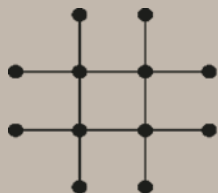

The 'Warp and the Weft' of spirituality in palliative care

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Objectives

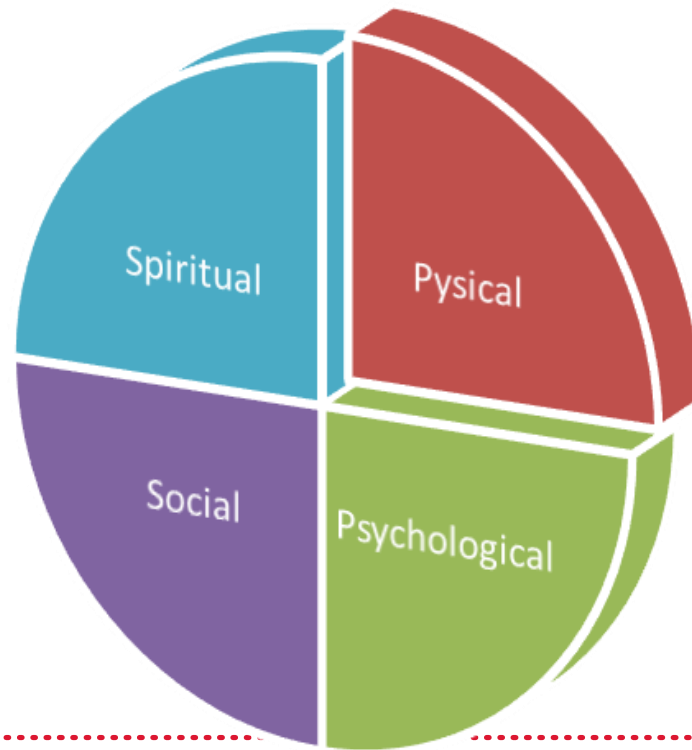
- Revisit contemporary definitions of spirituality to untangle, demystify the meaning and relevance for palliative care
- Delineate the 'Warp and Weft' of the spiritual dimension so that all providing holistic person-centred care can recognize spirituality in the fabric of people's lives
- Through the story of James reflect and weave spirituality throughout the tapestry of palliative and end of life care

WHO Definition of Palliative Care

“Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

<http://www.who.int/cancer/palliative/definition/en/>

Standard representation of holistic care



Something there?

Hay writes:

“It is therefore of interest that in recent years a considerable body of evidence has been accumulating in both the physical and social sciences suggesting that our spiritual nature is real and not illusory. Or many of the people I have spoken with during my research put it ‘there is something’.

[he goes on to say]

... that spiritual awareness is a necessary part of our biology , whatever our religious belief or lack of them.”

2006 pp xi –xii

National care of the dying audit for hospitals, England

Discussions between clinicians and patients regarding spirituality in end-of-life care only occurs in 15 per cent of cases, and in an additional 27% of cases, people important to the patient had these discussions. This suggests that only in 42% of cases the patient and those important to them were asked about their spiritual needs

<https://www.rcplondon.ac.uk/projects/outputs/end-life-care-audit-dying-hospital-national-report-england-2016>

Why are we failing to recognise the Warp and Weft of spirituality?

- Misconceptions about the meaning of the concept
 - Viewed or perceived synonymously with religion
 - Fear of proselytising and reprisal
 - Time, busy not enough staff, resources
 - Lack of education and training?
 - Secularisation of society and healthcare?
-

Telegraph reports

Christian nurse
sacked for
offering to pray
with patients
was just
showing
'compassion',
tribunal hears

<https://www.telegraph.co.uk/news/2017/03/30/christian-nurse-sacked-offering-pray-patients-just-showing-compassion>

<https://www.telegraph.co.uk/news/health/news/4409168/Nurse-suspended-for-offering-to-pray-for-patients-recovery.html>



