Spirituality in Oncology Social Work: part of total cancer care

OSWANZ Oncology Social Work Australia New Zealand

29 October, 2020

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



Outline

What, why and how?

- I. Spirituality matters a framework to understand it:
 - a. Scope / definition matters
 - b. Principle & model matters
 - c. Evidence informed matters
 - d. Zeitgeist matters
- 2. Approaches to spiritual care build on your spiritual care toolbox.



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)



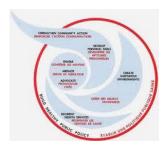














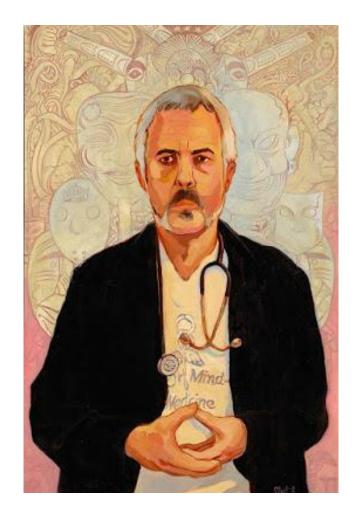


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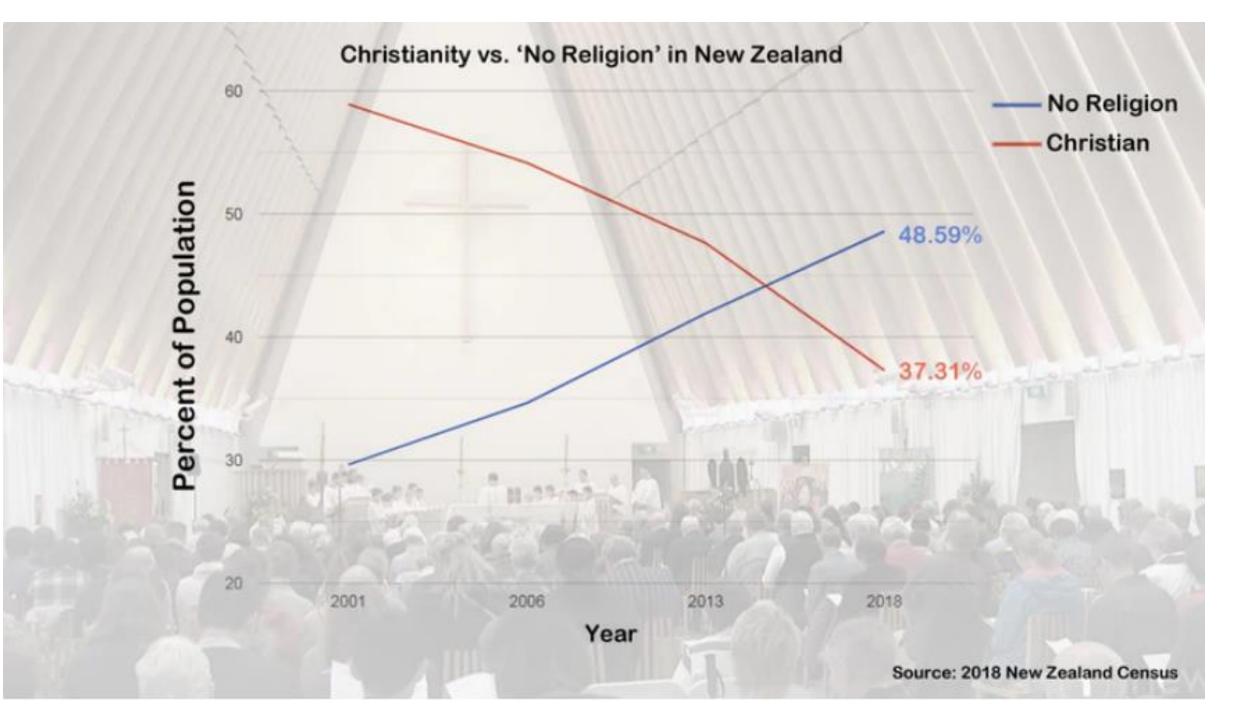


Cancer challenges

- Mortality leading cause
- Morbidity survivorship and chronic illness
- Inequalities
- Growth expected
- Cost
- How to cope, how to die



Dr B Koffman



Spirituality: A framework to understand 'it'

A framework to understand spirituality:

- i. Scope / definitions matters
- ii. Principle / model matters
- iii. Evidence informed
- iv. Zeitgeist

"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." <u>Journal of</u> <u>palliative medicine **17**(6): 642-656.</u> p.5

Spiritual care definitions

Spiritual Care (Clinical definition)

Spiritual care is the provision of assessment, counselling, support and ritual in matters of a person's beliefs, traditions, values and practices enabling the person to access their own spiritual resources.

