Setting the scene: what's happening with spirituality and healthcare?

Dr Richard Egan
richard.egan@otago.ac.nz
Selwyn Ageing and Spirituality Conference,, 1 Sept, 2017

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

Outline

- Introductions
- Where we've come from: traditional spirituality
- Recent developments: democratic spirituality
- Challenges
- Future possibilities: spirituality matters
- Discussion

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.
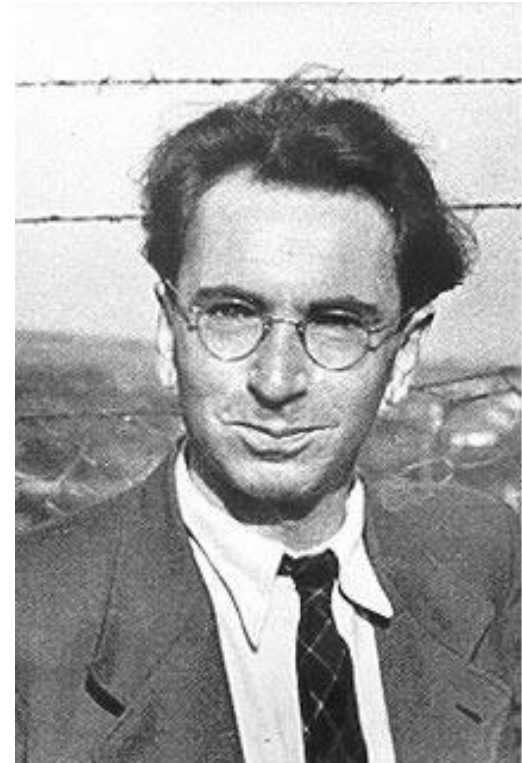
(Schneiders, 1989, p.694)
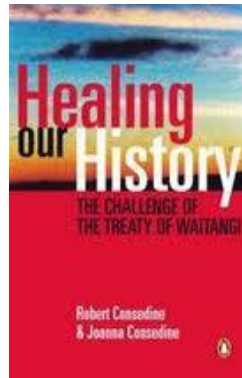
Generally speaking...

"For centuries, physicians and other healers have witnessed how illness focuses attention on "ultimate meaning, purpose, and transcendence, and ... relationship to self, family, others, community, society, nature, and the significant or sacred."

VanderWeele, T. J., T. A. Balboni and H. K. Koh (2017). "Health and spirituality." JAMA.

Victor Frankl

Generally speaking…

"Interest in spirituality and aging has increased recently, primarily owing to empirical research overwhelmingly demonstrating the various health benefits of spirituality and religious participation . Studies have also shown that spirituality tends to increase during later adulthood."

Lavretsky, H. (2010). "Spirituality and aging." Aging health 6(6): 749-769.

Spirituality – semantic evolution

Etymologically: from Hebrew – rua ; Greek – pneuma: Which both signify wind or breath, a principle of vital activity.

Conceptual evolution

Salvador Dali

Spirituality concepts related to worldviews

Pre-modern / pre-scientific worldview

    Religious worldview

Modern / scientific worldview

    Spirituality and religion same thing

Contemporary

    Impact of postmodern thought – critique and integration of worldviews

Robyn Kahukiwa

Outline

- Introductions
- Where we've come from: traditional spirituality
- Recent developments: democratic spirituality
- Challenges
- Future possibilities: spirituality matters
- Discussion

Contemporary understandings

- Reverses traditional approach – religion a subset of spirituality (if at all related)

- Development of 'Nones' and "I'm spiritual but not religious"

Nancy Eckles

Contemporary understandings

- Secularity (Taylor, C. 2007): we now chose what to believe – plurality, relativism (?),
- Positively portrayed
- Inclusive, flexible and patient led

Bill Hammond

Contemporary spirituality matters

A framework to understand it

- Scope / definition matters
- Principle & model matters
- Evidence informed matters
- Zeitgeist matters

Contemporary spirituality: NZ expert view

Spirituality can be considered as being essentially about **primary relationships**. In this regard there are at least four qualitative relationships that express spirituality, and these are the relationships between: **people and their environment** (land, mountains, sea, sky, etc); **people and other people** in terms of justice and love (families, communities, nations, etc); **people and their and other persons' heritage** (ancestry, culture, history, etc); and **people and the numinous** (that which is other, beyond the physical, transcendent, what some people refer to as God (Waldegrave, 2003).

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

What is spirituality?
Map of the terrain

"Spirituality is a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices."

Puchalski, C. M., R. Vitillo, S. K. Hull and N. Reller (2014). "Improving the spiritual dimension of whole person care: Reaching national and international consensus." Journal of palliative medicine **17**(6): 642-656. p.5

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

Contemporary spirituality in healthcare

It is in fact the vagueness of the concept that is its strength and value. ... the vagueness and the lack of clarity around the term spirituality is actually a strength that has powerful political, social, and clinical implications." (p.226)

Swinton, J. and S. Pattison (2010). "Moving beyond clarity: towards a thin, vague, and useful understanding of spirituality in nursing care." Nursing Philosophy **11**(4): 226-237.

