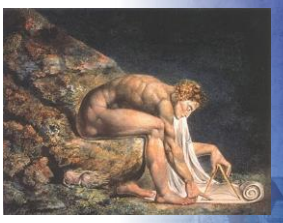
Contemporary spirituality in healthcare: a re-emerging issue



Dr Richard Egan
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Sea of Faith Conference 2014
4 October 2014
Dunedin

Cancer Society Social & Behavioural Research Unit (SBRU)
Te Hunga Rangahau Ārai Mate Pukupuku

Spirituality in healthcare: outline

1. Introduction
2. Why spirituality in healthcare?
   a) Zeitgeist & principled based approach
3. Why spirituality in healthcare?
   a) Evidence-informed considerations
4. Some final considerations
5. Questions for Core Group

Who am I?

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. (Schneiders, 1989, p.694)

Why Spirituality in Healthcare?

Zeitgeist and principled based considerations

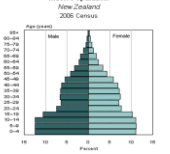
Spirituality in healthcare: the zeitgeist

Spirituality and Religion

- Contested
- Low attendance/rise of 'nones'
- Disentwining thesis: growth of contemporary spiritualities
- "I'm spiritual, not religious"

The zeitgeist: demographics, mortality & plurality

- NZers getting older (mostly) and more multicultural.
- The long dying: move from communicable to chronic diseases dominating death (Murray, S. et al. 2005)
- Spiritual plurality & democratization



Spirituality in healthcare : the zeitgeist

Spiritual Vacuum / Gap?

- Growth of meaninglessness.
- Materialism not enough?
- Individual and Societal issue (a Public Health issue)
- Re-emergence?

Spirituality in Healthcare : the zeitgeist

- Religious spirituality
- Scientific era - impact
- Post-religious age
  - Re-emergence of spirituality in healthcare

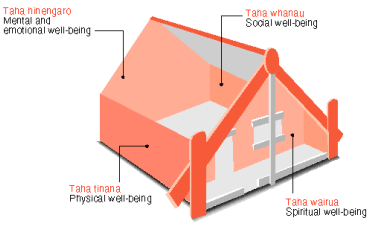
Why Spirituality in Healthcare?

Zeitgeist and principled based considerations

Spirituality in Healthcare: principle-based approach

- Whole person principle and approaches – holism, total care, Te Whare Tapa Wha, Fono fale
- "All patients have spirituality"
  (Frank Brennan Renal & Supportive Care Position Statement, 2013, Nephrology, p. 422)

Spirituality in healthcare: Māori Contribution Te Whare Tapa Wha



Durie, M. 1985

Spirituality in healthcare: Māori Contribution

"Taha wairua is generally felt by Māori to be the most essential requirement for health". (Durie, 1999)

"Without a spiritual awareness and a mauri (spirit or vitality, sometimes called the life-force) an individual cannot be healthy… ." (Durie, 1999)

NZ MoH Guidelines

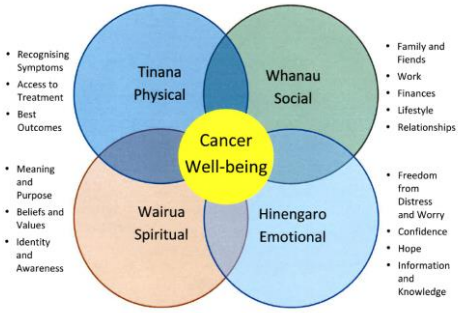
"It is essential that all staff working in cancer treatment services have a basic understanding of the spiritual needs of people with cancer, possess the skills to assess those needs and know how to go about contacting spiritual caregivers when required. Training specific to the cultural and spiritual needs of Māori is essential."

Ministry of Health (2010). Guidance for Improving Supportive Care for Adults with Cancer in New Zealand. Wellington: Ministry of Health. P.46

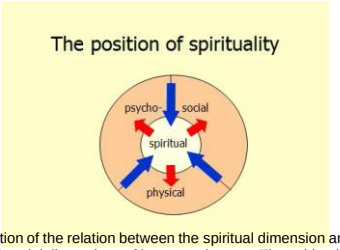
NZ Spirituality Study: Context matters

- [T]he confrontation with death lays bare the spiritual core of the human condition (Byock, 2007, p. 438).
- 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.* (NZPC Strategy 2001)
- Hospice mandate includes spiritual care (Saunders 1968, WHO 2002).