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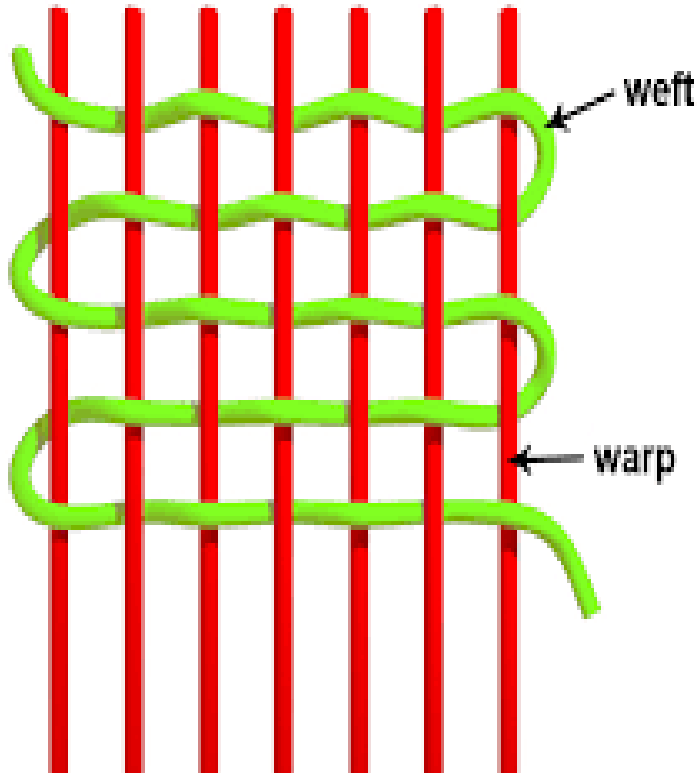
Royal College of Nursing Survey

28) *“I feel currently out of pressure of work nurses do not have enough time to spend with their patients/clients to address spiritual issues. I also believe there is a lot of cultural issues related to this and at times this creates a barrier. I also feel there is no freedom of expression for fear of "imposing" one's view yet sometimes its in sharing that someone would gain spiritually.”*

1474) *Given recent media coverage e.g. Caroline Petrie case, further guidance is definitely needed*

1914) *I have been very disturbed by recent cases, eg Mrs Petrie. I have always been open about my own faith, though not pushy, but have found it at times appropriate to raise the topic with some patients at certain times. The Petrie case disturbed me as I thought I also would be open to similar attack if someone decided to pursue it.*

The Warp and the Weft



Stoll's (1987) The person's spiritual interrelatedness (two dimensional model)

The vertical dimension (The Warp) 'as do with the person's transcendent (beyond and/outside self) relationship, the possibility of a person-relatedness to a higher being-God-not necessarily as defined by a particular religion

The horizontal facet reflects and fleshes out the supreme value experiences of one's relationship with God through one's beliefs, values, life-style, quality of life, and interactions with self, others and nature vertical

Stoll, R, I. (1989) The essence of spirituality, in Carson, V, B. (editor) (1989) Spiritual dimensions of nursing practice, Philadelphia: W B Saunders Company. Chapter 1 pages 6-8

McSherry (2009) Definition of Spirituality

Spirituality is universal, deeply personal and individual; it goes beyond formal notions of ritual or religious practice to encompass the unique capacity of each individual. It is at the core and essence of who we are, that spark which permeates the entire fabric of the person and demands that we are all worthy of dignity and respect. It transcends intellectual capability, elevating the status of all of humanity.

McSherry, W. Smith, J (2012 p 118) Spiritual Care In McSherry, W.,
McSherry, R., Watson, R. (Eds) (2012) Care in Nursing Principles values
and skills Oxford University Press, Oxford



Puchalski et al 2014 p 646

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Special Reports

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

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Sharon K. Hull, MD, MPH³, and Nancy Reller⁴

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.

Introduction

ALTHOUGH THE CLOSE CONNECTION between spirituality and health has been acknowledged for centuries, a strong emphasis on science in the practice of medicine over time has caused some to question or dismiss its potential therapeutic effects. By the early 1990s, however, hospitals and a variety of medical training programs began to recognize the role of spirituality in patient care, particularly in palliative care.¹ Since that time, the professional literature reflects growing interest in and debate about this topic.²⁻⁸ Recent years have witnessed extensive growth in research on the ways in which spirituality can support health in the contexts of medicine, nursing, ethics, social work, and psychology. This has been especially true in the field of palliative care.⁹ Data indicate that a focus on spirituality improves patients' health outcomes, including quality of life.¹⁰⁻²² Conversely, negative spiritual and religious beliefs can cause distress and increase the burden of illness.²³⁻²⁶

Given that global health outcomes are influenced by health care access, and considering increases in patient dissatisfaction and clinician burnout, addressing spirituality is both

relevant and timely. Moreover, as the population ages worldwide, clinicians often feel ill equipped to be present to the suffering of patients and the overwhelmingly complicated medical and social issues associated with care for patients with complex chronic issues. Health care settings face challenges in providing compassionate care that focuses on honoring the dignity of each person.

