

#### Spirituality: what is it?

## Evidence from NZ Hospice Study

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## Overview

- Introduction (author, context, studies)
- Results (qualitative & quantitative)
- Discussion
  - Other research (overseas / NZ)
  - Criticisms
  - Definitions reflect worldview
  - Definition typology
- 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 (whänau), emotional (hinengaro) and spiritual (wairua) aspects of care to help the dying person and their family/whänau attain an acceptable quality of life.* 

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



#### **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

#### **Study 1: Definition One Liners**

- *I really struggle with the definition of the word* (Carl, 62, education, Ca),
- never gave it a thought (Frank, 75, photography, Ca);
- how one looks at the world and oneself (Henry, 76, finance, Ca)
- *it extends to my whole being, relationships and where I am in this world* (Ida, 45, hospice nurse).
- *I think being spiritual is being a good Christian* (Aida, 65, hospitality, FM)
- *it is the essence of who I am* (Abigail, 64, chaplain)
- *"[it] embraces the essence of what it means to be human*. (Damien, a 55, spiritual carer)

#### **Study 1: Definition Themes**

#### Religious/transcendent Responses

- "Old Fashion Concept of Religion"
- Religion equals Spirituality
- Religion as One Expression of Spirituality
- Spirituality as the extra-ordinary

#### Humanist/existential Responses

- Beliefs / Values / Ethics
- Meaning and Purpose
- Core / essence / identity /wellbeing
- Relational / integration / wholeness
- Aesthetic
- Mindfulness

#### Summative/Integrative Responses

Most participants' definitions included a range of descriptors, drawing from the religious and existential; these definitions were categorized as summative or inclusive responses.

#### 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)

#### **Study 2: Definition Descriptors**



#### **Literature Overview**

- 1. Definition a ubiquitous issue
- 2. Discourse dependent (country, community, demographic, culture, academic, religion)
- 3. Spirituality religion relationship some agreement
- 4. No consensus / gold standard definition
- 5. Commonalities
- 6. Universal?
- 7. Assessment / care / carer / ethics
- 8. Criticisms

#### **Definitions reflects worldview**

Framework: spirituality in healthcare literature

- Biomedical
- Biopsychosocial
- Social (holistic)

(Rumbold, 2007)

## **Spirituality Definitions**

Definition typology / categories:

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

4. Other

#### **Conclusions / Recommendations**

Develop:

- NZ Spirituality Definition Consensus Project (a working definition)
- NZ academic/research spirituality group (e-discussions etc...)

#### **Conclusions / Recommendations**

#### Advocate

- For spirituality to be recognized
  - Ministry of Health / Education / Social
    Development / Treasury …
  - Pre-service healthcare professional training
  - In-service training
  - As a Treaty / inequalities issue

#### **Conclusions / Recommendations**

Promote

• Further research and evidence to inform spiritual care



People study for weeks for a birth. Why not study for a death?

Anastasios, A. Dying to know: Bringing death to life. 2007, p.1

#### '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)

### Definition Commonalities in Literature

- Unruh found 92 definitions which he categorized into seven themes:
- 1. relationship to God, a spiritual being, a higher power, or a reality greater than the self;
- 2. not of the self;
- 3. transcendence or connectedness unrelated to a belief in a higher being;
- 4. existential, not of the material world;
- 5. meaning and purpose in life;
- 6. life force of the person, integrating aspect of the person;
- 7. summative (Unruh, et al., 2002, p. 7).

## **Thesis Survey Response Rates**

#### Table 5.4 Survey response rates

	Survey No's sent by Researcher	Survey #s Given Out by Hospice Key Contact	Surveys Received by Researcher	Response Rate
Staff	600	550	364	66.16%
Patients	415	277	141	50.90%
Family Members	403	269	137	50.92%
Totals	1418	1096	642	58.57%

# Relationship between spiritual well-being and spiritual distress

Spirituality components	Spiritual distress	
Values, beliefs, hope	Valuelessness, normlessness, angst, fear	
Meaning, purpose	Meaninglessness, ennui, hopelessness, despair	
Awareness	Uncertainty, lack of awareness	
Transcendence, religiosity	Self centered, religious pain/guilt	
Identity, relationships, connectedness	Dissolution, disconnection, isolation, guilt	





#### **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)

#### Staff Definition Descriptors (weighted)

