What doctors have up their sleeves

PONZ Conference ‘The BIG C’

Palmerston North. November 21-22 2014

Ethnographic Study

Explored the stories of people who had been referred to palliative care services following diagnosis with a life-limiting illness.

Themes that emerged

- The need for open and honest Communication about diagnosis and prognosis
- The need for accurate information about treatment options
- The need for medical professionals to diagnose dying
- The need to have conversations about dying and the place of death

When these needs weren't met participants encountered barriers to palliative care

- They stayed involved and invested in treatment options
- They looked closely at the words spoken by their oncologists and 3 of them mentioned that their oncologists had told them that they still had something up their sleeves that could be looked into later on
- Although this statement appeared to foster hope in the early stages of treatment, it may also have delayed acceptance of the life limiting nature of participants' illnesses, and the need for end of life planning.

Doctors BIG sleeves

- Is saying that you have something up your sleeve, for later on, an example of
  - Creating hope?
  - Illusion?
  - Optimism?
  - False optimism?
  - Goal oriented medical activism?
  - Therapeutic Narratives?
  - Something else?

Case studies

A number of brief participant case studies have been given out for you to think about during the presentation. Please write notes or thoughts on the sheets and hand them back to me today or tomorrow.

Case Studies from ethnographic research

Helen

Alice

Tom

With conference delegates' permission, the feedback you provide may be incorporated into a publication on this topic.

Helen

- **Helen** is 53 years old, she was diagnosed with breast cancer and underwent a mastectomy, and chemotherapy treatment. Three years later she was diagnosed with metastatic bone, lung, and brain cancer. The following is an extract of my field-notes from my fourth meeting with her.

- *My oncologist never gave me a time frame, he said that they have lots of weapons up their sleeves and can also pull out the big guns. I've had one of the regular strains of chemo. They didn't use the stronger ones. They said they would leave them up their sleeves for further on. I was told a year ago that I would have another 18 – 24 months chemo to undergo, but this year I am doing better.*

10 months later

- *Helen explains that she has always known that she won't live to grow old, but she thought she would have longer, she now realises that she won't. She said again that she had hoped to get more time out of this chemotherapy treatment. She also said that her oncologist had told her that if this new round of chemotherapy doesn't work he still had something else up his sleeve.*

Tom

- Tom is 52 and I have just met him today. The following is an extract of my field-notes from this first meeting.

- *Tom explained that he originally got cancer of the palate about a year ago and they were able to operate and remove most of it. He then explains that after the operation, he thought the cancer was all cured. Then he and Michelle were on holiday and he started getting terrible pain in his back and legs. He said that by the time they got back to New Zealand he could hardly walk. Once he was home they made an appointment with the hospital and because of Tom's history they thought he should see his Oncologist. His oncologist organised a scan. Then when they saw Tom's oncologist he said that there was a spot in the bones that looked like it could be cancer. They decided to give him a single dose radiation treatment, which they did. He said that he's not sure why they didn't give him any more treatment and they said they still have a few things up their sleeves.*

Alice

- **Alice** is a 32 year old woman with metastatic liver cancer. She was diagnosed with bowel cancer five years earlier and underwent surgery at the time. The following is an extract of my field-notes taken approximately 9 months after my first meeting with Alice.

- *Alice is currently receiving chemotherapy. She has come to see her oncologist today, her feet and legs are swollen and numb, she has a number of bruises on her stomach, her back is sore, and she feels itchy all over. She thinks that her side-effects and her depression are related to the medication she is receiving. Alice discusses stopping some of the painkillers with her oncologist, she explains that she keeps forgetting things and her husband is worried about her being at home alone. Her oncologists suggests that Alice stays in hospital for a couple of days so they can look at a couple of other options they have up their sleeves. The oncologist says that she is concerned about Alice's back pain and leg weakness, and would like to do a scan to double check what is going on.*

Communicating bad news and hope

- ‘When bad news is communicated, it can almost always be done with a hopeful element woven into it.’
- Hope is often associated with treatment, and cure. In Palliative care, a redefining of hope is required.
- One argument is that: Communicating a certain amount of uncertainty may be important in the initial stages of diagnosis, as it may create illusion which may allow a person to positively adapt to bad news (McKay, 2004).
- *Does the sleeve contain hope? Does it provide important uncertainty? Does it create illusion that assists adaptation?*

Are these Therapeutic Narratives?

The term “therapeutic narratives” is used to describe the doctors’ discussions of treatment options with patients.