Shane Cotton

Sir Paul Callaghan

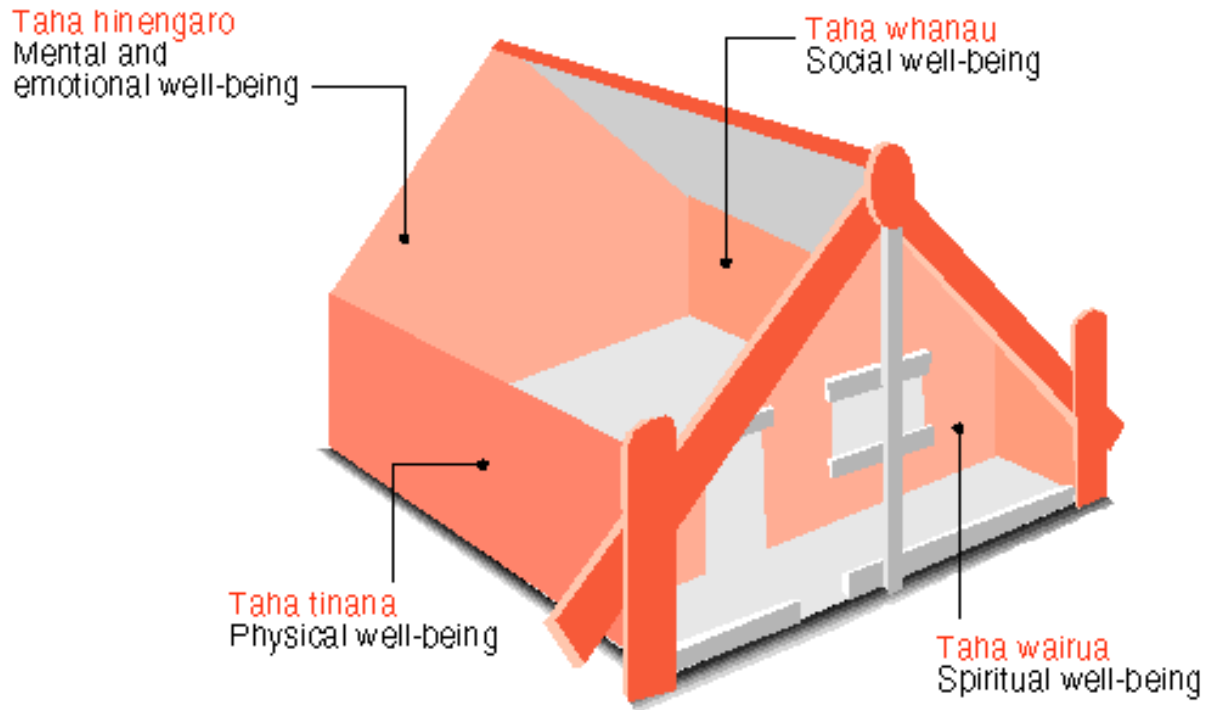"with the cancer, I resolved that I would not waste a day, that every day I would fill with purpose and spirit".

"I'm an atheist in the sense that I don't believe in an omnipotent, all-knowing, omnipresent creator. **That's not to say I'm not a spiritual man.** I acknowledge the mystery. In the sense that there are questions there that are not answered by simple paradigms around evidence and consistency, which is the way science works. Around values and why we're here at all".

Principle & model matters
Māori contribution

Taha hinengaro
Mental and emotional well-being

Taha whanau
Social well-being

Taha tinana
Physical well-being

Taha wairua
Spiritual well-being

Durie, M. 1985
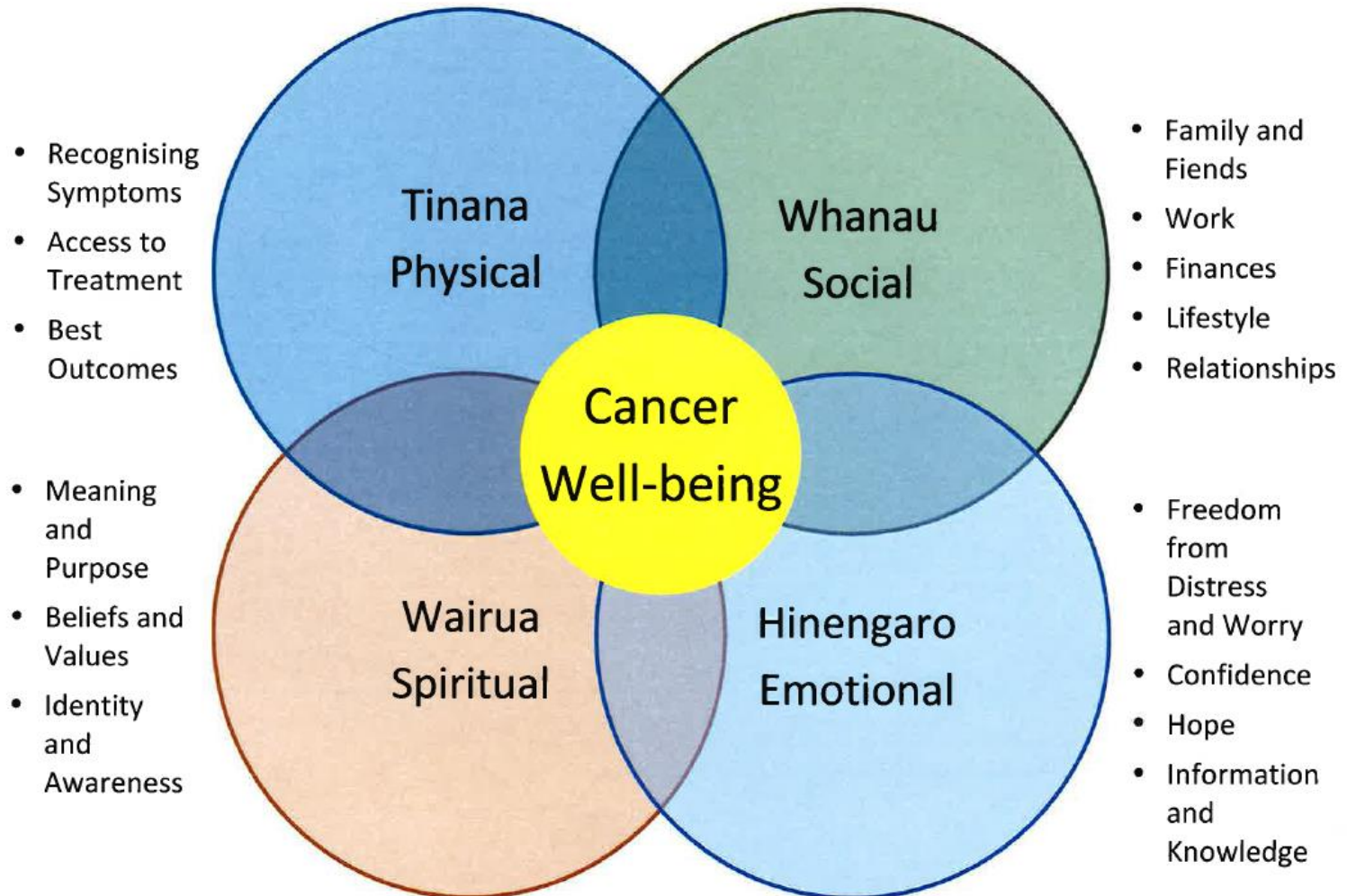
Principle & model matters
Samoan contribution