Spiritual Care (Consumer definition)

Spiritual care can help you feel more connected with yourself, other people or to something beyond. It may involve your religious beliefs and practices or the values that are important to you. It is about supporting what gives meaning and purpose to your life.

Spiritual Health Association. (2019). Guidelines for Quality Spiritual Care in Health. In. Abbotsford, Australia. P.15



THAN YOURSELF

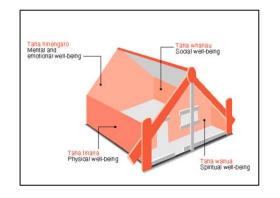
Meaningful Age

Meaning

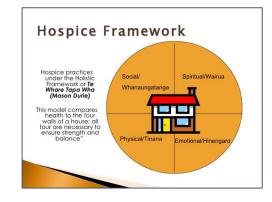
A framework to understand 'it'

A framework to understand spirituality:

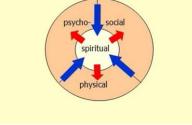
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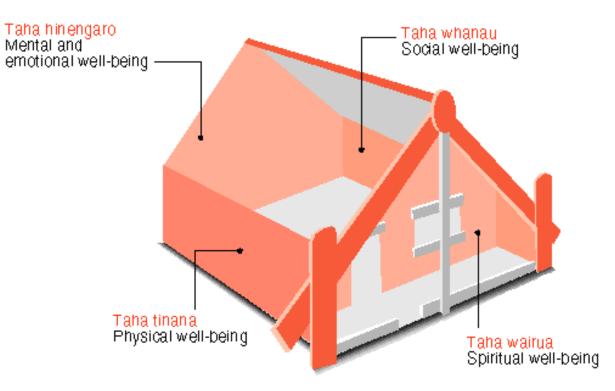






