Dr Richard Egan

Senior Lecturer

Co-Director

Cancer Society Social & Behavioural Research Unit

University of Otago

Friday, August 09, 2019

(Plenary)

15:00 - 15:20 Spirituality in Cancer Care

Spirituality in cancer care

NZMA. South GP CME
3.00-3.20. 9 August, 2019

Richard Egan PhD
Senior Lecturer
www.otago.ac.nz/sbru
richard.egan@otago.ac.nz

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

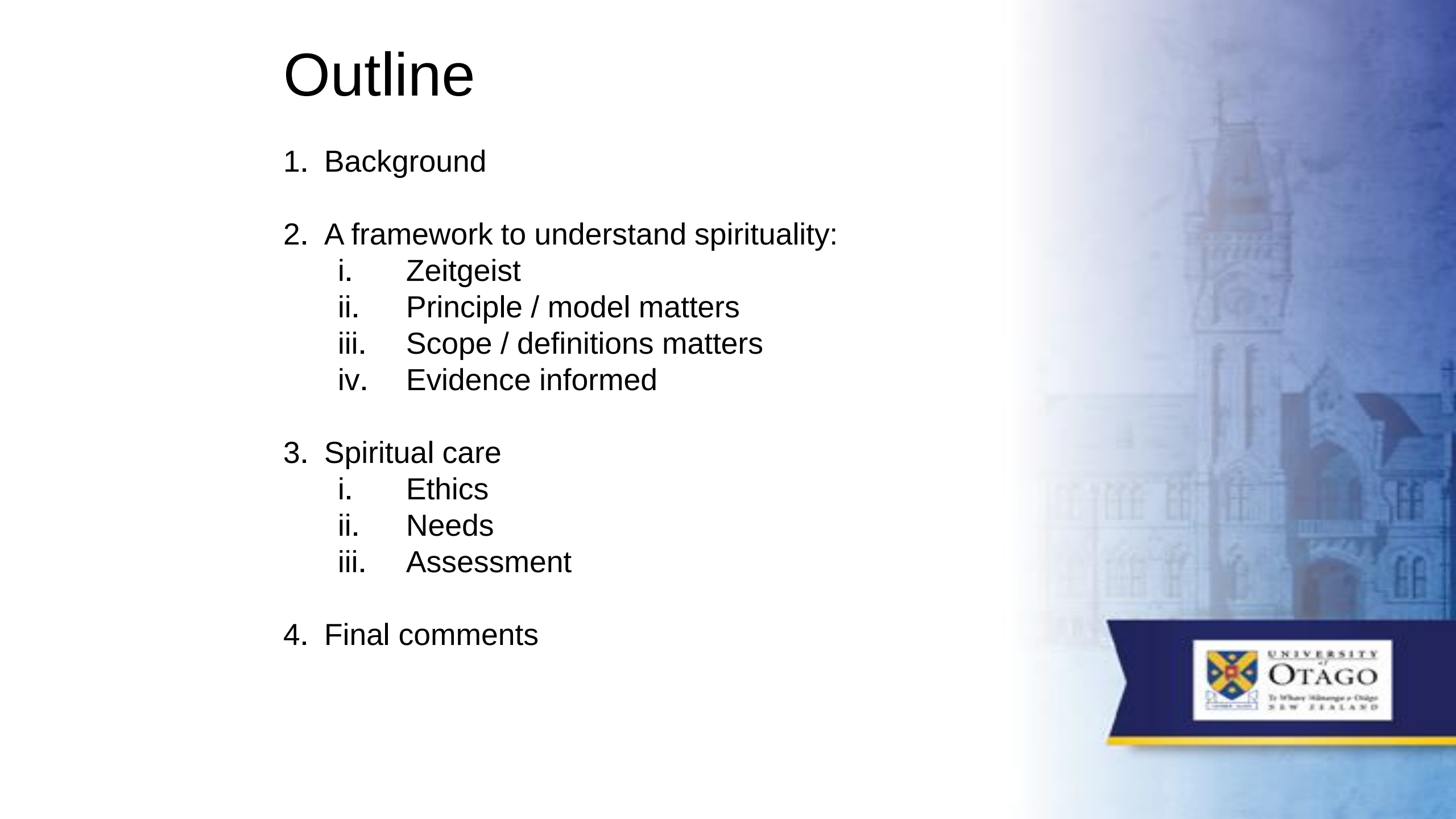
Outline

1. Background

2. A framework to understand spirituality:
    i. Zeitgeist
    ii. Principle / model matters
    iii. Scope / definitions matters
    iv. Evidence informed

3. Spiritual care
    i. Ethics
    ii. Needs
    iii. Assessment

4. Final comments



Background

Personal & professional

- public health practitioner
- researcher with a focus on spirituality, health promotion and supportive care in cancer

What you know?