Fonofale Model of Health by Fuimaono Karl Pulotu-
Endemann 2001

Principle & model matters

Cancer Society NZ Supportive Care Model

- Recognising Symptoms
- Access to Treatment
- Best Outcomes

- Meaning and Purpose
- Beliefs and Values
- Identity and Awareness

Tinana Physical

Whanau Social

Cancer Well-being

Wairua Spiritual

Hinengaro Emotional

- Family and Fiends
- Work
- Finances
- Lifestyle
- Relationships

- Freedom from Distress and Worry
- Confidence
- Hope
- Information and Knowledge

Principle & model matters

Hospice framework

Source: http://www.slideshare.net/NorthTecNursing/palliative-care-a-team-approach-final North Haven Hospice
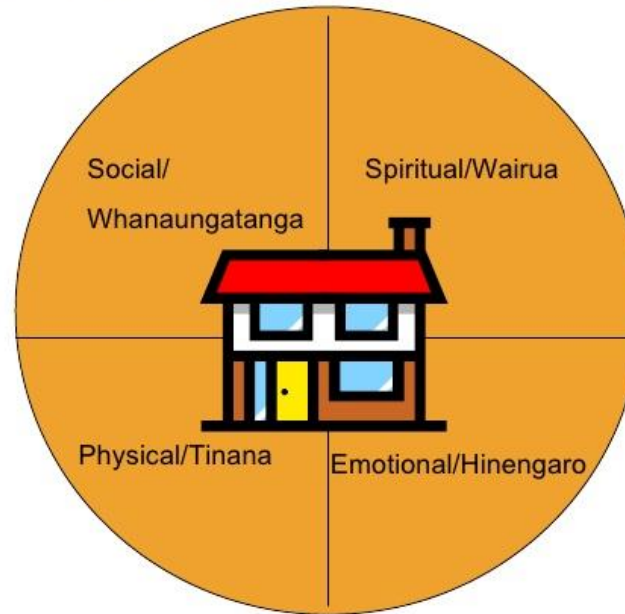
Principle & model matters
Netherlands oncology guidelines

The position of spirituality
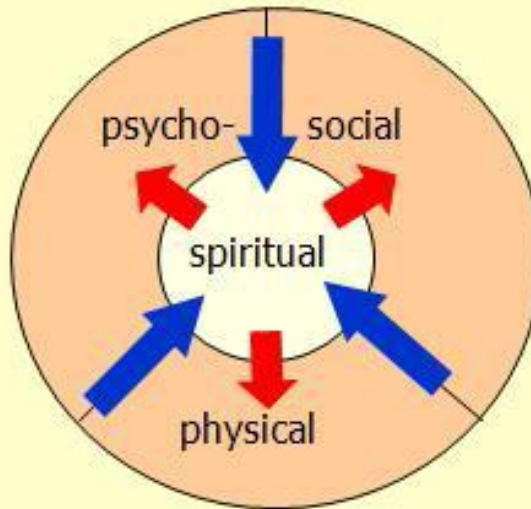
Principle & model matters

Our model of health & healthcare matters

bio-reductionist   ⟷   bio-psycho-social-spiritual
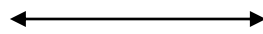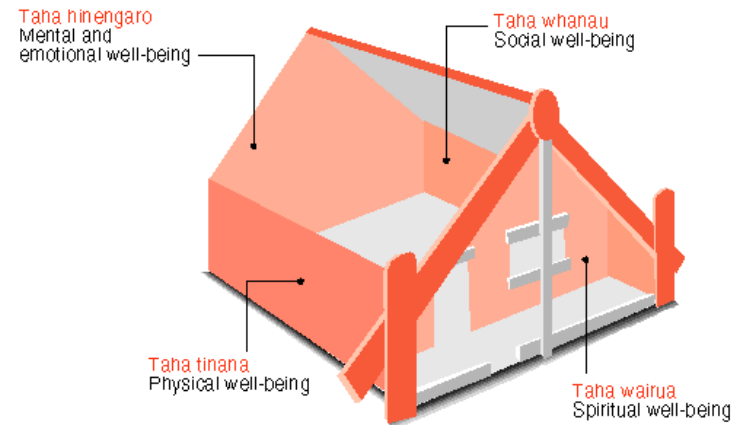

Whole person principle and approaches – holism, Total Care, Te Whare Tapa Wha, Fono Fale etc.

Cross-paradigm dialogue (Chuengsatiansup, K. (2003))

Evidence informed matters

Literature: spirituality and other health outcomes

- A "positive effect" on a range of health outcomes (Sinclair, et al., 2006, p. 468) ; 98 review articles

- Quality of life studies (Whitford, 2008, Sawatzky, 2005))

- Negative religious coping (Hills, et al., 2005).

- Qualitative studies (A. L. Williams, 2006, p. 407)

- Quantitative questions remain (See Sloan et al, 2002)

- Pain tolerance, mood & satisfaction with life (Siddall et al. 2014)

- Spirituality decreases depression/suicide ideation (Portnoff, L. 2017)

Kharitonov, S. A. (2012).