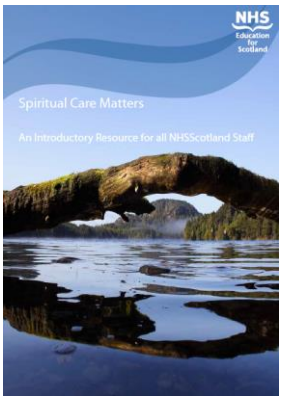
Spirituality in healthcare: CSNZ Supportive Care Model



Spiritual care: the Netherlands nation-wide guidelines (2013)

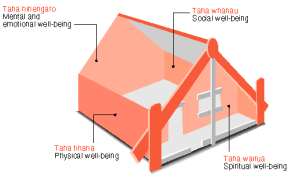


"Visual representation of the relation between the spiritual dimension and the physical, psychological, and social dimensions of human existence. The spiritual dimension is depicted as the most intimate and concealed dimension: less measurable than the other three, but continually in a relationship of reciprocal influence with them". (Oncoline Agora *Spiritual care guideline* working groupp.p. 2-3); http://www.oncoline.nl/index.php?language=en



Spirituality in healthcare: models of health

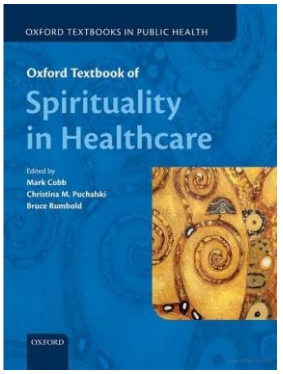
bio-reductionist ⟷ bio-psycho-social-spiritual



What do you think so far?

Why Spirituality in Healthcare

Evidence-informed considerations



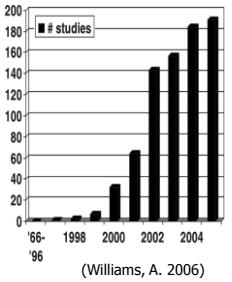
Spirituality Studies – building evidence

- Spirituality in New Zealand education
- Spirituality in New Zealand hospice care
- Psycho-social-spiritual supportive care in cancer
- Spirituality in ODHB oncology ward
- Spirituality in medical education
- Spirituality in aged care
- Spirituality and dementia study
- Spiritual care professional development project
- Spiritual care in cancer care across 16 countries
- Funding applications in…

Evidence -informed

Literature: spirituality and other health outcomes

- A "positive effect" on a range of health outcomes (Sinclair, et al., 2006, p. 468)
- Quality of life studies (Whitford, 2008, p. 1121)
- Negative religious coping (Hills, et al., 2005, p. 782).
- Qualitative studies (A. L. Williams, 2006, p. 407)
- Quantitative questions remain (See Sloan et al, 2002)
- A positive contributor to health and well-being (Egan, 2010).



(Williams, A. 2006)

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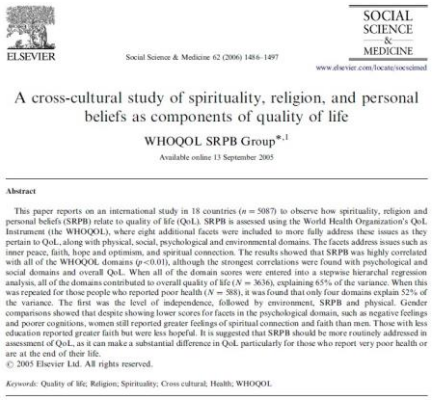
Special Reports

Improving the Spiritual Dimension of Whole Person Care: Reaching National and International Consensus

Christina M. Puchalski, MD, MS, FAPC,[1] Robert Vitillo, MSW, ACSW,[2] Sharon K. Hull, MD, MPH,[3] and Nancy Reller[4]

Abstract

Two conferences, Creating More Compassionate Systems of Care (November 2012) and On Improving the Spiritual Dimension of Whole Person Care: The Transformational Role of Compassion, Love and Forgiveness in Health Care (January 2013), were convened with the goals of reaching consensus on approaches to the integration of spirituality into health care structures at all levels and development of strategies to create more compassionate systems of care. The conferences built on the work of a 2009 consensus conference, Improving the Quality of Spiritual Care as a Dimension of Palliative Care. Conference organizers in 2012 and 2013 aimed to identify consensus-derived care standards and recommendations for implementing them by building and expanding on the 2009 conference model of interprofessional spiritual care and its recommendations for palliative care. The 2013 conference built on the 2012 conference to produce a set of standards and recommended strategies for integrating spiritual care across the entire health care continuum, not just palliative care. Deliberations were based on evidence that spiritual care is a fundamental component of high-quality compassionate health care and it is most effective when it is recognized and reflected in the attitudes and actions of both patients and health care providers.