A lot

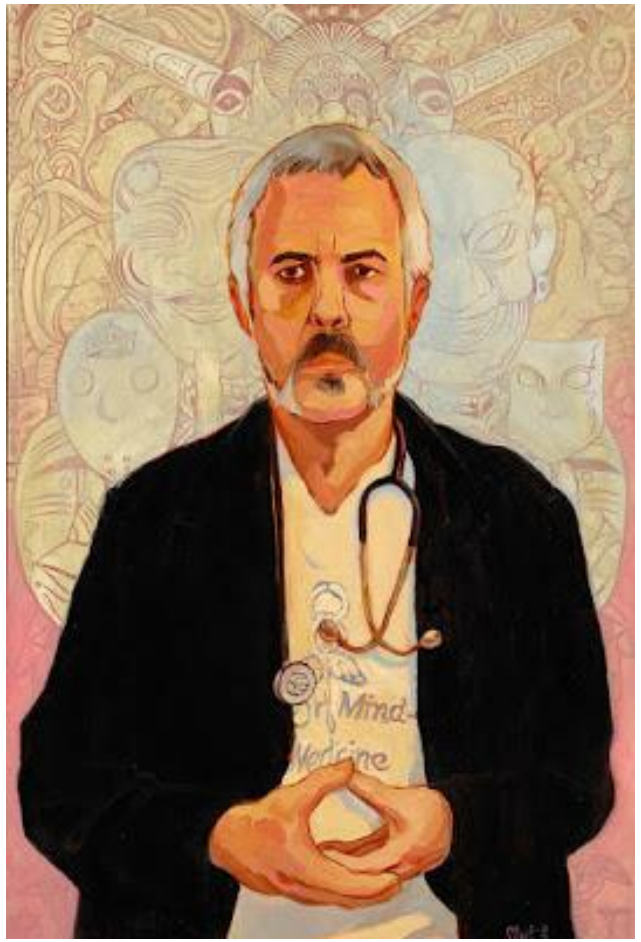
Cancer and spirituality

"While increased attention in oncology has been given to psychological and social aspects, s*piritual care* is often neglected."

Puchalski, C. M., A. Sbrana, B. Ferrell, N. Jafari, S. King, T. Balboni, G. Miccinesi, A. Vandenhoeck, M. Silbermann, L. Balducci, J. Yong, A. Antonuzzo, A. Falcone and C. I. Ripamonti (2019). "Interprofessional spiritual care in oncology: a literature review." ESMO Open 4(1): e000465.

Cancer zeitgeist / challenges

- Mortality – leading cause
- Morbidity – survivorship and chronic illness
- Inequalities
- Growth expected
- Cost

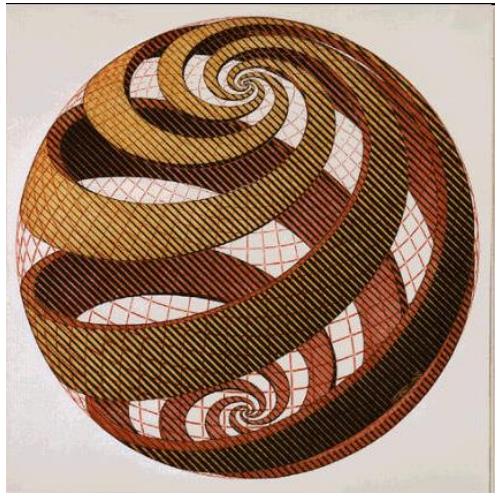


Dr B Koffman

Zeitgeist matters

Spirituality and Religion

- Contested
- Low attendance / rise of ‘nones’
- Disentwining thesis: contemporary spiritualties / inter-spirituality
- “I’m spiritual, not religious”
- “Post-religious age”

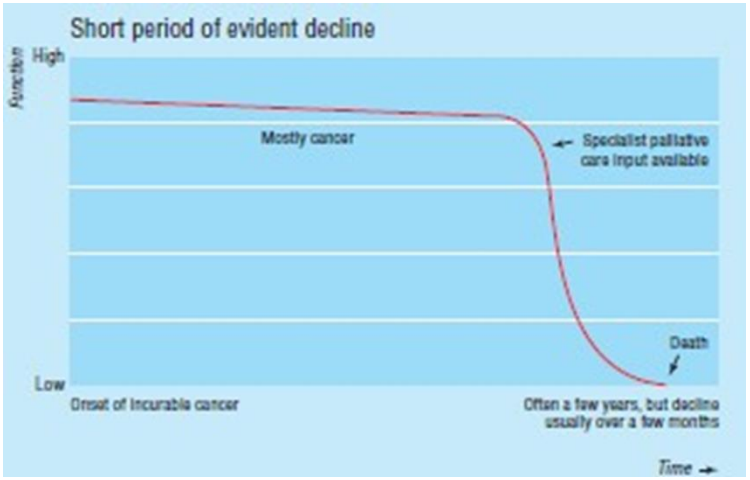


Zeitgeist matters

Demographics & plurality

- NZers getting older (mostly) and more multicultural.

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



Zeitgeist matters

Māori Contribution

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

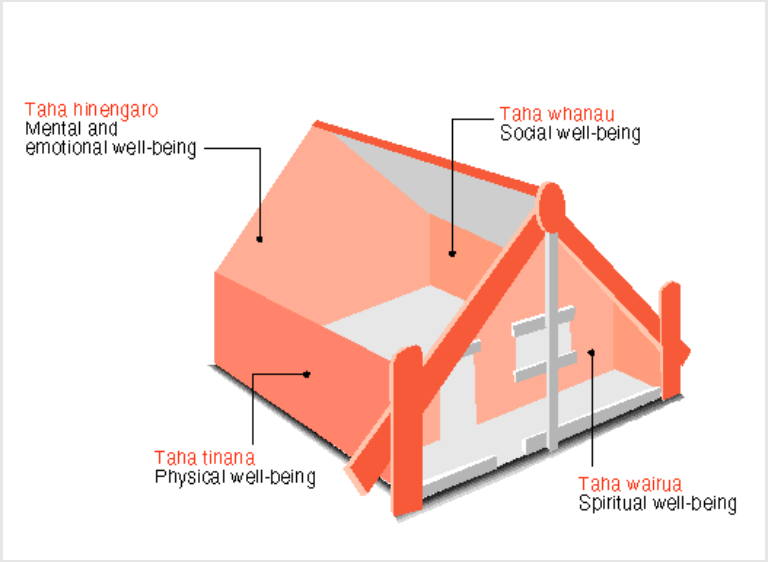
"Without a spiritual awareness and a mauri (spirit or vitality, sometimes called the life-force) an individual cannot be healthy… ." (Durie, 1999)