Aging: 5

1 or 2: food, music adolescence, bereavement, caregiver, chaplaincy, pain, domestic violence, communication, occ therapy, physical activity, QoL, Med Ed., Soc Wk., Sport

Mental health 16

Spirituality Review Articles

Generic 11

Nursing 9

Cancer 14

Measurements 2

Palliative Care 16
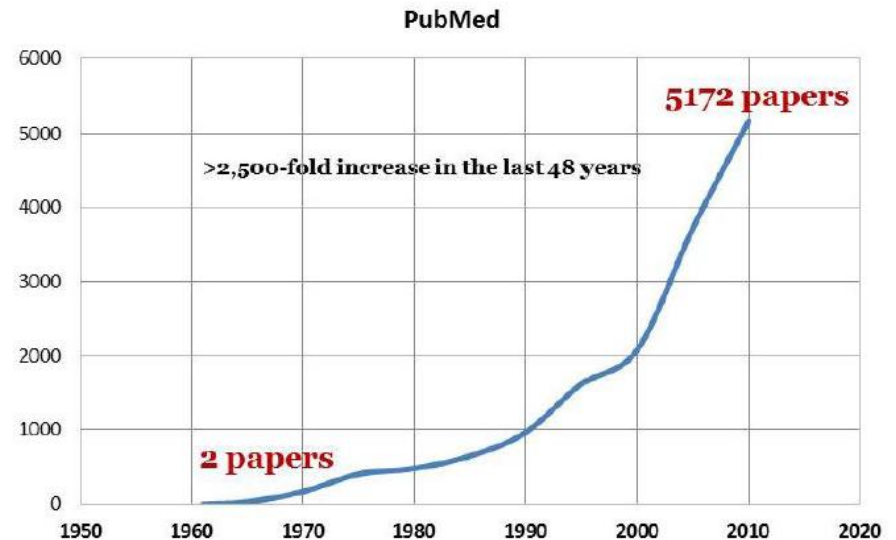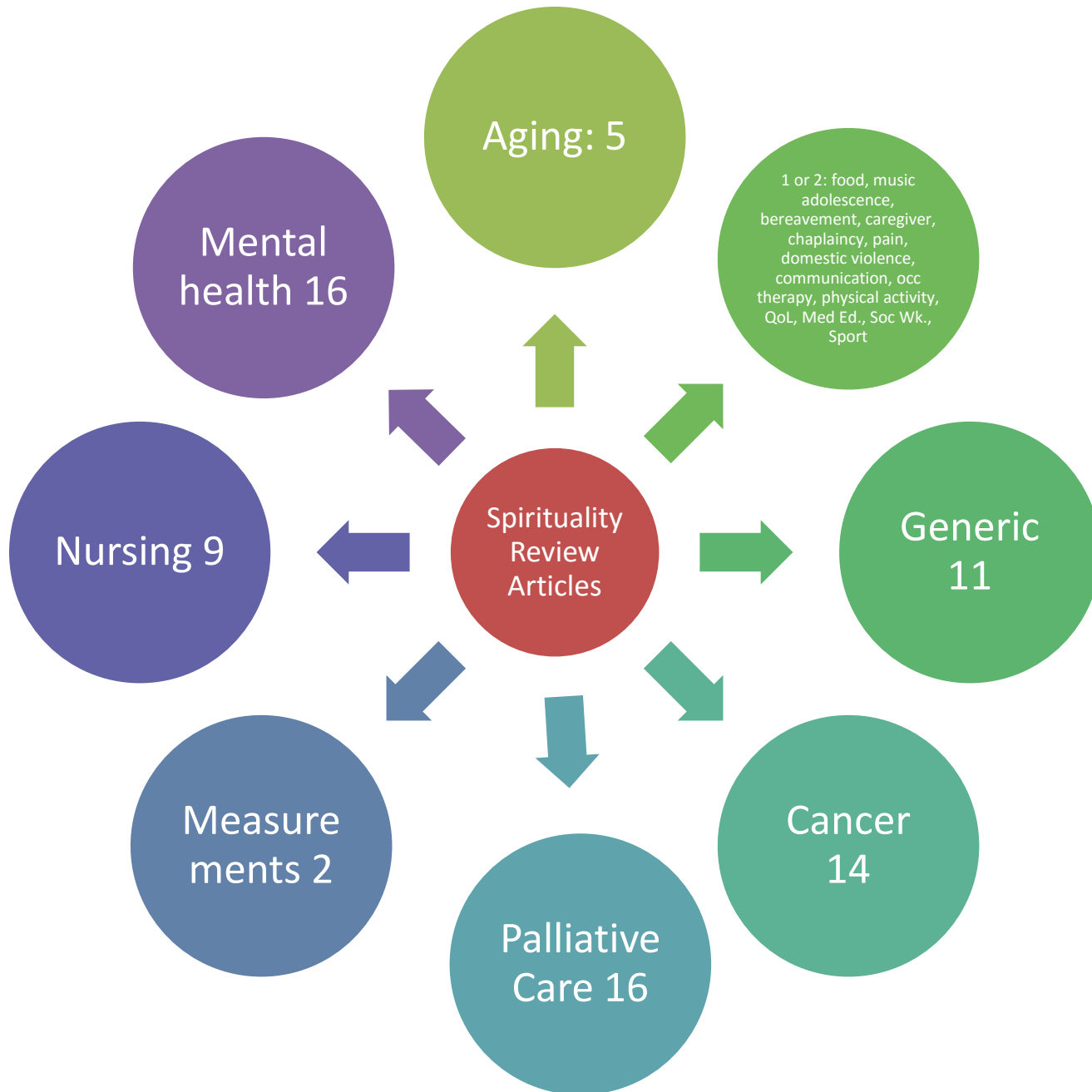
Spirituality research: an emergent field