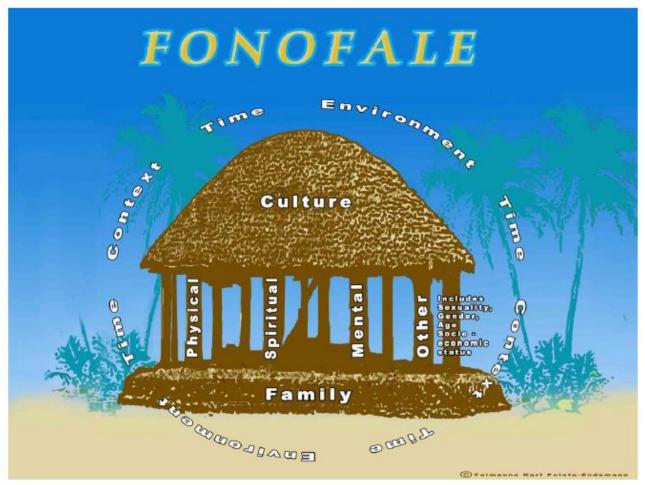


Principle & model matters Māori contribution



Durie, M. 1985

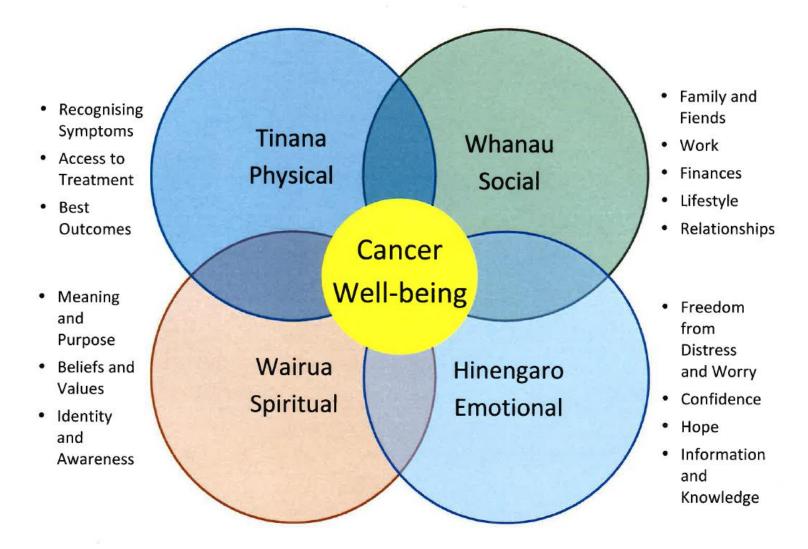
Principle & model matters Samoan contribution



Fonofale Model of Health by Fuimaono Karl Pulotu-Endemann 2001

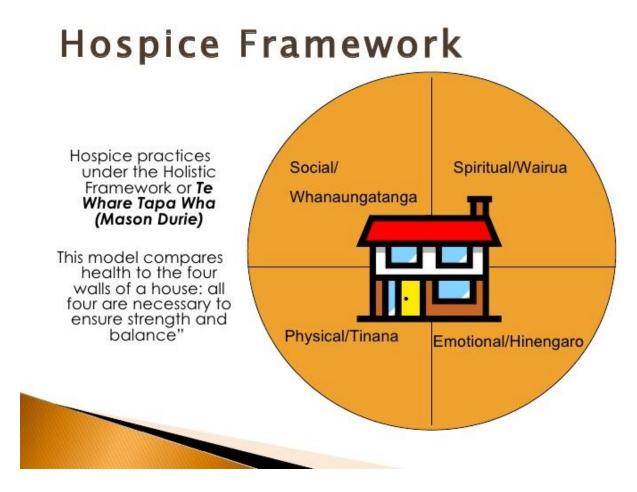
Principle & model matters

Cancer Society NZ Supportive Care Model

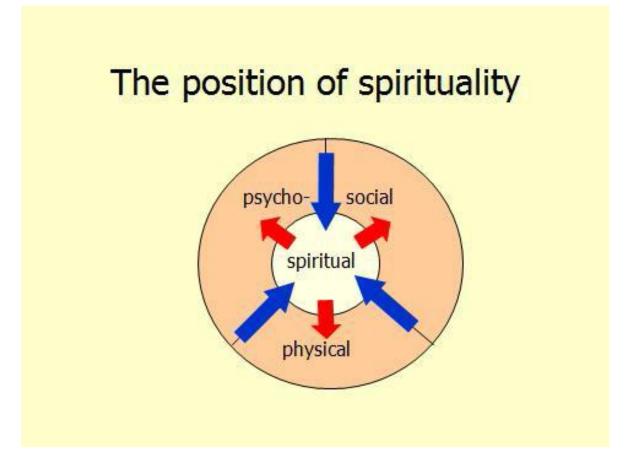


Principle & model matters

Hospice framework



Principle & model matters Netherlands oncology guidelines



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

Principle & model matters Australia: Spiritual Health Association

When spiritual needs are recognised and responded to as an integral part of person-centred care an essential contribution is made to peoples' health and wellbeing.





Spiritual Health Association

Source: https://www.spiritualhealth.org.au/resources

Principle & model matters

Our model of health & healthcare matters

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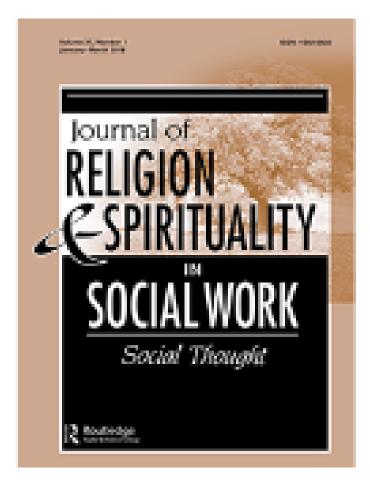
Whole person principle and approaches – holism, Total Care, Te Whare Tapa Wha, Fono Fale etc.