"Once my wairua was intact I was able to do anything". (Rea Wikaira, 2015)

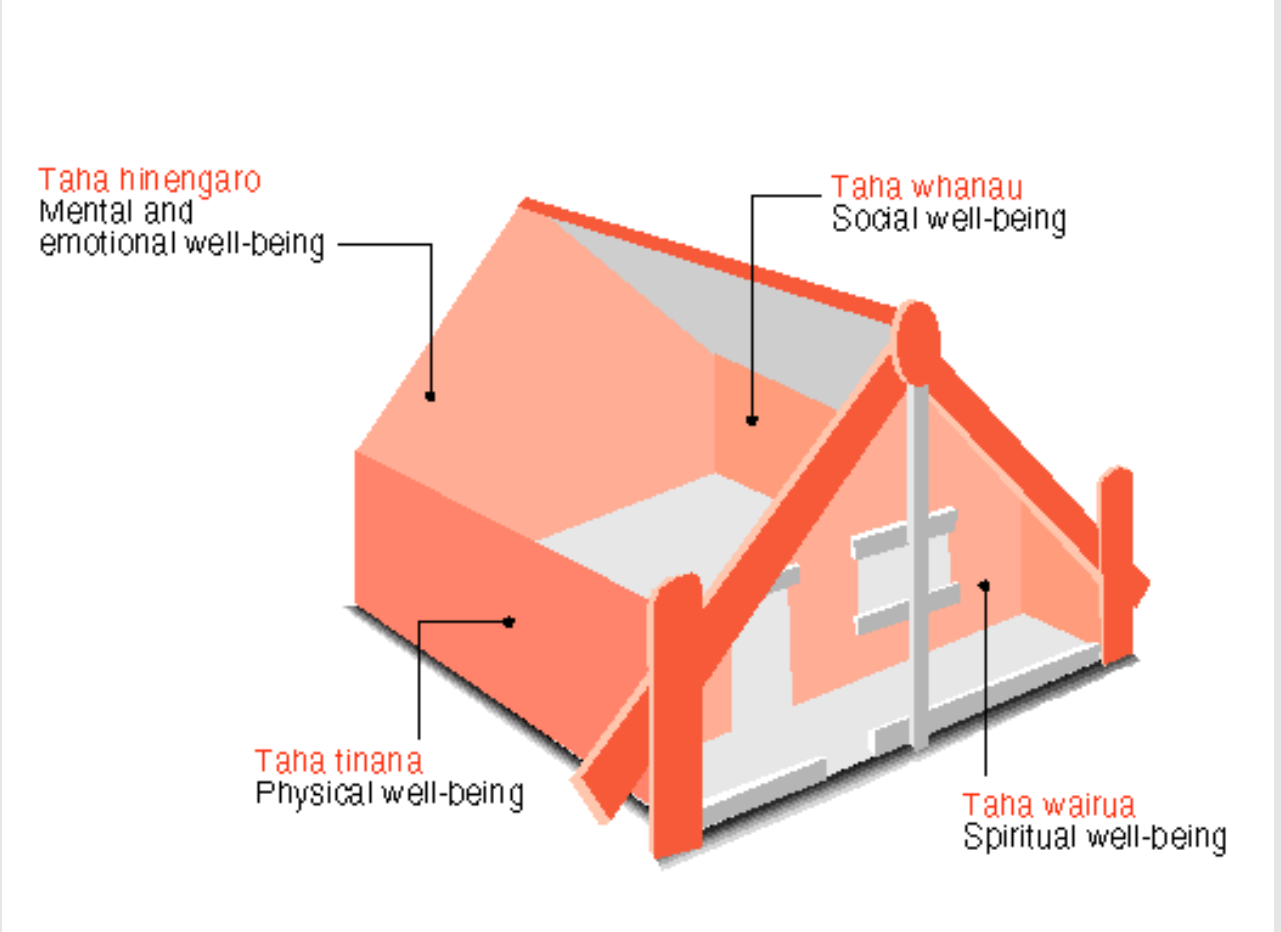
Principle & model matters

Our model of health & healthcare matters

bio-reductionist ⟷ bio-psycho-social-spiritual