- Egan and colleagues are developing the spirituality, health and public health field, studies include:
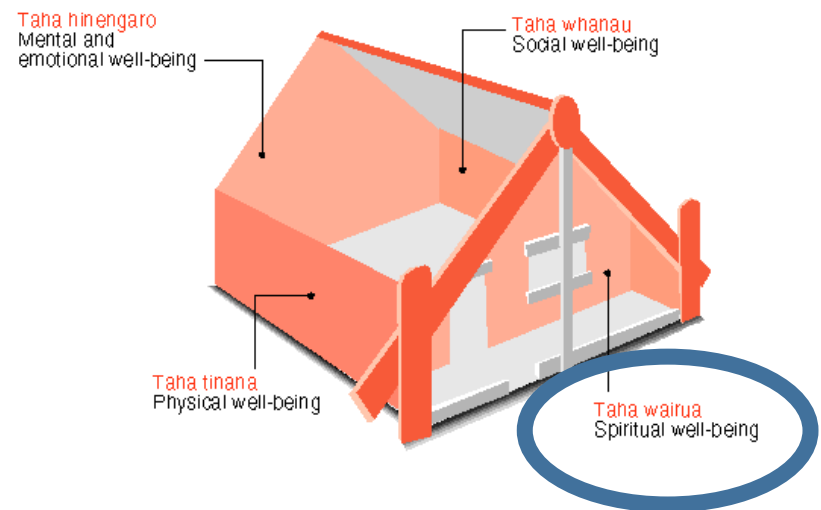
  - Spirituality in New Zealand hospice cancer care*
  - Psycho-social-spiritual supportive care in cancer*
  - Spirituality in ODHB oncology ward
  - Spirituality in medical education*
  - Spirituality in aged residential care*
  - Renal specialists & spirituality*
  - Spirituality and dementia study*
  - Spiritual care professional development project*
  - Spiritual care in cancer care across 16 countries*
  - Spirituality in NZ nursing care*
  - Spirituality in the Salvation Army Bridge Programme*
  - Current: Co-design - spirituality in elder & cancer care / chaplaincy; spirituality in public health.

*published papers

Taha hinengaro
Mental and emotional well-being

Taha whanau
Social well-being

Taha tinana
Physical well-being

Taha wairua
Spiritual well-being

Reasonable evidence

[In 2015] the results confirm that R/S is significantly though modestly associated with patient reported mental, physical, and social health. Park et al., 2015. p. 5

outcome either related to the disease itself, or to quality of life and adjustment measures." Salsman et al., 2015. p.2

These results underscore the importance of attending to patients' religious and spiritual needs as part of comprehensive cancer care. Jim et al., 2015. p. 1

Well over a hundred measures of R/S have been

J... ...sical h...

S... ...eorge, C... ...der and J. M. Salsman (2015). "A meta-analytic review of religious or spiritual involvement and **social health** among cancer patients."

... ...between religion/spirituality and **mental health** in cancer. Cancer. Salsman et al., 2015. p.3

Salsman, n/a-n/a, Fitchett, T. V. Merluzzi, A. C. Sherman and C. L. Park (2015). "Religion, spirituality, and health outcomes in cancer: A case for a meta-analytic investigation." Cancer: n/a-n/a.

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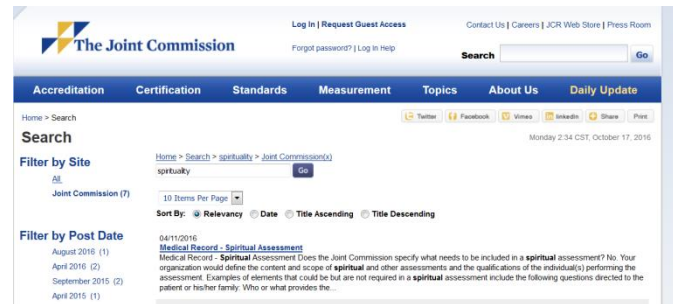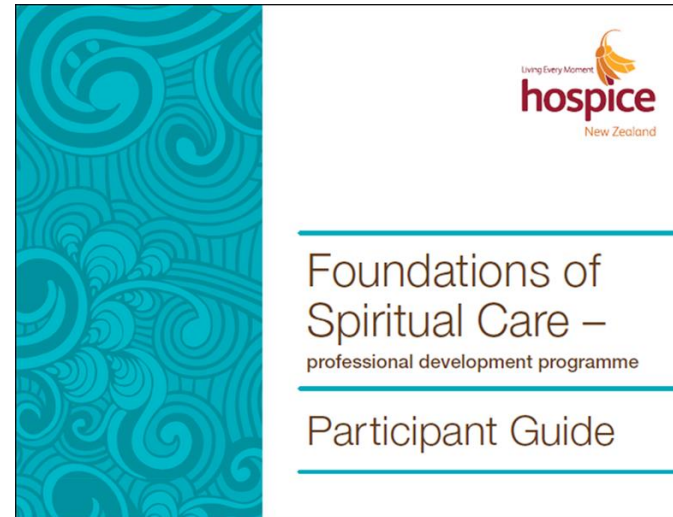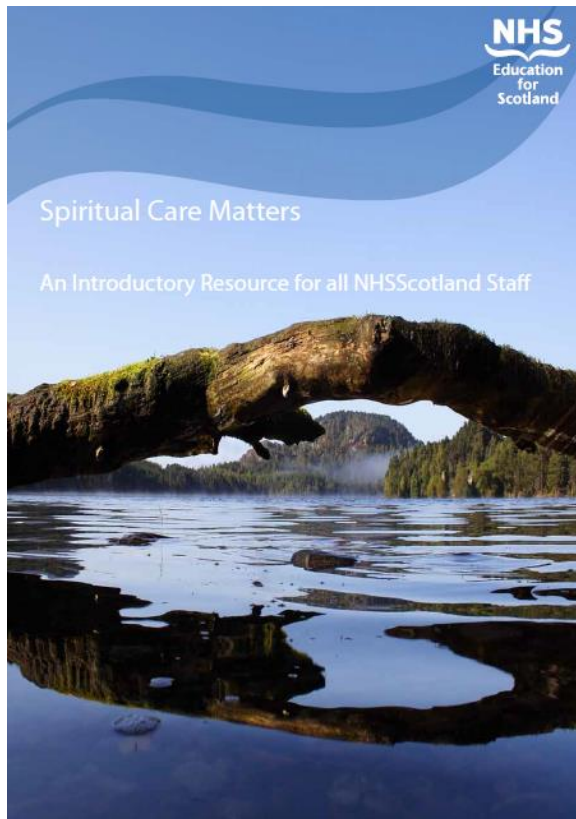
"It is essential that all staff working in cancer treatment services have a basic understanding of the spiritual needs of people with cancer, possess the skills to assess those needs and know how to go about contacting spiritual caregivers when required. Training specific to the cultural and spiritual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

Spirituality in quality control

"the Joint Commission requires organizations to include a spiritual assessment as part of the overall assessment of a patient to determine how the patient's spiritual outlook can affect his or her care, treatment, and services. This assessment should also determine whether more in-depth assessments are necessary."