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

A framework to understand 'it'

A framework to understand spirituality:

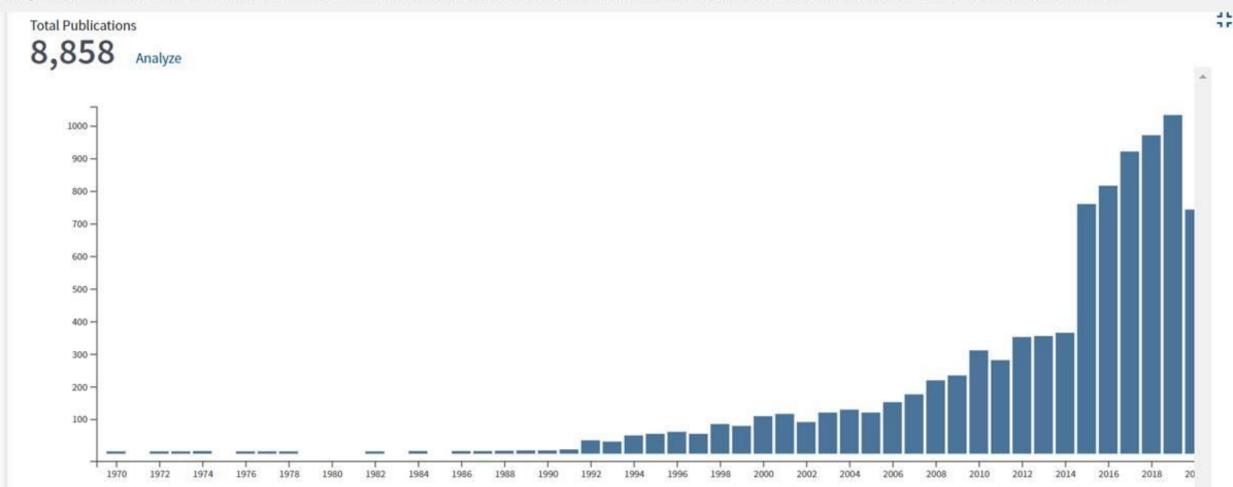
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Citation report for 8,858 results from Web of Science Core Collection between 1970 - and 2021 - Go

You searched for: TOPIC: (social work*) AND TOPIC: (spiritual* OR relig*) ... More

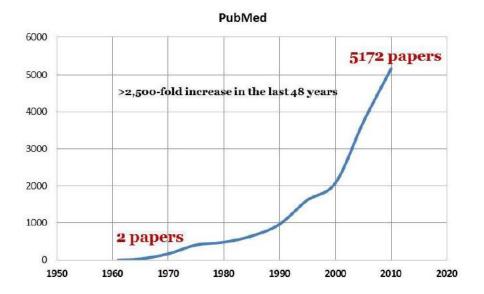
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Evidence informed matters

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)
- Hodge, D. R. (2018). The evolution of spirituality and religion in international social work discourse: Strengths and limitations of the contemporary understanding. Journal of Religion & Spirituality in Social Work: Social Thought, 37(1), 3-23.



Kharitonov, S. A. (2012).

Spiritual lens – learning from A/NZ Pacific peoples

"Spirituality and its various expressions are central to the role of Elders as well as a core part of their own activities. Many Elders had the role of guiding younger family members in spirituality practices." (p.51)

"Spirituality plays a significant role in maintaining their overall wellbeing." (p.52)

"spirituality is not just an element of age or the ageing process. It is not equivalent to such elements as housing, electricity and power, information and transport. ... Viewed from this perspective, **spirituality is the key constituent force in the whole life process**.."

The Family Centre.

Spiritual lens – reclaiming pakeha contributions: 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".

Sir Paul Callaghan: Kiwi visionary looks back on life NIKKI MACDONALD, March 26, 2012. DomPost website

"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." <u>ESMO Open 4(1): e000465. p.3</u>

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

rorgiveness 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 deliberations had already been published ³ The 2000

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.

G.

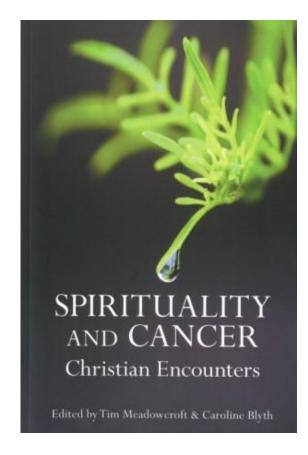
cients:

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.