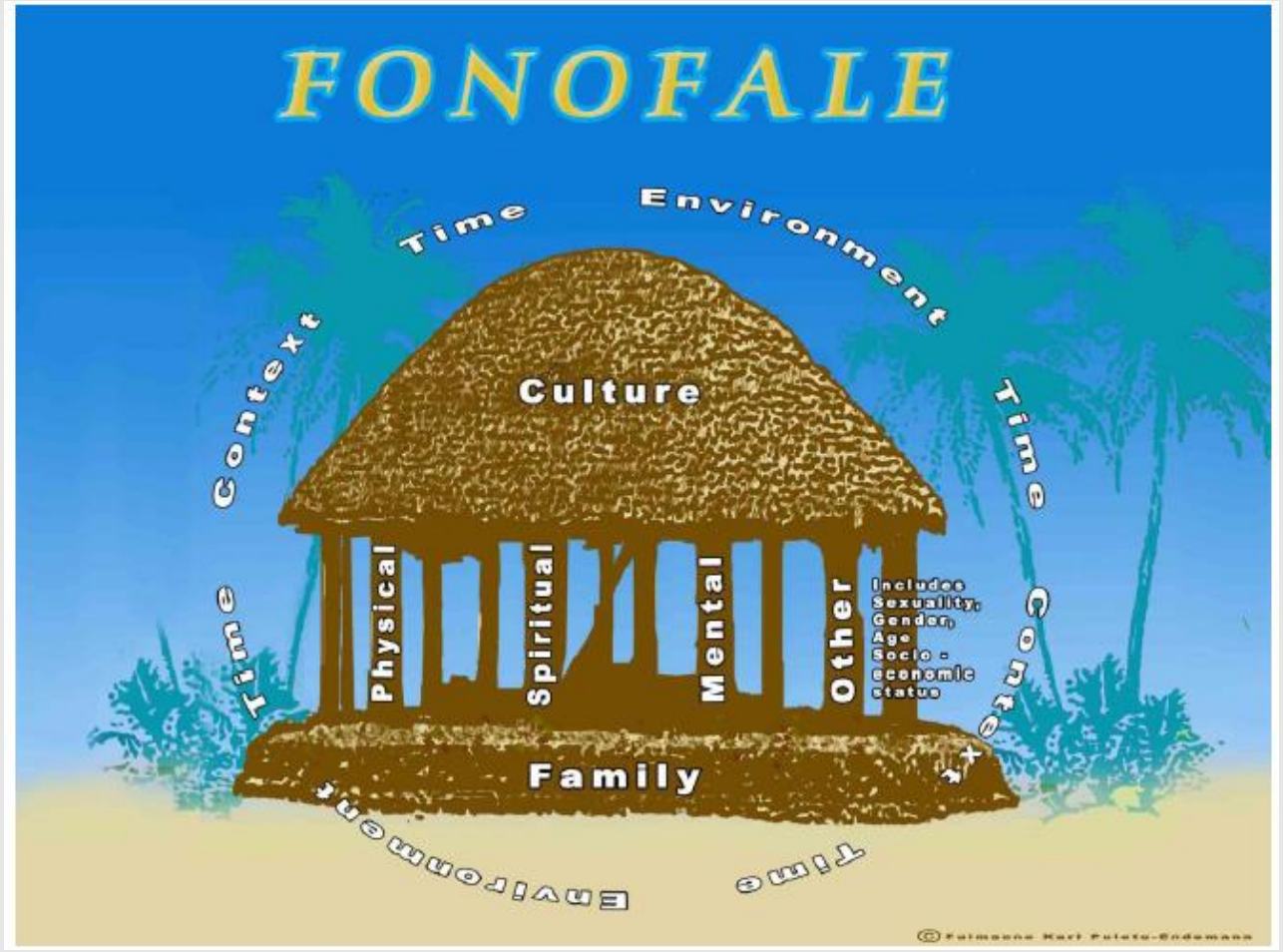


Principle & model matters
Māori contribution



Durie, M. 1985

Principle & model matters
Samoan contribution



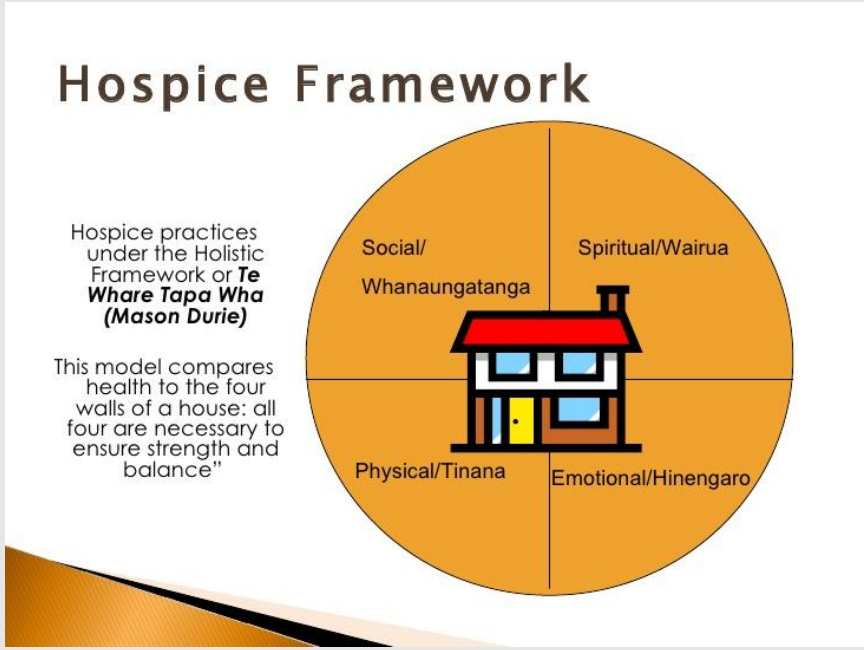
Fonofale Model of Health by Fuimaono Karl Pulotu-Endemann 2001