NZ MoH Healthy Ageing Strategy 2016

"As a health system we should acknowledge and respect the diversity of our older population, and the profound emotional and spiritual significance of the end of life process." p.31

Zeitgeist matters
Demographics & plurality

- NZers getting older (mostly) and more multicultural.

- The long dying: move from communicable <u>to</u> chronic diseases dominating death (Murray, S. et al. 2005)

- Spiritual plurality & democratization

Short period of evident decline

High

Mostly cancer

Specialist palliative care input available

Death

Low

Onset of incurable cancer

Often a few years, but decline usually over a few months

Time →
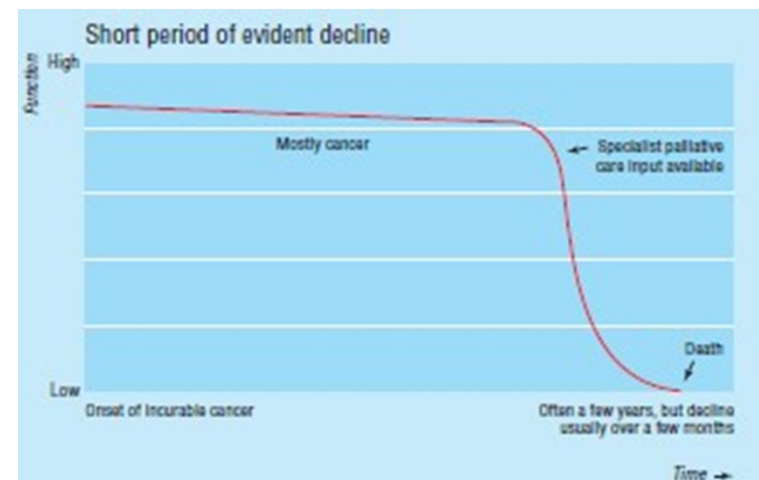
Contemporary spirituality around the globe

https://meaningfulageing.org.au/
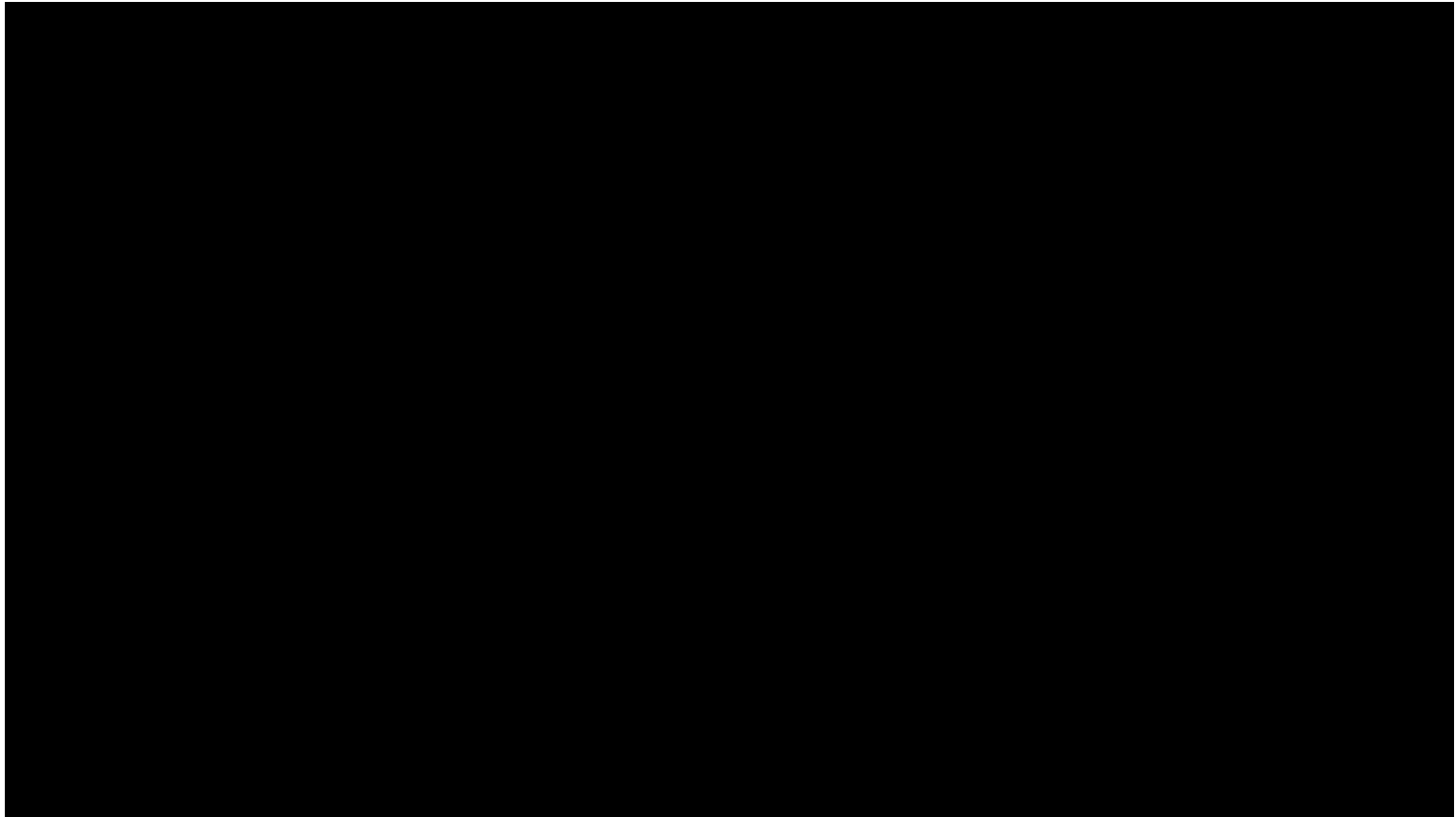
Timmins: Nurse spiritual assessment

1. Beliefs: understand beliefs and impact on illness (and visa versa)
2. Acknowledge: patients beliefs and concerns – and impact on health
3. Patient led: Be guided by the patient
4. Refer: know when, where and how to refer to spiritual care expert
5. Know yourself: understand your own spirituality
6. Only do assessment if competent and confident to do so.

