วิทยาลัยพยาบาลบรมราชนนี นครลำปาง รายชื่อผู้เข้าร่วมอบรม

เรื่อง การจัดกิจกรรมพัฒนาศักยภาพอาจารย์ด้านจริยธรรมการวิจัยในมนุษย์และการทำวิจัยเชิงคุณภาพ วันจันทร์ที่ ๒๖ มิถุนายน ๒๕๕๗ ณ ห้องประชุมสะบันงา

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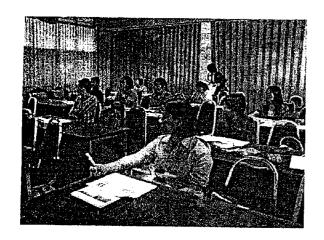
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Researching Death and Dying

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



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

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=4weNYcp

http://www.youtube.com/watch?v=4weNYcp NwcM

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





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.



Storylines and Discourses of dying

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



Emotional/ Psychological Discourses

Hope Keeping Going — Having a Goal' My two goals. are to see my eldest son's new baby. and my daughter's wedding. I think that is what keeps you going.

Emotional/ Psychological Discourses

- , 'It's Very Hard Watching Them Die'
- The worst part is of course
- watching other people die and every one of them so quickly,
- quickly died.
- . It's very hard to watch

- It gets you down a bit. But it's taught me so much.
- it has taught me,
- as from now, not to fear,



Emotional/ Psychological Discourses

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

Emotional/ Psychological Discourses

· 'Some Forms of Death Worry Me'





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.
- Ldon't want to die alone either.

'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



Data from Pamela's Phd

After her visualisation session Wendy muses about the southing and relaxing effects:

I enjoyed the neck.
I like the feet too, maybe more than the hands.

That was a wonderful massage I've been thinking about the rain forest, trees and waterfalls. Heft the snow. Yes I went into the rain forest

That was lovely. I really enjoyed it, Yes.
I'm feeling relaxed, contented, nice and peaceful, Soothing.

Just relaxed,



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 lightMy body just feels so relaxed.



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)



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)

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

(McCorkel and Myers, 2003, Fonow and Cook, 1991, Hertz, 1997, and DeVault, 1995).

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





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



Questions



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