Principle & model matters

Hospice framework

- 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.*

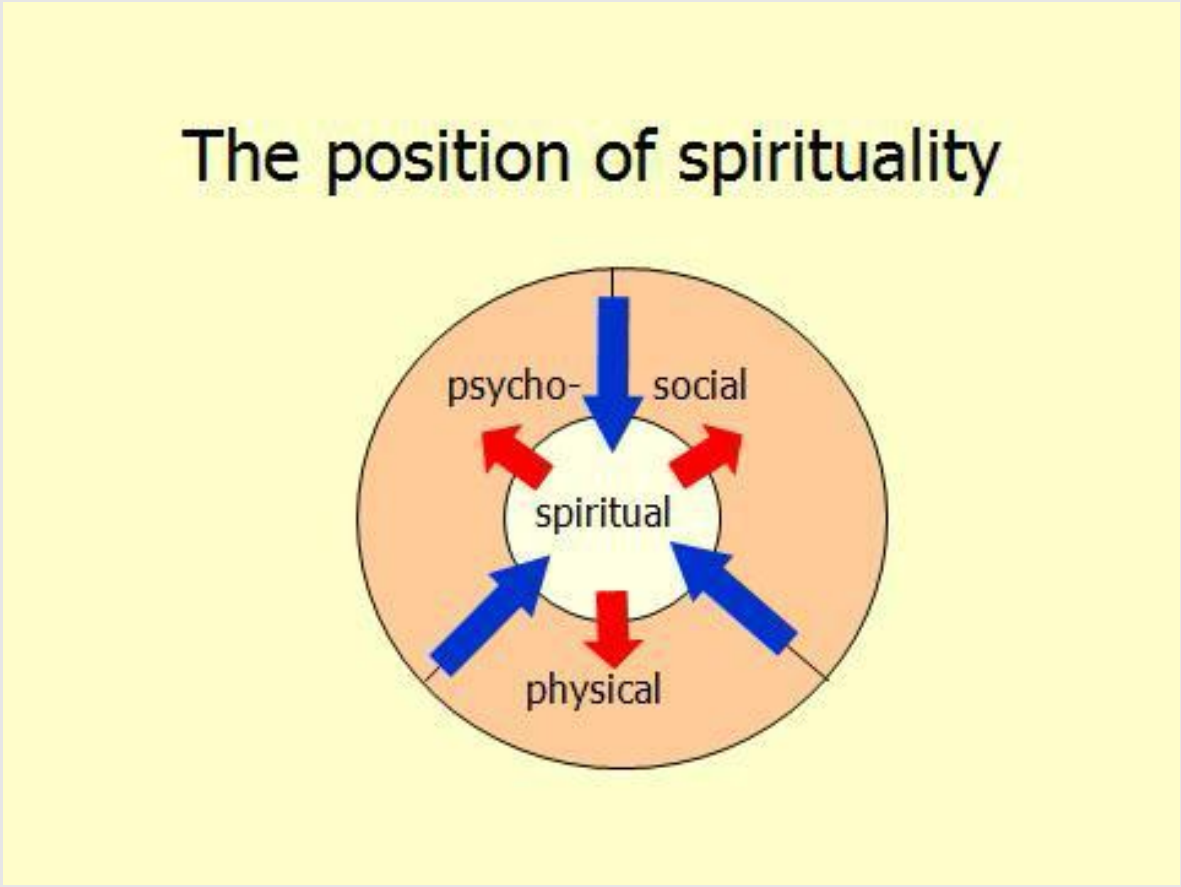
(NZPC Strategy 2001)



Source: http://www.slideshare.net/NorthTecNursing/palliative-care-a-team-approach-final North Haven Hospice

Principle & model matters

Netherlands oncology guidelines



(Oncoline Agora Spiritual care guideline working group.p. 2-3); http://www.oncoline.nl/index.php?language=en

Scope: What is spirituality?

Defining spirituality is a complex undertaking because there seems to be neither one specific spiritual experience nor single spiritual quality. (p.10)

Chuengsatiansup K. Spirituality and health: an initial proposal to incorporate spiritual health in health impact assessment. Environmental Impact Assessment Review. 2003;23(1):3-15.

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)

Egan, R., R. MacLeod, C. Jaye, R. McGee, J. Baxter and P. Herbison (2014). "The spiritual environment in New Zealand hospice care: identifying organisational commitment to spiritual care." BMJ Support Palliat Care 4(3): 299-302.

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., 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

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.

Evidence informed matters

Literature: spirituality and other health outcomes

"Spirituality has been demonstrated to impact health outcomes of patients with cancer across the trajectory of disease."

Puchalski, C. M., A. Sbrana, B. Ferrell, N. Jafari, S. King, T. Balboni, G. Miccinesi, A. Vandenhoeck, M. Silbermann, L. Balducci, J. Yong, A. Antonuzzo, A. Falcone and C. I. Ripamonti (2019). "Interprofessional spiritual care in oncology: a literature review." ESMO Open **4**(1): e000465. p.3

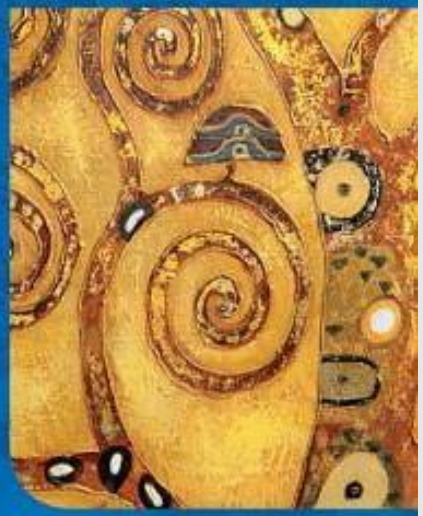
- Quantitative questions remain (See Sloan et al, 2002)
- Pain tolerance, mood & satisfaction with life (Siddall et al. 2014)

Kharitonov, S. A. (2012).