Christian responses

"My reading of these chapters identified a common thread of "making sense", a spiritual endeavour in itself. We see each author grappling with how to make sense of the cancer experience personally, professionally, and/or theologically. Most profound for me are the insights that have been informed by religious belief and thought but are nonetheless relevant to all, theist and atheist alike."

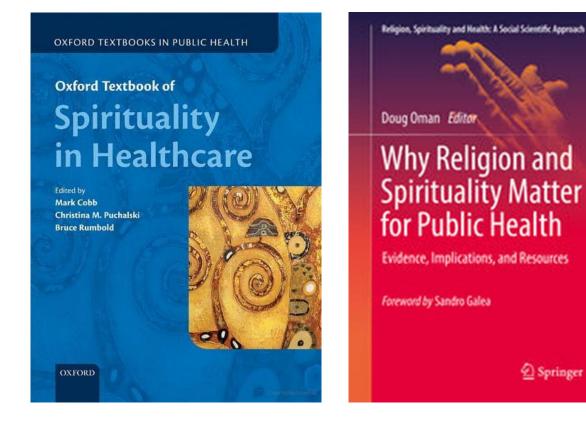


Egan R. (2015). Spirituality and Cancer: "Not a Saccharine Additive". Spirituality and Cancer : Christian Encounters. T. Meadowcroft, Blyth, C. Auckland, New Zealand, Accent Publications.

A framework to understand 'it'

A framework to understand spirituality:

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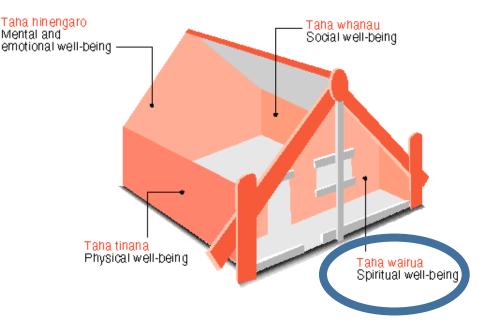


Springer

Spirituality research: an emergent field

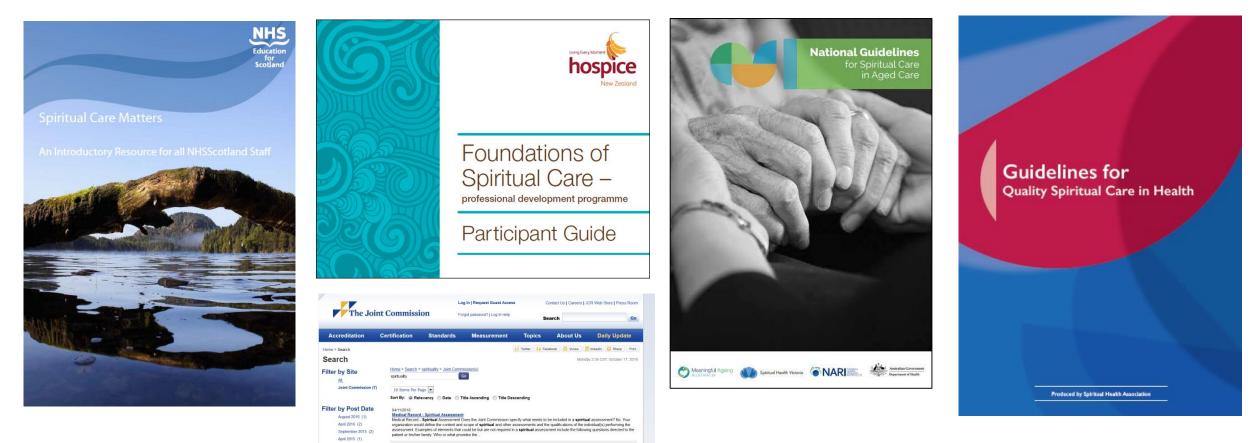
Egan and colleagues are developing the spirituality, health and public health field, studies include:

