

Spirituality mandated in hospice care: meaning what?

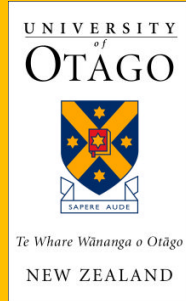
How well is this done in New Zealand?

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Study participants

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Overview

- Introduction
- Study Overview / Methods
- Results
- Conclusions / Recommendations

Introduction

- “It is important to locate the researcher’s lens so as to understand how these lenses might influence the research process because the researcher is the instrument. (Yick, 2008 #352@1290).
- How one understands, studies and explains spirituality may be considered as much related to the individual researcher’s beliefs and worldview, as to his or her discipline, methods or subjects (Berry, 2005 #60; Schneiders, 1989 #503@694)

Introduction – Context

Re-emergence of spirituality (in health)

- **Spiritual vacuum** (Frankl, 1984; Taylor, 2007)
- **Bio ----- biopsychosocialspiritual continuum** (Sulmasy, 2002; Puchalski, 2006)
- **Growth in academic interest** (Stefanek, 2005; Williams, 2006)
- **Patient-led / bottom up** (Tacey, 2005; McCord, 2004)
- **Maori contributions / aspirations** (Durie, 1998; Rochford, 2004)
- **Policy, guidelines, curricula** (NZ Health Strategy (2000), Palliative Care Strategy (2001), NZ State School Curricula (1999), Treaty of Waitangi, UK National Health Service)
- **Disentwining thesis** (Arai et al, 1989, World Council of Churches)
- ..., globalization, democratization (of belief), pluralism, postmodernism...

Study Overview

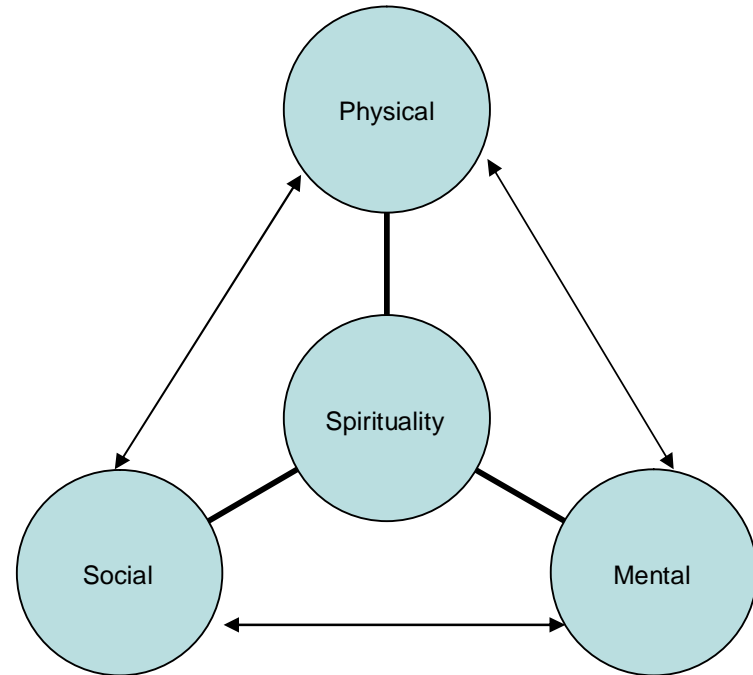
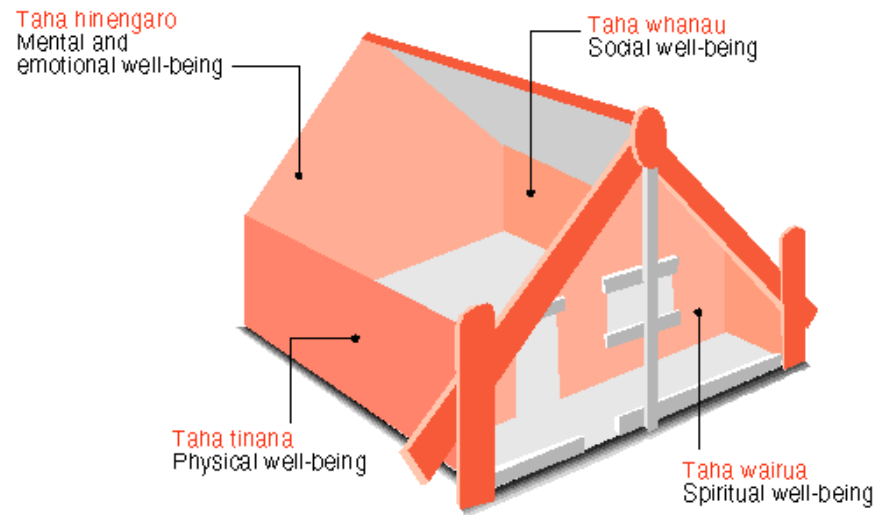
Topic: Spirituality in NZ End-of-life Cancer Care (hospice focus)