OXFORD TEXTBOOKS IN PUBLIC HEALTH

Oxford Textbook of Spirituality in Healthcare

Edited by
Mark Cobb
Christina M. Puchalski
Bruce Rumbold



OXFORD

Abstract

Spiritual care is recognised as an **essential element** of the care of patients with serious illness such as cancer. **Spiritual distress can result in poorer health outcomes** including quality of life. The American Society of Clinical Oncology and other organisations **recommend addressing spiritual needs in the clinical setting**. This paper reviews the literature findings and proposes recommendations for interprofessional spiritual care.

Received 31 October 2018
Revised 10 December 2018
Accepted 11 December 2018

the literature findings and proposes recommendations for interprofessional spiritual care.

INTRODUCTION

Forgiveness in Health Care') and were built on the work of a 2009 Consensus Conference, 'Improving the Quality of Spiritual Care as a Dimension of Palliative Care', whose deliber-ations had already been published.[3] The 2009

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

measures." Salsman et al., 2015. p.2

Fitchett, H. S. L. Jim, A. R. Munoz, S. C. Danhauer, M. A. Snyder and J. M. Salsman (2015). "A meta-analytic review of religious or spiritual involvement and social health among cancer patients." Cancer 121(21): 3779-3788.

Well over a hundred measures of R/S have been used in research.

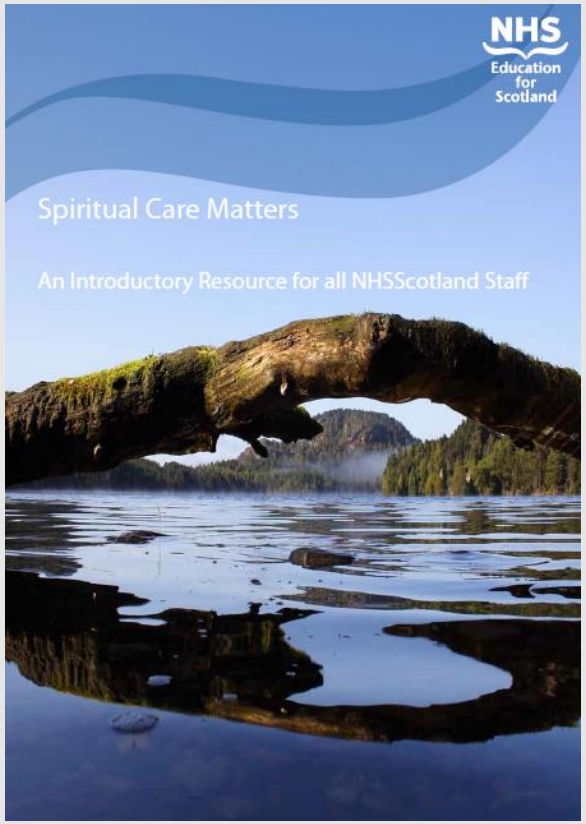
These results underscore the importance of attending to patients' religious and spiritual needs as part of comprehensive cancer care. Jim et al., 2015. p. 1

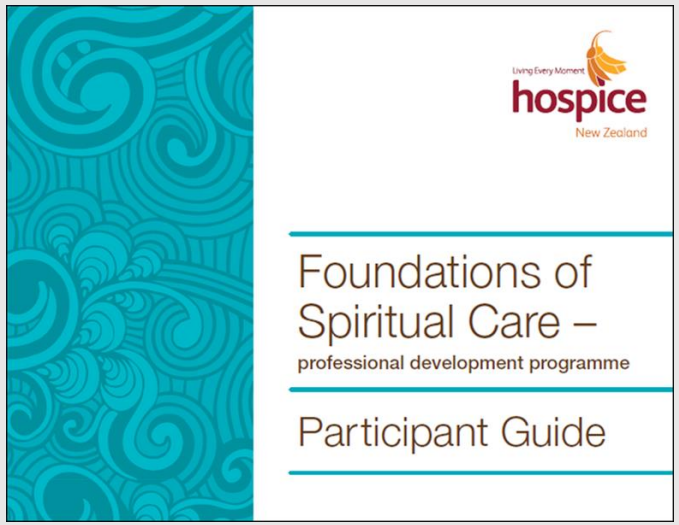
Salsman, J. M., G. Fitchett, T. V. Merluzzi, A. C. Sherman and C. L. Park (2015). "Religion, spirituality, and health outcomes in cancer: A case for a meta-analytic investigation." Cancer 121(21): 3754-3759.

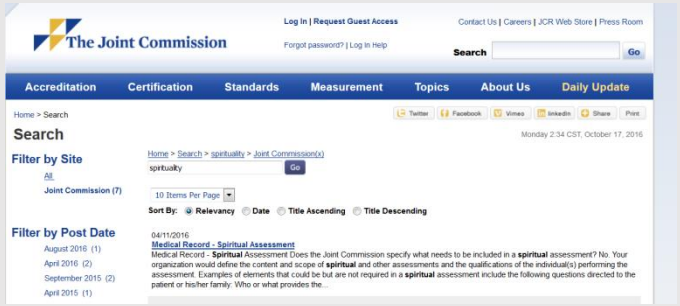
Lay spirituality re-emerging

- 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. The most acceptable scenarios for spiritual discussions were life-threatening illnesses (77%), serious medical conditions (74%), and loss of loved ones (70%).” (McCord, 2004)
- NZ: 67% wanted spiritual care in hospice survey (Egan et al., 2016)

Evidence informing policy/practice







"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

Implementing spiritual care

- *The clinician–patient relationship*: compassionate presence

- Assessment and treatment of spiritual distress
  - Clinicians – spiritual care generalists
  - Chaplains – spiritual care specialists

- “All clinicians should address patients’ spirituality, identify and treat spiritual distress and support spiritual resources of strength. In-depth spiritual counselling is referred to the trained chaplain” p.2

Puchalski, C. M., A. Sbrana, B. Ferrell, N. Jafari, S. King, T. Balboni, G. Miccinesi, A. Vandenhoeck, M. Silbermann, L. Balducci, J. Yong, A. Antonuzzo, A. Falcone and C. I. Ripamonti (2019). "Interprofessional spiritual care in oncology: a literature review." ESMO Open 4(1): e000465.