- 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* / Armed Forces*
- 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*
- Co-design spirituality in elder & cancer care / chaplaincy;
- Spirituality in public health.
- Oranga Tu Māori prostate cancer
- Euthanasia / MHP / Pal Care education



*published papers

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

See also recent Australian and NZ Ageing policy documents

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https://carolinasanches.com/Zeitgeist

Zeitgeist matters: Spirituality

- Low attendance / growth of 'nones' & 'Spiritual but not religious
- Long dying, multi-culturalism, pluralism, democratization of spirituality
- Spiritual vacuum? Re-emergence?
- Māori contribution: "Taha wairua is generally felt by Māori to be the most essential requirement for health". (Durie, 1999)
- Aboriginal study: "It was noted that insufficient emphasis is placed on the positive aspects of the spiritual dimension of Aboriginal life." (McGrath & Phillips, 2008)
- Dispirited healthcare workforce





Spirituality and social work: Introducing a spiritual dimension into social work education and practice

Carol Phillips

Carol Phillips has been a social worker since 1985, working in the community sector with prisoners and their families, with women affected by the criminal justice system, and as a fostering social worker, manager, supervisor and lecturer in social work at Te Wānanga o Aotearoa.

Abstract

Against a background of growing international interest in the place of spirituality in social work education and practice, this paper describes a qualitative study of the spiritual experiences of non-Māori social work students at Te Wānanga o Aotearoa, and the application of spirituality to their practice as social workers. The study found that both the programme and Wānanga environment enhanced and deepened participants' own spirituality and flowed through into their practice. Elements of the Wānanga programme which contributed to the students' spiritual development are identified, along with a discussion of the influence of the bicultural nature of the programme and take pū on their practice.

Phillips, C. (2016). Spirituality and social work: Introducing a spiritual dimension into social work education and practice. Aotearoa New Zealand Social Work, 26(4), 65-77.

Social work and spirituality framework

- Scope / definition matters
 - "The literature generally distinguishes between spirituality and religion"
 - "Definitions of spirituality ... holistic and inclusive"
- Principle & model matters
 - "spiritual practice has always been part of holistic Indigenous social work"
 - Western social work: "increasingly secularised, ... secular humanism, psychology, ... evidence-based models"
 - "Māori models of practice have been developed which are based on tikanga"

All quotes from: Phillips, C. (2016). Spirituality and social work: Introducing a spiritual dimension into social work education and practice. Aotearoa New Zealand Social Work, 26(4), 65-77.

Social work and spirituality framework

- Evidence informed matters
 - "The 1990s, however, saw the beginning of a resurgence of interest"
 - "some feel unable to do so ... "
 - In SW education: "concerns about proselytising, fear of offending"
 - Findings: "integral part of the Wānanga programme", confidence?, "own spiritual awareness", "linked to culturally appropriate practice"
- Zeitgeist matters
 - "growing international interest in the place of spirituality in social work education and practice"
 - Decolonisation context
 - "Social work in Aotearoa New Zealand demands competency in working with Māori and increasingly with other cultures."

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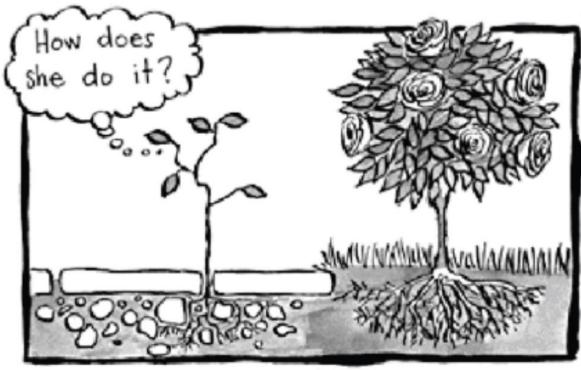


The future (present) challenge

• 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.



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cxmedia.com

Mandata for chiritual accossment / care

Good Practice Points Service/Organisation

- There is an organisational approach to how a need for spiritual care is identified and there is a referral pathway to how this need will be addressed.
- Health and supportive care workers are encouraged to participate in spiritual awareness education.

Maintains a level of cultural competency that ensures they are able to integrate the spiritual beliefs of Māori affected by cancer into care and are aware of where to access additional support.