Aim: to investigate and improve understandings and practices of spirituality in New Zealand hospice care

Context: Palliative care services: *integrates physical (tinana), social (whānau), emotional (hinengaro) and spiritual (wairua) aspects of care to help the dying person and their family/whānau attain an acceptable quality of life.*

(NZ Palliative Care Strategy, Ministry of Health, 2001)

Te Whare Tapa Wha & Integrative Model



Research Design: Method

Pilot study: 'interview' and 'survey' piloted at the Otago Community Hospice.
Focus group with Otago Cancer Society

Populations: patients, family members, staff, chaplains, Maori experts

Study 1: 52 interviews (24 patients, 9 family members, 8 staff, 8 chaplains/spiritual carers, 3 Māori experts).

Analysis Study 1: recorded interviews; systematic write up after each interview ;
transcribed; thematic coding

Study 2: surveyed 25 New Zealand's hospices (response rate 59%).

Analysis Study 2: returned surveys logged; data input; analysis using STATA

Working Definition:

Please note: 'spirituality' means different things to different people. In this study, spirituality includes beliefs, values, sense of meaning and purpose, identity, and for some people religion.

Thesis Questions and Results

Thesis Questions

- What does spirituality mean for those affected by terminal illness?
- What are their spiritual needs?
- What do Māori say about spirituality / spiritual care?
- How can spiritual care be improved?

Results: Meta-themes

- Spirituality Definitions
- Spiritual Practices and beliefs
- Spiritual Needs and Care

Spirituality Definitions

Definition typology / categories:

1. Religious / transcendent approach
2. Behavioural / secular / humanist / existential
3. Summative / integrative / inclusive
4. Other

Study 1 Interview Results

Religious: “I do see it as religion” (nurse)

Existential: “I believe it’s about belief systems”
(patient)

Summative: “[it] embraces the essence of what it means to be human. It is concerned with personhood, identity and meaning and purpose in life. The spirit holds together the physical, psychological and social dimension of life”
(chaplain)

Maori expert's view of spirituality

- Te taha wairua is generally felt by Māori to be the most essential requirement for health (Durie, 1998b, p. 72)
- “one of the single most important words is about connecting and connecting generations, connecting families, ... that connection between people”. ... “we know there is the spiritual stuff because the spiritual stuff is connected with the past and the future.
(Dr Ngata, thesis interview)
- “I call it communion, .., communion in being able to commune with something, ..., inanimate or person”.
(Peter, thesis interview)

Spiritual Practices and Beliefs

Practices

- Religious activity / Spiritual activity higher slightly higher than general population

Beliefs

- High beliefs in God, afterlife, paranormal
- 'No beliefs' high
- Some religious beliefs
- Importance of spirituality – very high
- Reprioritization common
- Spirituality cp psychology

Spiritual Needs

- Dependent on life before cancer
- Identity challenged
- Challenges and opportunities

Common spiritual needs included

- religious needs (small number),
- existential needs (meaning & purpose),
- peace of mind (relationships, financial, hope, humour, identity, congruency)
- blocks to peace of mind (spiritual pain, anger, fear, guilt, regret, worry, uncertainty, grief and despair).

“A significant part of the work of the dying is dealing with spiritual issues.”

(Hospice chaplain, Study 1)

Spiritual Care

Provision

- Who does it?
 - Role / Job Description
 - Multi / inter Disciplinary

Process

- How is it done?
 - Assessment
 - Care plan
- Timing, training, staff care
- Ethical issues
- Barriers