Timmins, F. and S. Caldeira (2017). "Understanding spirituality and spiritual care in nursing." Nursing Standard 31(22): 50-57.

Spiritual Care

- Screening, history, assessment

- What lifts your spirits? (Rumbold, 2012)

- Formal enquiry / Spiritual history (Puchalski, 2006)
  - F – do you have a spiritual belief and/or faith?
  - I – importance to you?
  - C – community to support you?
  - A – action to be taken (if any)

- "What role does spirituality or religion play in your life?" (Sulmasy 2002)

- Are you at peace? (Steinhauser, 2006)

- See also Spirit (Maugins, 1996), Hope (Anandarajah, 2001)

our voice | Advance
tō tātou reo | Care Planning

Last Name ....
First Name.. DOB....../....../......
Address ....
Phone .... Mobile ....

MY ADVANCE CARE PLAN
(Page 1 of 4)

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

If I can no longer tell you myself I want those who care for me to know:

The following is important to me (this can include your hopes and fears, practical matters [eg you like the TV on, you like to be outside], family concerns, spiritual care you would like, anything else you can think of):

....

....

....

....

This is what makes life meaningful to me (this may include values, people, pets, ways you would like those caring for you to look after your spiritual and emotional needs, and anything else you want);

....

When I am dying the following are important to me (tick):

☐ Keep me comfortable

☐ Take out tubes and lines that are not adding to my comfort

☐ Let my family and friends be with me

☐ Offer me something to eat and drink

☐ Stop medications that do not add to my comfort

☐ Attend to my spiritual needs

☐ Other:

Role of chaplaincy

The role of health care chaplaincy has changed a great deal from being the sole providers of traditional religious ritual to one of being a resource to people undertaking this much wider search for meaning within the illness or dying process (Speck, 2004, p. 22).

Whole person assessment and plan

Mrs Baxter is a 48 year old woman with end stage cancer	
Physical	Continue with current management, liaise with hospice
Mental / emotional	Counselling option – to consider issues of depression
Social	Understand family and key friends support
Spiritual	Initial screening suggests questions of 'why me?', so referral to spiritual care expert (whoever is most appropriate)

- Comments or questions?

Outline

- Introductions
- Where we've come from: traditional spirituality
- Recent developments: democratic spirituality
- Challenges
- Future possibilities: spirituality matters
- Discussion

Limitations / critiques

- 'A-spiritual people'?
- Inflexibility – religious but not spiritual group not included in generic spiritual construct
- Lack of specificity – difficult to distinguish from other aspects of human experience / tautological
- See Hodge, 2017

WARNING

CHALLENGES AHEAD

Limitations / critiques

- Racial bias and spiritual colonialism
- De-contextualization of spirituality
- Incongruent with clients' view

- See Hodge, 2017, & Koenig, Doherty

Marilyn Manson

The future (present) challenge

"During their daily caregiving to patients with a life-threatening illness, nurses have many opportunities to explore spiritual issues, but they do not often recognize them. If they do, they tend not to explore the spiritual issues."

van Meurs, J., W. Smeets, K. C. P. Vissers, M. Groot and Y. Engels (2017). "Nurses Exploring the Spirituality of Their Patients With Cancer: Participant Observation on a Medical Oncology Ward." Cancer Nurs.

"modern day clinicians regularly overlook dimensions of spirituality when considering the health of others—or even themselves."

VanderWeele, T. J., T. A. Balboni and H. K. Koh (2017). "Health and spirituality." JAMA.
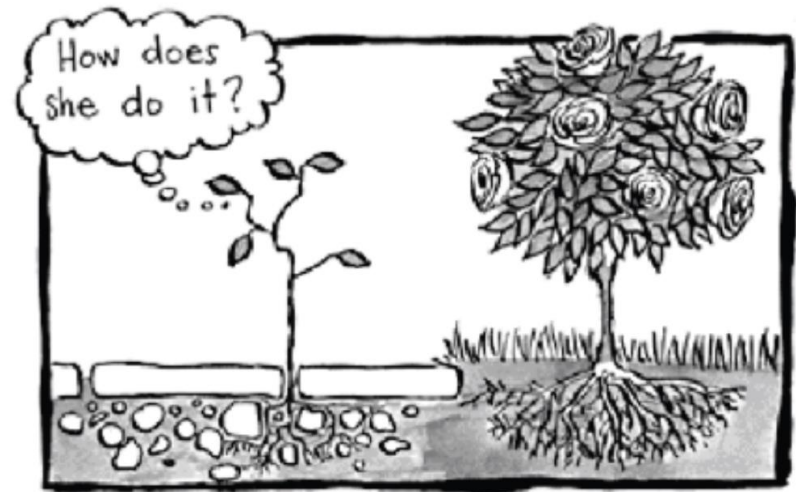
The future (present) challenge

"The stressful healthcare environment limits clinicians' ability to provide whole person care that considers the physical, psychological, social, and spiritual needs of those with chronic disabling illness."

Koenig, H. (2014). "The Spiritual Care Team: Enabling the Practice of Whole Person Medicine." Religions **5**(4): 1161.

The future (present) challenge

- ## Rumbold suggests:

The recent revival of interest in spirituality in later life marks a significant step forward in the person-centred care of ageing people. The benefits will, however, be of limited value if we do not attend to the settings in which spirituality is to be lived.

Rumbold, B. (2006). "The Spirituality of Compassion A Public Health Response to Ageing and End-of-Life Care." Journal of Religion, Spirituality & Aging 18(2/3): 31.

©hris Morgan 1994   cxmedia.com

The future (present) challenge

Spiritual Vacuum / Gap

- Growth of meaninglessness.

- Materialism not enough?