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Social Science & Medicine 62 (2006) 1486–1497

SOCIAL SCIENCE & MEDICINE

www.elsevier.com/locate/socscimed

A cross-cultural study of spirituality, religion, and personal beliefs as components of quality of life

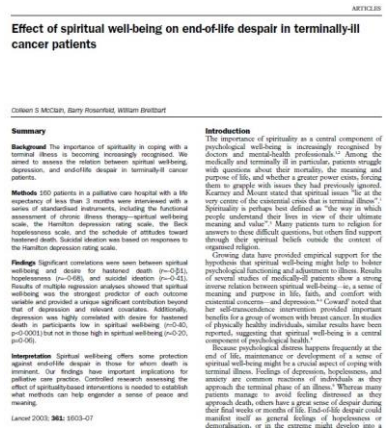
WHOQOL SRPB Group*,1

Available online 13 September 2005

Abstract

This paper reports on an international study in 18 countries ($n = 5087$) to observe how spirituality, religion and personal beliefs (SRPB) relate to quality of life (QoL). SRPB is assessed using the World Health Organization's QoL Instrument (the WHOQOL), where eight additional facets were included to more fully address these issues as they pertain to QoL, along with physical, social, psychological and environmental domains. The facets address issues such as inner peace, faith, hope and optimism, and spiritual connection. The results showed that SRPB was highly correlated with all of the WHOQOL domains ($p < 0.01$), although the strongest correlations were found with psychological and social domains and overall QoL. When all of the domain scores were entered into a stepwise hierarchal regression analysis, all of the domains contributed to overall quality of life ($N = 3636$), explaining 65% of the variance. When this was repeated for those people who reported poor health ($N = 588$), it was found that only four domains explain 52% of the variance. The first was the level of independence, followed by environment, SRPB and physical. Gender comparisons showed that despite showing lower scores for facets in the psychological domain, such as negative feelings and poorer cognitions, women still reported greater feelings of spiritual connection and faith than men. Those with less education reported greater faith but were less hopeful. It is suggested that SRPB should be more routinely addressed in assessment of QoL, as it can make a substantial difference in QoL particularly for those who report very poor health or are at the end of their life.

Keywords: Quality of life; Religion; Spirituality; Cross cultural; Health; WHOQOL



ARTICLES

Effect of spiritual well-being on end-of-life despair in terminally-ill cancer patients

Colleen S McClain, Barry Rosenfeld, William Breitbart

Summary

Background The importance of spirituality in coping with a terminal illness is becoming increasingly recognised. We aimed to assess the relation between spiritual well-being, depression, and end-of-life despair in terminally-ill cancer patients.

Methods 160 patients in a palliative care hospital with a life expectancy of less than 3 months were interviewed with a series of standardised instruments, including the functional assessment of chronic illness therapy—spiritual well-being scale, the Hamilton depression rating scale, the Beck hopelessness scale, and the schedule of attitudes toward hastened death. Suicidal ideation was based on responses to the Hamilton depression rating scale.

Findings Significant correlations were seen between spiritual well-being and desire for hastened death ($r_s = -0.31$), hopelessness ($r_s = -0.48$), and suicidal ideation ($r_s = -0.41$). Results of multiple regression analyses showed that spiritual well-being was the strongest predictor of each outcome variable and provided a unique significant contribution beyond that of depression and relevant covariates. Additionally, depression was highly correlated with desire for hastened death in participants low in spiritual well-being ($r_s = 0.40$, $p < 0.0001$) but not in those high in spiritual well-being ($r_s = 0.20$, $p < 0.06$).

Interpretation Spiritual well-being offers some protection against end-of-life despair in those for whom death is imminent. Our findings have important implications for palliative care practice. Controlled research assessing the effect of spirituality-based interventions is needed to establish what methods can help engender a sense of peace and meaning.

Lancet 2003; **361**: 1603–07

Introduction

The importance of spirituality as a central component of psychological well-being is increasingly recognised by doctors and mental-health professionals.[1,2] Among the medically and terminally ill in particular, patients struggle with questions about their mortality, the meaning and purpose of life, and whether a greater power exists, forcing them to grapple with issues they had previously ignored. Kearney and Mount stated that spiritual issues "lie at the very centre of the existential crisis that is terminal illness".[3] Spirituality is perhaps best defined as "the way in which people understand their lives in view of their ultimate meaning and value".[4] Many patients turn to religion for answers to these difficult questions, but others find support through their spiritual beliefs outside the context of organised religion.