- avoidance of patients’ questions about prognosis and deference to the immediacy of current issues, such as clinical tests and “therapeutic housekeeping”, side effects of treatment, current medication, and other treatment options.

- oncologists seek to ‘emplot’ therapeutic action, they attempt to formulate experiences for patients designed to instil hope

Del Vecchio Good, M. J., Munakata, T., Kobayashi, Y., Mattingly, C., & Good, B. J. (1994). Oncology and narrative time. *Social Science Medicine, 38,* 855-862.

Is this Medical Activism?

- Doctors can provide small goals relating to medical investigations and treatments, these often assist in the development of hope. This may be okay in the short term but it can also lead to a person seeking ongoing treatments without realistic insight.

- If people live in the medicalised moment, which is full of hope, they may well develop false optimism about their recovery.

- In turn this may lead to a high expectation of cure rather than seeking timely palliative care. More seriously it may result in people seeking ongoing invasive or inappropriate treatments.

- In turn this process may increase suffering by betraying hope. It may also stop hope from evolving into acceptance, transcendence, preparedness for the end of life.

McKay, D. (2004). Is there hope in palliative care? **NZFP, 31.** 6

Is it a way of giving hope?

- Hope is: A feeling of desire for something and confidence in the possibility of its fulfilment
- To have a wish
- To trust expect or believe
- It is a ‘multi dimensional dynamic life force characterised by a confident yet uncertain expectation of achieving good, which is realistically possible, and personally significant‘ (McKay, 2004).

Communicating Misrepresentations of Hope

- Bad news may be delivered with a exaggerated or misguided promise of potentially curative treatments that can promote false optimism…creating false expectations of investigations, treatment, and cure'

- *Does the sleeve contain misguided hope as a way of mitigating the bad news?*

McKay, D. (2004). Is there hope in palliative care? ***NZFP, 31.*** 6

Communicating Hope in Palliative Care

- A synthesis of literature on palliative care and hope, found that there are **three main perspectives** on hope of palliative care patients
  - Realistic perspective – hope should be truthful and adjustable.
  - Functional perspective – hope is coping mechanism that should help patients adjust
  - Narrative perspectives – hope as meaning should be valuable for patients and health care professionals
- Health care professionals need to be able to work with all three perspectives

(Olsman, et al 2013).

Perspective 1. Realistic Hope

Realistic perspective:

- Hope is an expectation that should be truthful or futile treatment can occur
- Hope can be destroyed by truth
- Hope can be destroyed by disclosure of prognosis
- Hope can be destroyed by disclosure of medical information, the words palliative care, or discussions on death and dying
- Truth must be balanced with hope with the careful weighing of words

Olsman et al., 2013

Perspective 2. Functional Hope

- Hope is something patients can psychologically hang on to
- Hope is a positive attitude and motivation
- Hope helps palliative patients keep on living
- Hope helps patients to accept treatment
- Hope is the achievement of events and goals
- Hope is spiritual
- Hope as peace and realistic acceptance

Olsman et al., 2013

Perspective 3. Narratives of Hope = meaning

- Hope is found in meaning
- Hope is the achievement of events
- Hope is good when it is useful
- Hope should be in line with the patient's life narrative.
- Hope is found in conversations that go beyond cure

Olsman et al., 2013

Hope, meaning and adaptation

- Hope is developed through meaning
- Meaning comes from a sense of achievement
- Meaning allows people to make sense of suffering
- Sometimes in this process of making sense, people are able to transcend beyond the immediate issues related to diagnosis and find a deeper, or even more spiritual belief about their illness
- Hope must be realistic and achievable (McKay, 2004).

Hope is the result of full communication

Review the three case studies again and contemplate the 3 perspectives. Is this a useful framework?

- Functional perspectives; does having something up your sleeve foster hope?
- Narrative perspective; does the hope provided give meaning to life?
- Realistic perspective is the hope provided realistic?

Hope and Hopelessness

- Hope changes, it may initially become hopelessness following diagnosis.
- As realisation sets in, hope is redefined
- More attainable goals are developed, negotiated and reviewed (McKay, D. 2004).
- Hope can give meaning, even in death.
  - Billy hoped he would wake up and pray as he died, unbelievably he did and his hope for a spiritual death was realised.
  - Helen hoped she would be at home, looking at her garden, with her family close by, and that is where she died.
  - Mary hoped she wouldn't make lots of noise when she died, she hoped she would die peacefully, and not in pain, and she did.