Ensures those a

spiritual suppor

Is aware of and

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concerns such

Has an understanding of the different religious and cultural rites around death and where to access additional advice and assistance. v to, access urces and

their own beliefs allenged within

Is able to utilise self-care techniques to ensure that their own sense of hope and compassion is maintained.

irituality (47

and:

Implementing spiritual care

- *The clinician–patient relationship*: compassionate presence
- Assessment and treatment of spiritual distress
 - Clinicians [social workers?] 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.

Role of chaplaincy / spiritual care experts

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, P. (2004). "Spiritual Care in Health Care." Scottish Journal of Healthcare Chaplaincy 7(1): 21 - 25., p. 22).

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: 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

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.

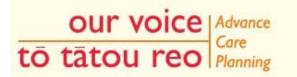
Conversation openers

- ➤ '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?

Hospice New Zealand Spiritual Care Resources

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)



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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:



https://meaningfulageing.org.au/

ConnecTo-A spiritual Self screening tool Nature Self Other Creativity Religion Something Bigger



TE RÔPŪ TAUWHIRO I AOTEAROA

AOTEAROA NEW ZEALAND ASSOCIATION OF SOCIAL WORKERS

SOCIAL WORK **EXPLAINED**

SOCIAL WORKERS ARE QUALIFIED REGISTERED PROFESSIONALS WHO:

Undertake psychosocial assessments, analysis and interventions

that holistically consider the ecological context of a person's situation and their environments.

Apply in-depth relational skills to work with a range of complex factors

that impact on the safety, wairuatanga, and wellbeing of individuals, families, whanau and communities.

Identify and address danger and harm factors

such as violence and addiction and promote inclusion, self-efficacy, belonging, whänaungatanga and social connectedness.

SOCIAL WORKERS RESTORE AND STRENGTHEN EMOTIONAL AND SOCIAL WELLBEING BY:

Enhancing and strengthening people's ability and capacity to address and manage

the challenge, difficulty and vulnerability that is experienced in situations where circumstances are not easily changed.

Assisting people experiencing crisis to endure and adapt to uncertainty, loss and grief and other impacts including fear, feelings of isolation and anxiety.

Using a range of specific social work methods and techniques to manage and normalise emotional responses

and provide support that restores wellbeing and assists with resilience both for individuals, families, whanau and communities.

SOCIAL WORKERS SEEK TO INFLUENCE PERSISTENT ISSUES OF POVERTY, INEQUALITY, VIOLENCE, DISCRIMINATION AND ONGOING FAILURES OF SOCIAL SYSTEMS BY:

Addressing wider impacts

such as the historical impacts of colonisation, assimilation, institutional racism, exploitation, violence and oppression and other social determinants of health.

develop their own solutions to Actively challenging discriminatory practices, inequality and social injustice in organisations and wider society.

They work to influence change at individual, family, whānau, hapū, iwi, community and government levels.

Collaborating with communities to

identified issues.

SOCIAL WORKERS WORK ACROSS A NUMBER OF FIELDS IN AOTEAROA NEW ZEALAND ...

Such as: Iwi Maori organisations, health, social services, justice, and statutory child protection services, and adhere to the requirements of legislation associated with these.

They apply their expertise in a variety of ways and roles.

including one to one clinical work, community development, advising, research, education, supervision, facilitation, advocacy, management, policy development and leadership.

Social workers are skilled in the application of critical reflection and questioning

and commit to a process of ongoing learning and development and professional accountability in order to deliver the best service to people and communities.

Source: https://anzasw.nz/anzaswadvocacy/social-workexplained-posters/

Spiritual care: what, why and how?

- What is spirituality?
 - Broadly understood, subjective yet intrinsic
- Why consider it?
 - Zeitgeist postmoderm condition, cultural imperative
 - Part of models of health/wellbeing/hauora
 - Research impacts on outcomes
 - Policy increasingly mandated
- How to address spiritual needs?
 - Self care
 - Increase spiritual literacy
 - Spiritual tool box build on strengths

Lets do some research!

Diverse realities: Flexible practice for spirited oncology social work

Contact me or Dr Ruth Panelli, (Social Worker, Southern District Health Board):

Ruth.Panelli@southerndhb. govt.nz

Richard.egan@otago.ac.nz

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

Anibersity

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