Growing data have provided empirical support for the hypothesis that spiritual well-being might help to bolster psychological functioning and adjustment to illness. Results of several studies of medically-ill patients show a strong inverse relation between spiritual well-being—ie, a sense of meaning and purpose in life, faith, and comfort with existential concerns—and depression.[5–7] Coward noted that her self-transcendence intervention provided important benefits for a group of women with breast cancer. In studies of physically healthy individuals, similar results have been reported, suggesting that spiritual well-being is a central component of psychological health.[8]

Because psychological distress happens frequently at the end of life, maintenance or development of a sense of spiritual well-being might be a crucial aspect of coping with terminal illness. Feelings of depression, hopelessness, and anxiety are common reactions of individuals as they approach the terminal phase of an illness.[9] Whereas many patients manage to avoid feeling distressed as they approach death, others have a great sense of despair during their final weeks or months of life. End-of-life despair could manifest itself as general feelings of hopelessness or demoralisation, or in the extreme might develop into a

Psycho-Oncology
Psycho-Oncology **21**: 602–610 (2012)
Published online 2 March 2011 in Wiley Online Library (wileyonlinelibrary.com). **DOI**: 10.1002/pon.1937

The multidimensionality of spiritual wellbeing: peace, meaning, and faith and their association with quality of life and coping in oncology

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Abstract

***Objective*: This study explored associations between the recently proposed three-factor structure of the 12-item Functional Assessment of Chronic Illness Therapy—Spiritual Well-being (FACIT-Sp) subscale (Peace, Meaning, and Faith), quality of life (QoL), and coping in an oncology population.**

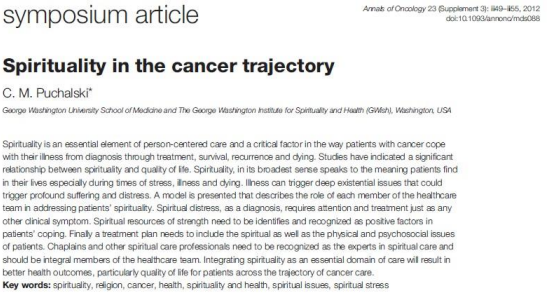
***Methods*: A total of 999 newly diagnosed, study eligible, consecutive cancer patients completed the FACIT-Sp and the Mental Adjustment to Cancer (MAC) scale.**

***Results*: Hierarchical multiple regressions revealed that Peace alone added 3% to the prediction of QoL and accounted for 15.8% of the overlap in Total Functional Assessment of Cancer Therapy—General (FACT-G) scores (both $p < 0.001$). Meaning alone added 1.3% to QoL prediction and accounted for 5.8% in overlap (both $p < 0.001$). Faith did not significantly contribute to the unique prediction or overlap of QoL. Correlational analyses revealed that Peace was most prominently associated with the QoL subscales of Functional ($r = 0.64$) and Emotional Wellbeing ($r = 0.61$) and the coping styles of Helpless/Hopeless ($r = -0.53$), Fighting Spirit ($r = 0.47$), and Anxious Preoccupation ($r = -0.34$). Meaning was also highly associated with Functional Wellbeing ($r = 0.56$), Helpless/Hopeless ($r = -0.53$), and Fighting Spirit ($r = 0.54$), but in addition, Social Wellbeing ($r = 0.49$).**

***Conclusion*: The three-factor model of spiritual wellbeing appears psychometrically superior to previous models as it further discriminates between which components are most highly associated with improved QoL facets and coping styles. This study provides normative data on newly diagnosed patients with cancer and further highlights the clinical contribution of such detailed assessment.**

Received: 3 August 2010
Revised: 16 November 2010
Accepted: 24 January 2011

Keywords: cancer; oncology; spirituality; quality of life; coping behavior; psychological adjustment



symposium article

Annals of Oncology 23 (Supplement 3): ii49–i55, 2012
doi:10.1093/annonc/mds088

Spirituality in the cancer trajectory

C. M. Puchalski*
George Washington University School of Medicine and The George Washington Institute for Spirituality and Health (GWish), Washington, USA