Hughes, C.R. 2010

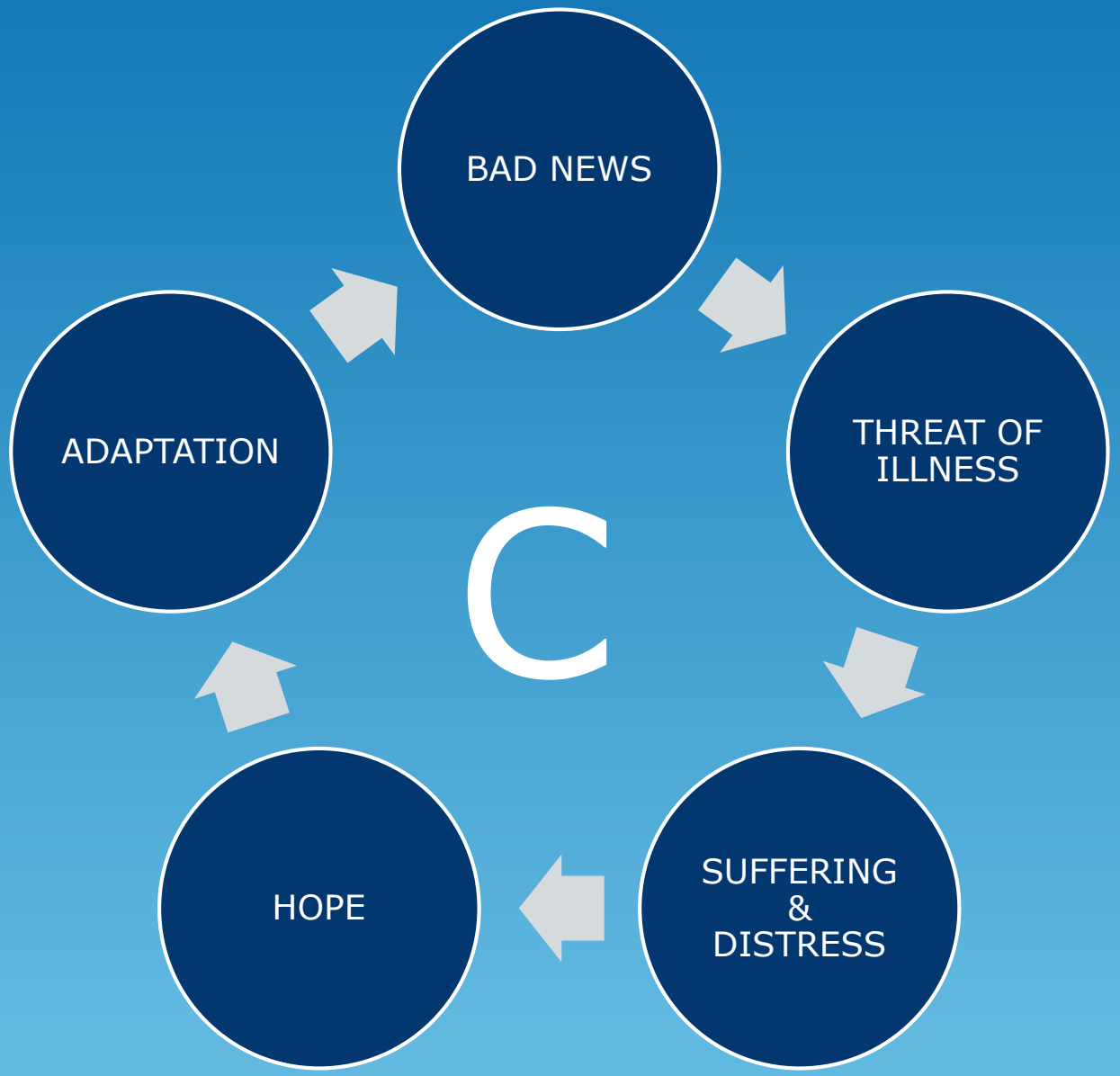
Hope grows in larger spaces, untethered from physical bodies

- When hope is only framed by the medical context it is more likely to become false optimism, leading to medical activism, engagement in therapeutic narratives, and unpreparedness for the end of life.

- A psychosocial spiritual definition of well-being is a larger landscape in which to grow hope. Within this construct hope can be defined as finding meaning from life, from illness, and from dying.

Olsman et al., 2013

Phrase hope appropriately so people can adapt



Recent articles and link to thesis

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- Cottle, M., Hughes, C.R., & Gremillion, H. (2013). A Community Approach to Palliative Care: Embracing Indigenous Concepts and Practices in a Hospice Setting. *Journal of Systemic Therapies. 32,* 1.

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