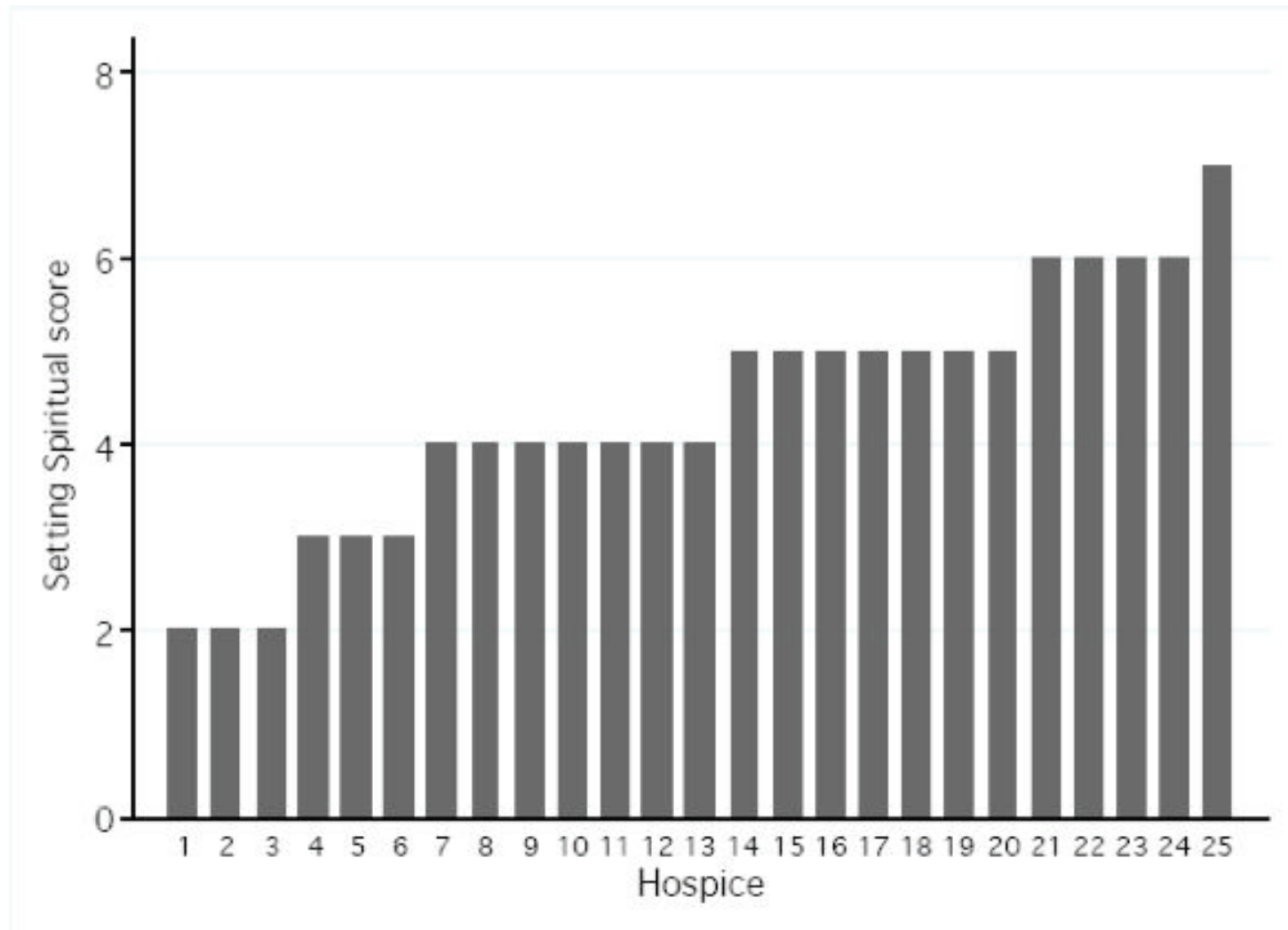
Patients and family members were largely not aware of receiving spiritual care

“ It is not really addressed in the assessment unless they come up with it themselves”
(hospice nurse)

“There isn't a specific care plan for spirituality” (hospice nurse)

“You can't do effective palliative care without going to the spiritual realm”
(palliative care medical specialist)

Spirituality Setting Score



How Can We Improve Spiritual Care?

- Upstream Issues
- Midstream Issues
- Downstream Issues
- Spiritual Care Challenges

Recommendations

1. **Provide evidence to prioritize funding at a national level for building spiritual care capacity up, mid and downstream within hospices.**
2. **Develop an inclusive working definition of spirituality for New Zealand hospices.**
3. **Facilitate structural spiritual audits in all hospices.**
4. **Develop spiritual care policies, guidelines, and competencies for pre and in-service training for New Zealand hospice care.**
5. **Implement pre-service spiritual care training courses for all healthcare professionals, particularly nurses and medical doctors.**
6. **Mandate annual and compulsory in-service spiritual care training as a component of hospice healthcare professionals' maintenance of professional standards and continuing professional development.**
7. **Develop a health promoting hospice pilot in New Zealand, with a spirituality focus.**
8. **Grow the evidence base for spiritual care efficacy through tagged research funding.**

Thesis Recommendations

9. **Prioritize Māori spiritual care capacity.**
10. **Encourage a spiritual care process in every hospice, including a spiritual history/ongoing assessment, a spiritual care plan and formal notes, and tailored spiritual care/interventions.**
11. **Hospice chaplains consider changing their title so as to be inclusive for their community.**
12. **Spiritual care experts be paid and employed enough hours to do their job appropriately.**
13. **Adequate physical space be made available and appropriately fitted out for spiritual care.**
14. **Develop qualitative and quantitative spiritual assessment tools relevant for New Zealand hospices.**
15. **Develop a spiritual care resource to up-skill family and friends.**

**‘Ko te Amorangi ki mua, ki te hapai o ki
muri’**

**‘Place the things of the Spirit to the fore,
and all else shall follow behind’**

Takitimu whakatauaki (proverb)

(Payne, Tankersley, & McNaughton A (Ed), 2003, p. 85)