Spirituality is an essential element of person-centered care and a critical factor in the way patients with cancer cope with their illness from diagnosis through treatment, survival, recurrence and dying. Studies have indicated a significant relationship between spirituality and quality of life. Spirituality, in its broadest sense speaks to the meaning patients find in their lives especially during times of stress, illness and dying. Illness can trigger deep existential issues that could trigger profound suffering and distress. A model is presented that describes the role of each member of the healthcare team in addressing patients' spirituality. Spiritual distress, as a diagnosis, requires attention and treatment just as any other clinical symptom. Spiritual resources of strength need to be identifies and recognized as positive factors in patients' coping. Finally a treatment plan needs to include the spiritual as well as the physical and psychosocial issues of patients. Chaplains and other spiritual care professionals need to be recognized as the experts in spiritual care and should be integral members of the healthcare team. Integrating spirituality as an essential domain of care will result in better health outcomes, particularly quality of life for patients across the trajectory of cancer care.

Key words: spirituality, religion, cancer, health, spirituality and health, spiritual issues, spiritual stress

Evidence-informed approach: Spirituality in renal care

- "Spiritual care has been identified as an essential domain of quality care by patients with ESRD, particularly near the end of life, and **studies have indicated the strong desire of these patients to have spirituality included in their care.**" (Davison & Jhangri, 2010. p.1975)
- "engaging patients in discussions about their spiritual concerns and attending to their spiritual well-being **may contribute to an improvement in their quality of life and medical outcome**" (Finkelstein et al., 2007, p. 2433).

Context is critical: Lay Spirituality Need

- Australia: "client led recovery of spirituality" (Tacey, 2005)
- UK: "Spiritual concerns were important for many patients … both early and later in the illness progression." (Murray, 2004)
- US: 83% wanted "physicians to ask about beliefs in at least some circumstances." (McCord, 2004)
- NZ: 67% wanted spiritual care in hospice survey (Egan, 2010)

What is spirituality in healthcare?

What does the evidence suggest?

NZ national hospice study

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

Questions

What does spirituality mean for those affected by terminal illness (Ca)?

What are their spiritual needs?

What do Māori say about spirituality / spiritual care?

How can spiritual care be improved?

NZ national hospice study: 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)

NZ national hospice study: Māori expert's view of spirituality

- "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)

Understanding Spiritual Definitions

Definition Type	Example	Comment
Religious/transcendent	"I do see it as religion" (hospice nurse)	focus solely on religious aspects {Vandara, 1989}.
Behavioural/secular /humanist / existential	"I believe it's about belief systems" (patient)	Totally immanent or of this world {Lindridge, 2007 #Geering, 2005}
Contemporary inclusive/mixed/ summative	"[it] embraces the essence of what it means to be human. … The spirit holds together the physical, psychological and social dimension of life" (chaplain)	Most common in the contemporary literature {Roudsari, 2007}.
Other (outside continuum)	"I think it is the wrong word" (hospice nurse)	Those who just cannot imagine themselves having anything to do with spirituality

All quotes from participants in author's PhD study {Egan, 2010 }

What is spirituality? Map of the terrain.

Spirituality **means different things to different people**. It may include (a search for):

- one's ultimate **beliefs** and **values**;
- a sense of **meaning** and **purpose** in life;
- a sense of **connectedness**;
- **identity** and **awareness**;
- and for some people, **religion**.

It may be understood at an **individual** or **population** level.

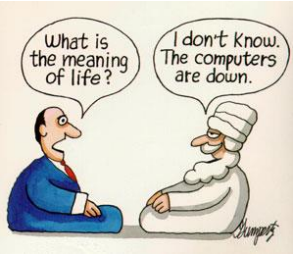
Egan, R., MacLeod, R., Jaye, C., McGee, R., Baxter, J., & Herbison, P. (2011). What is spirituality? Evidence from a New Zealand hospice study. *Mortality, 16(4), 307-324.*

NZ national hospice study: Spiritual Needs?

"There are not many people that have got it all together when they die" (hospice nurse)

I think it's important, but especially important in the situation I'm in. It would be very difficult if I didn't have any sense of spirituality.

Fran, 62, education, Ca



NZ national hospice study: Spiritual Needs

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

Common spiritual needs included

- religious needs (small number),
- Mystical needs?
- 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).
- Family needs least met

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

(Hospice chaplain)

NHS Scotland: spiritual care

- **Spiritual care** is usually given in a one-to-one relationship, is completely person-centred and makes no assumptions about personal conviction or life orientation.
- **Religious care** is given in the context of the shared religious beliefs, values, liturgies and lifestyle of a faith community.