- Individual and Societal issue (a Public Health issue)

Death an easier burden for believers

By SUSAN PEPPERELL

THE THOUGHT of loved ones dying makes most Kiwis uneasy, but those who believe in the afterlife are less troubled, a new survey shows.

Hospice New Zealand commissioned the research, which looks at how Kiwis regard death and dying, and what they know about hospice services.

On the eve of Hospice Awareness Week, researcher Professor Rod MacLeod, of North Shore Hospice Trust palliative care development, said the results surprised them and showed hospices needed to do more to meet Kiwis' spiritual needs. More than a third of respondents rated spirituality as important in their lives.

The results complement a three-year, $3.9 million research project undertaken by Oxford University in England which showed human

> **It's clearly important for New Zealanders.**

beings are predisposed to believe in God and the afterlife.

The New Zealand survey found people made a distinction between spirituality and religion, and showed those under 40 were most likely to say religion was of low importance, while 40% of women rated spirituality as important compared to 28% of men.

"People who identified spirituality as important are less anxious about their death," MacLeod said.

They were also less likely to be concerned about not being able to communicate, or feel guilt or loneliness over a loved one's death.

"Hospices need to be better about providing spiritual care

because it's clearly important for New Zealanders." About seven in 10 agreed they became anxious thinking about a loved one dying, but for those who valued spirituality, 83% believed their soul or spirit would continue afterwards.

MacLeod said as people got sicker, spirituality occupied more of their thinking. "We need to help people articulate and address it."

While hospices had "great success" in managing physical symptoms, there was a need to focus on the psychological and social issues around palliative care.

He said there was increasing interest in advanced-care plans, or directives provided by people that included what they wanted their death to be like, and instructions on how they wanted to be cared for if they were unconscious.

"If you start the conversation early enough it doesn't come as a shock," MacLeod said.

Death an easier burden for believers

Sunday Star Times 15 May 2011.

"people made a distinction between spirituality and religion"

"Hospices need to do more to meet Kiwis' spiritual needs. More than a third of respondents rated spirituality as important in their lives."

"People who identified spirituality as important are less anxious about their death" MacLeod said.

"start the conversation" Macleod

because it's clearly important for New Zealanders." About seven in 10 agreed they became anxious

and dying, and what they know people made a distinction

40% of women as important of men. ntified spiritu- re less anxious MacLeod said. They were also less likely to be concerned about their ... comm ... liness "Ho about

respondents rated spirituality as important in their lives.

The results complement a three-year, $3.9 million research project undertaken by Oxford University in England which showed human

focus on the psychological and social issues around palliative care.

He said there was increasing interest in advanced-care plans, or directives provided by people that included what they wanted their death to be like, and instructions

"… and no out-of-body experiences. We're not insured for them."

http://www.strathmor.com/assets/pdf/0810-IPOS_pp2_Spirituality.pdf

Outline

- Introductions
- Where we've come from: traditional spirituality
- Recent developments: democratic spirituality
- Challenges
- Future possibilities: spirituality matters
- Discussion

More research needed

The spiritual nature of humanity is just as amenable to empirical research as many other phenomena, such as attitudes, beliefs, self-conceptions, and feelings, that cannot be observed directly yet have become respected social and behavioral science topics.

(Moberg 2002)

Spirituality and healthcare professional education

Association of American Medical Colleges (AAMC) guidelines / objectives.

With regard to spirituality and cultural issues, before graduation students will have demonstrated to the satisfaction of the faculty:

- *The ability to elicit a spiritual history.*
- *…*
- *…*
- *Knowledge of research data …*
- *An understanding of, and respect for, the role of clergy and other spiritual leaders, …*
- *An understanding of their own spirituality …*

{Puchalski, 2006}.

Recommended Standards
for Spiritual Care

1. Spiritual care is **integral to compassionate, person-centered health care and is a standard for all health settings**.

2. Spiritual care is a **part of routine care** and integrated into policies for **intake and ongoing assessment** of spiritual distress and spiritual well-being.

3. **All health care providers are knowledgeable** about the options for addressing patients' spiritual distress and needs, including spiritual resources and information.

4. Development of spiritual care is supported by **evidence-based research**.

5. Spirituality in health care is developed in **partnership with faith traditions and belief groups**.

6. Throughout their training, **health care providers are educated on the spiritual aspects of health** and how this relates to themselves, to others, and to the delivery of compassionate care.

Recommended Standards
for Spiritual Care

7. Health care professionals are **trained in conducting spiritual screening or spiritual history as part of routine patient assessment**.

8. All health care providers are **trained in compassionate presence, active listening, and cultural sensitivity**, and practice these competencies as part of an interprofessional team.

9. All health care providers **are trained in spiritual care commensurate with their scope of practice**, with reference to a spiritual care model, and tailored to different contexts and settings.

10. Health care systems and settings provide opportunities to develop and sustain **a sense of connectedness with the community** they serve; healthcare providers work to create healing environments in their workplace and community.

11. Health care systems and settings support and encourage health care providers' **attention to self-care**, reflective practice, retreat, and attention to stress management.

12. Health care systems and settings **focus on health and wellness** and not just on disease.   Source: Puchalski, C. M., R. Vitillo, S. K. Hull and N. Reller (2014). "Improving the spiritual dimension of whole person care: Reaching national and international consensus." Journal of palliative medicine **17**(6): 642-656.

"The spiritual life is the cheapest, most accessible and most effective medicine we have after warm houses, good food and clean hands. When we truly connect to another individual, the intimacy is rewarding of itself, but if we are lucky there can also be for a moment a glimpse of the interconnectedness of all things beyond this, a sense that we are a part of a larger whole. This is a healing intuition and a powerful succour for individual loss."

Colquhoun, G., Late love: Sometimes doctors need saving as much as their patients. 2016, Wellington, New Zealand: Bridget Williams Books Ltd. Page 42.

Outline

- Introductions
- Where we've come from: traditional spirituality
- Recent developments: democratic spirituality
- Challenges
- Future possibilities: spirituality matters
- Discussion

Aging is a spiritual experience, and one that we can help create literal and metaphorical space for it to thrive individually and collectively.

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)

THANK YOU