Mandate for spiritual assessment / care

Spirituality and medical education

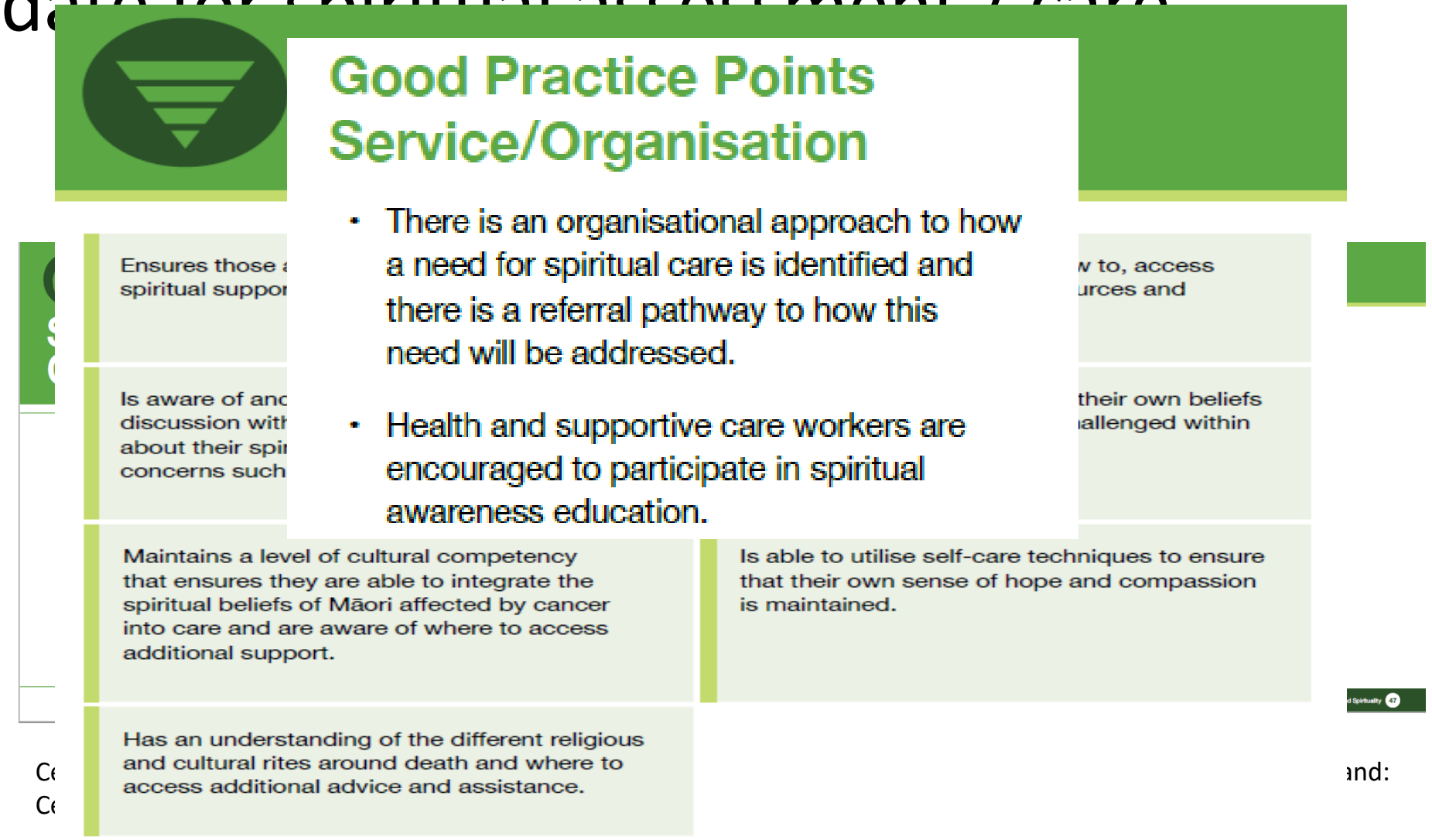
Association of American Medical Colleges (AAMC) guidelines / objectives.