NZ national hospice study: spiritual care

- Who received it?
- Who wanted it?
- Who gave it?
- Assessment
- Spiritual care tools
- Barriers

- Other studies: variable care (dementia, renal, oncology)

Spiritual care and kidney disease Conclusions

- Spirituality in Renal study:
  - Broadly understood
  - Patients spiritual needs not clear
  - Implicitly attended to
  - A recognised lack
  - HCPs role?
- Further research needed
  - "fallen behind the 8 ball in dealing with this" (doctor)
  - Patient need?

Spirituality in Dunedin's Residential Aged Care: Background

- The New Zealand *Health of Older People Strategy* (Ministry of Health, 2002) requires service providers and health professionals to take a holistic approach to the care and support of the elderly, "including consideration of physical, mental health, social, emotional and *spiritual needs* of older people" (emphasis added).

Spiritual care: ethical Issues

Five Guidelines

1. Understand each patient's spirituality
2. Follow patient's wishes
3. Don't impose spiritual care
4. Understand one's own spirituality
5. Proceed with integrity.

(Winslow 2003)

Spirituality in healthcare

Some final comments

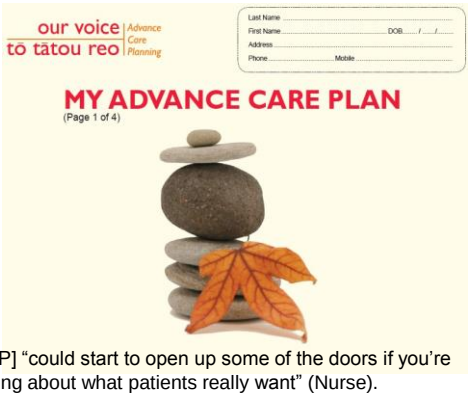
Limitations

"we are dealing with a field of experience where there is not a single conception that can be sharply drawn"

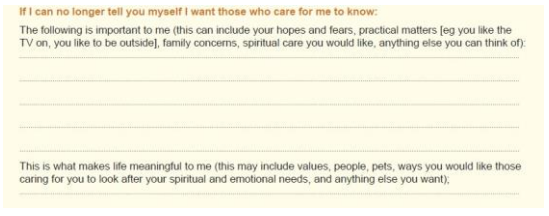
(William James 1901)

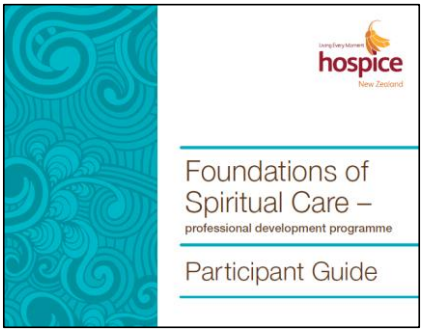
"So much depends on our perspective, and on the evidence on which we draw." (Eckersley 2004)

Research limitations

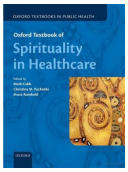


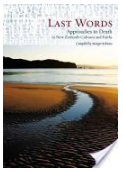
[ACP] "could start to open up some of the doors if you're talking about what patients really want" (Nurse).

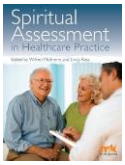


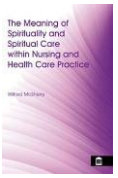


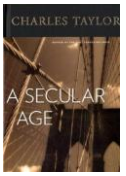
Recommended Books

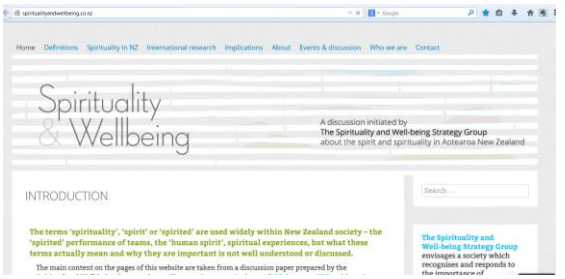












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Take home messages

Spirituality:

- A fundamental and seminal part of hospice care, elsewhere?
- Not well understood by staff or management
- Important to staff well-being
- Inherent in all interactions
- Variably assessed or addressed
- Not part of regular professional development
- A growing issue in a fragmented world
- Understood broadly and part of each individual and community.
- HNZ professional development plan happening.
- Context/zeitgeist: spiritual needs growing – important questions about heroic treatment, euthanasia/PAS, care options
- Further NZ research / policy / practice needed

Comments or questions

'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)

Otago : University

THANK YOU