธรรมการวิจัยของอาจารย์ วันที่ ๒๒ พฤศจิกายน ๒๕๕๕

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Researching Death and Dying

Presentation to
Boromarajonani College of Nursing,
Nakhon, Lampang
Associate Professor Pamela van der Riet

Factors that impact on the quality of end of life

Casey et al (2011)

- Knowing the person and individualised care
- Ethos of open communication between staff and patients about bad news, prognosis and treatment options
- Culture, philosophy of the organisation of care
- Multidisciplinary approach
- Physical environment and resources

Outline

- The importance of research in palliative care
- Factors that impact on the quality of end of life. A recent study
- Pamela's PhD storylines and discourses on death and dying
- Complementary therapies for end of life care
- Ethical issues in doing research on death and dying
- Challenges in researching end of life care

Storylines and Discourses of dying

- Emotional/ Psychological Discourses
Feeling Threatened, Fear of Dying/Uncertainty,
Shock, Loss and Concern for Children

- *It is pretty frightening*
- *for the kids to think*
- *that they are going to lose their mum.*
- *That's how I feel,*
- *I felt threatened*
- *to think*
- *that the kids mightn't have a mother.*

The importance of research in palliative care

- You might ask why research? Research is about improving practice and, therefore, producing good patient outcomes.
- See podcast with Professor Margaret O'Connor Vivian Bullwinkle Chair in Palliative Care Nursing
<http://www.youtube.com/watch?v=4weNYcpNwCM>

Storylines and Discourses of dying

- *'Cancer Means Death'*
- *'I Just Accept Each Day as it Comes'*

[illegible]

Emotional/ Psychological Discourses

- *'It's Very Hard Watching Them Die'*
 - *The worst part is of course*
 - *watching when people die*
 - *and every one of them so quick*
 - *quickly died*
 - *"*
 - *It's very hard to watch*
 - *them die*
 - *It gets you down a lot*
 - *But it's taught me so much*
 - *"*
 - *It has taught me,*
 - *as from him,*
 - *not to fear*
 - *death.*

Emotional/ Psychological Discourses

- » *Time to say goodbye to people*
 - I suppose like most people
 - I don't really look forward
 - to a prolonged death
 - Although I feel there is value
 - in having a little time to die
 - and people are aware of you dying
 - I think I would want:
 - I would want time to say goodbye to people
 - I would like some time
 - to explore my own dying.
 - Sudden death
 - would be okay,
 - but I'd rather have a little time
 - to get used to dying.
 - I don't want to die alone either

Emotional/ Psychological Discourses

- ▶ *'The Quicker the Better'*
- ▶ *I just want to be comfortable and free of pain.*

'Holding On' and 'Letting Go' Discourses

- This holding on discourse often intersects with other nursing and medical discourses of dying.

Spiritual Discourse

- ▶ Easing into a Peaceful Death
Massage
- Giving permission to die

Ethics

- ▶ Field of ethics is very broad
- ▶ It covers the full expanse of thought and action directed toward answering the question, "What should I do?"
(Komesaroff 2008. p. Xx iii)

Data from Pamela's Phd

- After her visualization session Wendy muses about the soothing and relaxing effects
 - I enjoyed the neck
 - I like the feet to -
 - maybe more than the hands
- That was a wonderful massage
- I've been thinking about the rain forest
- trees and waterfalls
- I felt the slow
- Yes I went into the rain forest
- That was lovely. I really enjoyed it
- Yes
- I'm feeling relaxed
- contented,
- nice and peaceful
- Nothing
- Just relaxed
- no stress
- I could drift off into the rain forest

Attending to Relational Ethics

- 1.Procedural-mandated by the Research Ethics committees
- 2.Situational-refers to ethics in practice: unexpected, unpredictable situations, where researcher has little control over events (Goodwin et al., 2003)
- 3.Relational-recognizes and values mutual respect, dignity and connectedness between researcher and researched, and between researchers and the communities in which they live and work (Lincoln in Ellis, 2007)

More data –After a massage and meditation session, Gary commented on the relaxation effects.

- What you are saying is very soothing
- Lovely, lovely you have got the voice and the tone and the right words
- You have used all the right words
- Very peaceful
- It just feels very relaxed
- You said take all the tension out
- There wasn't any tension to take out
- because you took it all out
- Yes. Just lying here my body could be elsewhere
- Just like floating on a cloud
- It feels very, very light
- My body just feels so relaxed.

Responsibilities of the researcher

- ▶ Need to Ensure:
Participants' rights of autonomy choice, informed consent, lack of harm, confidentiality, anonymity respect and dignity are protected

(Seymour & Ingleton 1999)

Reflexivity

- Researchers should subject themselves to the same level of scrutiny they direct towards their participants. How?
- Why did we choose to study what we study
- What is the problem to be explored?
- What are our assumptions?
- What are our expectations about our participants?
- Acknowledge how aspects of our identities (gender class) and how they affect data and the participants

(McCrackel and Myers, 2001; Fonnwa and Cook, 1991; Hertz, 1997; and Devault, 1995).

Questions

Ethical issues in researching death and dying

- Maintaining ethical conduct – talking about death
- Informed consent
- Recruitment of participants – gatekeepers
- Emotional challenges for the researcher
- Design needs to reflect core principles of palliative care

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Challenges in researching end of life care

- Difficulties in design
- Lack of agreed definitions of end of life care, palliative care
- Variable levels of awareness of diagnosis and prognosis in patients
- Difficulty in obtaining funds
- High attrition rates
- Managing the researcher's role
- Managing the emotions of participants, carers and researcher
- Inclusion approaches