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 …*

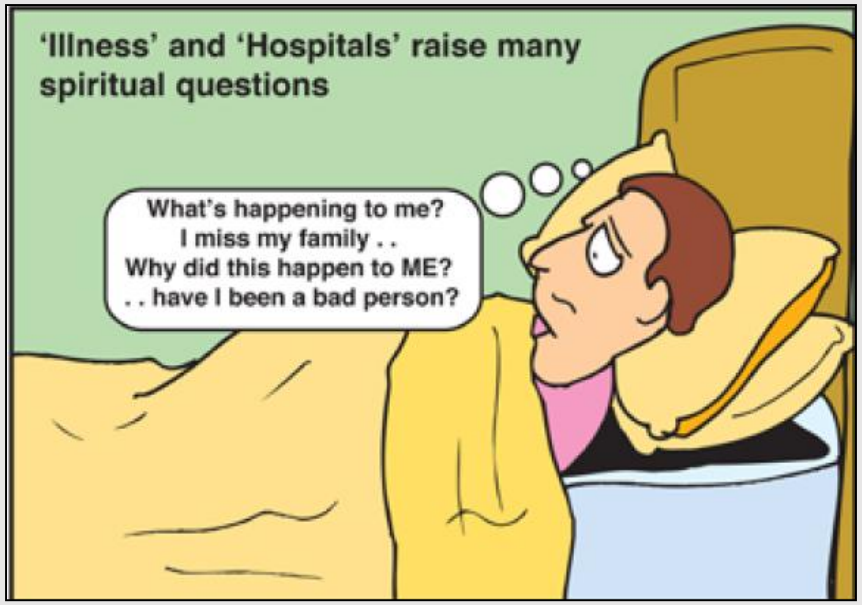
{Puchalski, C. M., Ed. (2006). A Time for Listening and Caring: Spirituality and the Care of the Chronically Ill and Dying. New York, Oxford University Press.}.

Mandate for spiritual assessment / care



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.



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 G. R. and Wehtje-Winslow B. (2007). "Ethical boundaries of spiritual care " Med J Aust 186 (10 Suppl): S63-S66.)

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).
- Family needs least met

"A significant part of the work of the dying is dealing with spiritual issues." (Hospice chaplain)

Egan, R., R. MacLeod, C. Jaye, R. McGee, J. Baxter, P. Herbison and S. Wood (2016). "Spiritual beliefs, practices, and needs at the end of life: Results from a New Zealand national hospice study." Palliative & Supportive Care FirstView: 1-8.

Spiritual Distress

Impaired ability to experience meaning and purpose in life through connectedness with self, others, art, music, literature, nature, and/or a power greater than oneself *(Herdman, T. (Ed.). (2009). North American Nursing Diagnosis Association International—Nursing Diagnoses: Definitions and classification 2009– 2011. Oxford: Wiley-Blackwell).*

Spiritual distress may occur when:

- A person's life situation is in conflict with their values or beliefs e.g. severe illness or disability, death of a child etc
- There is a loss of meaning, hope or purpose
- There is an inability to express and find comfort in usual sources of strength
- Spiritual distress in cancer patients: 17 – 44% (Hui et al. 2011; Gielen et al. 2017; Caldeira et al. 2017)

Signs of Spiritual Distress

- Anger at God, healthcare providers and other people.
- Feelings of hopelessness, bitterness, denial and guilt
- Fear of the future
- Sense of despair
- May feel abandoned
- Rejection of others
- Nightmares and/or sleep disturbances
- Intractable pain or nausea
- Questions about the meaning of life/own existence or identity
- Questions own values and beliefs
- Lack of interest in participating in usual spiritual or religious practices.

Herdman, T. (Ed.). (2009). North American Nursing Diagnosis Association International—Nursing Diagnoses: Definitions and classification 2009– 2011. Oxford: Wiley-Blackwell).

Hospice New Zealand Spiritual Care Resources

MacKinlay, E. 2012. Palliative Care, Aging and Spirituality. London: Jessica Kingsley.

Conversation openers

- *‘Tell me about…’*
- *‘I’m wondering about…’*

- What has sustained you through hard times in the past? ie sources of strength.
- What is most important to you right now?
- What worries you most?
- What gives you meaning and purpose in life?
- If you could have/achieve one thing, what would it be?
- Who are the people who are most important to you?
- The things or people who inspire you?
- What gives you hope?
- What is it that keeps you going?

Conversation openers

- What lifts your spirits? (Rumbold, 2012)
- Are you at peace? (Steinhauser, 2006)
- Formal enquiry / Spiritual history (Puchalski, 2006)
  - F – 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)
- ‘‘What do I need to know about you as a person to give you the best care possible?’’ (Chochinov et al. 2014)

Joanne's assessment and plan (integrating spiritual issues with the psychosocial and physical)
Joanne is a 68-year-old woman with end-stage metastatic breast cancer, severe pain managed on opioids, medicationassociated nausea, constipation, occasional insomnia, and spiritual and existential distress
Physical: Continue with current pain regimen, add 5-HT3 antagonists, add trazodone prn, and bowel regimen referral to ortho-oncologist for possible surgery to treat pain and improve mobility so patient can travel.
Emotional: Supportive counselling, presence
Social: Encourage family meeting to discuss prognosis, goals of care, encourage patient sharing if she would like.
Spiritual: Spiritual counselling with chaplain, team continues to be present, exploring sources of hope, life story, meaning.

Puchalski, C. M., A. Sbrana, B. Ferrell, N. Jafari, S. King, T. Balboni, G. Miccinesi, A. Vandenhoeck, M. Silbermann, L. Balducci, J. Yong, A. Antonuzzo, A. Falcone and C. I. Ripamonti (2019). "Interprofessional spiritual care in oncology: a literature review." ESMO Open 4(1): e000465

our voice | Advance Care Planning
tō tātou reo | 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:

.....

“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.

Take home messages:
Spirituality and cancer care

- Spiritual care is important for many patients
- Spiritual distress can negatively impact quality of life
- Remember the framework suggested to understand it: zeitgeist, models, scope/definitions, evidence informed
- You already know a lot / build on strengths - develop your own toolbox
- Important to your well-being
- Know basic assessment approaches and refer on as necessary
- Need spiritual care guidelines, recommendations, working group?
- 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)

THANK YOU

Cancer Society
Te Kāhui Matepukupuku o Aotearoa

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

University of Otago
Te Whare Wānanga o Otāgo
New Zealand