Too often individuals visiting health care facilities are seen as a "disease that needs to be fixed" quickly and cheaply rather than as human beings with complex needs, including those of a spiritual nature. As a result, patients feel overwhelmed by the myriad tests and pharmaceuticals offered to them as "fixes" instead of having the opportunity to find their own inner resources of health and healing. In sum, they do not experience the care and compassion that relieves the burden and stress of illness—care they desire.^{23,26} For example, a large Canadian study reported that 96.8% of patients identified "receiving health care that is respectful and compassionate" as being very or extremely important.²⁷

Palliative care, built on the biopsychosocial-spiritual model of care, has long recognized the critical role of spirituality in the care of patients with complex, serious, and

After a robust and dynamic discussion with several rounds of voting, agreement was reached on the following definition of spirituality:

“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.”

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Accepted April 7, 2014.

Puchalski, C, M., Vitillo, R., Hull, S, K., Reller, N. (2014) Improving the Spiritual Dimension of Whole Person Care: Reaching National and International Consensus, *Journal of Palliative Medicine*, 17(6): 642–656.



EAPC Task Force on Spiritual Care in Palliative Care

Spirituality is the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred.

The spiritual field is multidimensional:

1. Existential challenges (e.g. questions concerning identity, meaning, suffering and death, guilt and shame, reconciliation and forgiveness, freedom and responsibility, hope and despair, love and joy).
2. Value based considerations and attitudes (what is most important for each person, such as relations to oneself, family, friends, work, things nature, art and culture, ethics and morals, and life itself).
3. Religious considerations and foundations (faith, beliefs and practices, the relationship with God or the ultimate).

<http://www.eapcnet.eu/Themes/ProjectsTaskForces/EAPCTaskForces/SpiritualCareinPalliativeCare.aspx>

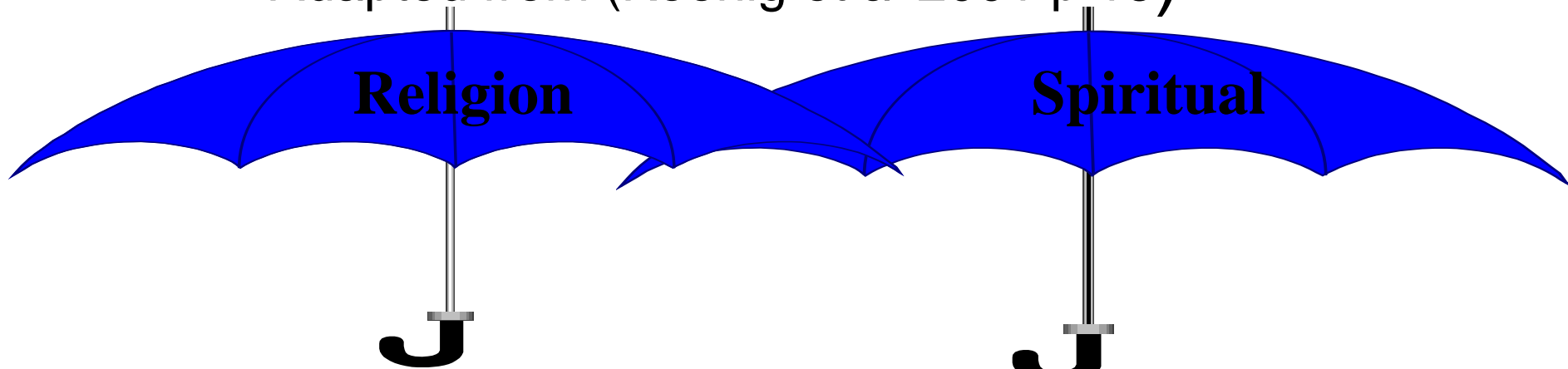
Ireland's own

“Spirituality is a way of being in the world in which a person feels a sense of connectedness to self, others, and/or a higher power or nature; a sense of meaning in life; and transcendence beyond self, everyday living, and suffering.”

Weathers, E., McCarthy, G., and Coffey, A (2016) Concept analysis of spirituality: An evolutionary approach, *Nursing Forum*, 51(2): 79-96.

Distinguishing Religion and Spirituality

Adapted from (Koenig et al 2001 p 18)



- **Community Focused**
- **Observable measurable, objective**
- **Formal orthodox, organized**
- **Behavior orientated, outward practices**
- **Authoritarian in terms of behavior**
- **Doctrine separating good from evil**

Individualistic
Less visible and measurable, more subjective
Less formal, orthodox, less systematic
Emotionally orientated, inward directed
Not authoritarian, little accountability
Unifying, not doctrine oriented

A taxonomy of Spirituality

DESCRIPTORS

Theistic: belief in a supreme being, cosmological arguments not necessarily a 'God' but deity.

Religious: affiliation – belief in a God, undertaking certain religious practices, customs and rituals

Language: Individuals may use certain language when defining spirituality such as inner strength, inner peace.

Cultural; Political; Social ideologies: an individual may subscribe to a particular political position or social ideology that influences governs their attitudes and behaviours. dependent upon world faith – religious tenants.

Phenomenological: one learns about life by living and learning from a variety of situations and experience both positive and negative

Existential: a semantic philosophy of life and being, finding meaning, purpose and fulfilment in all of life's events.

Quality of Life: although quality of life is not explicit in definitions it is implicit.

Mystical: relationship between the transcendent, interpersonal, transpersonal, life after death.

LEFT.....RIGHT

CONSIDERATION

The order or sequencing of the descriptors present in the taxonomy are individually determined depending upon ones beliefs, values and life experience or worldview. The taxonomy is restrictive in that it implies the ability to intellectualise supporting the position that such definitions are exclusive and restrictive. The taxonomy implies that an individual's worldview will determine their definition of spirituality. The descriptors listed in the taxonomy are not exhaustive because they may well be infinite. The taxonomy suggests two form of spirituality the 'old' and the 'post modern'. The old = religious and theist while the 'The post-modern' = Phenomenological and existentially focused.

Individually tailored tartan

“The taxonomy suggests that there are no constant elements, threads that are common to every individual in how they may perceive or define spirituality. The threads are continually in a state of flux with no consistency in the tapestry or weave that they create. The idea that we all weave our own pattern or fabric is apparent. In the Scottish highlands an individual could be distinguished or identified as belonging to a particular clan by the tartan worn. This cannot be said of spirituality since the tartan woven is unique and specific to the individual and to some extent the society in which they live or worldview that they share. The fact that we all create our own definition of spirituality brings into question ‘universality’ and the general application and usage of the term”.

McSherry, W., Cash, K. (2004) The Language of Spirituality: An emerging Taxonomy. International Journal of Nursing Studies 41 issue 2 p151-161

Reflections from a Sideward

- Questions to consider as I am reading:
- What are the Warp and the Weft of spirituality in this situation?
- McSherry, W. (1996) Reflections from a Sideward. Nursing Times 92 (33) p29, 31

Time for weaving the Warp and Weft

<https://www.menti.com>

Warp and Weft of spirituality?

Existentialism: the way individuals derive and find meaning, purpose and fulfilment in life.

Relationship: the relationships that are significant to an individual's sense of identity, health and wellbeing – these could be relationships with family, friends, the environment, community and creatures

Transcendence: a sense of something greater and beyond self this could be God, deity, supreme being or Higher Power. It could also be aspects of life that enable the individual to transcend themselves or situations.

Connection: the sense of connection individuals have within themselves, with others, the environment and for some God or higher Power

Religiosity: for some people their spirituality and worldview is based upon adherence to a specific religious teaching, doctrine and practice. These inform and influence belief, attitudes, values and behaviours.

McSherry, W. (2016) Reintegrating spirituality and dignity in nursing and health care: a relational model of practice In Tranvåg, O, Synnes, O, McSherry, W. (2016) (Eds) Stories of Dignity within Healthcare: Research, narratives and theories, M&K Publishing, Keswick. Chapter 6 pages 75 - 96

RCN (2010) Spirituality is about:

- Hope and strength
 - Trust
 - Meaning and purpose
 - Forgiveness
 - Belief and faith in self, others and for some this includes a belief in a deity/higher power
 - Peoples values
 - Love and relationships
 - Morality
 - Creativity and self expression
-

For me spirituality is absent when:

- It devalues, diminishes the identity of the person, leading to a violation of their dignity
- Leads to an intentional destruction of human life, communities, societies, environments, natural world
- Ideologies that are divisive, oppressive, disempowering, promoting propaganda that lacks sensitivity and respect for equality diversity and fundamentally upholding of human rights

Conclusion

If we are to be successful in recognizing the Warp and Weft of spirituality then:

- We must be aware of the Warp and Weft of spirituality within our own lives
- Acknowledge this is a multidimensional, subjective and complex concept yet central to the lives and identity of many people
- This dimension focuses our attention on the individual, the person, not just the medical condition or treatment



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