### Back to the fundamentals: Reintegrating dignity and spirituality within person-centred care

Dr Wilfred McSherry Professor in Nursing, Department of Nursing, School of Health and Social Care, Staffordshire University, University Hospitals of North Midlands NHS Trust, England, United Kingdom, ST18 0YB

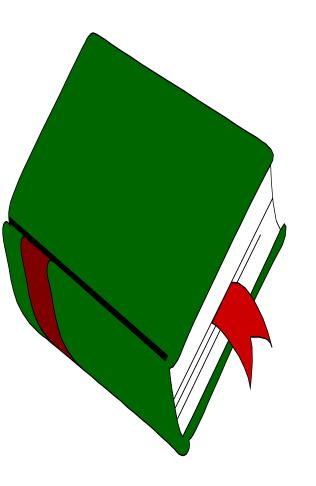
Part-time Professor VID University College (Haraldsplass) Bergen, Norway

11th July 2019









#### A Quote

- "I would probably rather tell you about my sex life than about my spiritual life. And I'm fairly sure that you would be more scandalised to find a bible at the bottom of my briefcase than a copy of the karma sutra."
- (Allen 1991pg 52)

Allen C 1991 The inner light. Nursing Standard 5 (20): 52–53



#### Objectives

- Demonstrate that these altruistic and humanistic aspects of the person are central to the delivery of care
- Highlight that dignity and spirituality are central to identity – an individual's own sense of purpose, values and beliefs
- Reinforce that these concepts are fundamental aspects of caring and compassionate care, integral to the concept of holistic practice and person-centred care



#### Recent Reports









# Debate in context 2017: Adult inpatient Survey

"Since 2009, the percentage of respondents who said they were 'always' treated with respect and dignity in hospital has increased, 82% in 2017 compared with 78% in 2009. Trend analysis indicates that there has been an underlying behavioural change since 2009, where results were below expected limits, and has risen above expected limits since 2015."



#### A turning point in my career

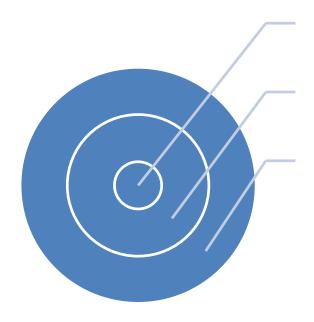
Peter, 72 years old, was known by his family and friends to like a short or two. He was admitted to hospital with an acute episode of chest pain. A diagnosis of angina was made since ECGs showed no evidence of recent infarct.

It came to light later that Peter was a practising Roman Catholic who found meaning and purpose in his beliefs. Peter had only been in hospital overnight and he had not seen his wife because she had taken herself off to their daughters 'down south' after an argument. Nevertheless she was informed by Peter of his admission into hospital and she was intending to visit as soon as possible. In the afternoon on the following day Peter was due to be discharged when he developed sudden severe central chest pain, collapsing with a cardiac arrest – resuscitation was initiated. During the resuscitation Peter's wife arrived on the ward. Unfortunately she did not see Peter before he died.

After Peter's death his wife asked if the Catholic priest had been. Inspection of the nursing notes showed that nothing in relation to religion had been entered.



#### Medical Model?



TRAUMA NURSING CARE MANIKIN, Clinical Training Model, medical model ,anatomical model http://susan0540.en.hisupplier.com/product-291775-TRAUMA-NURSING-CARE-MANIKIN-Clinical-Training-Model-medical-model-anatomical-model:html



### Frequently used terms

- Individualized care
- Holistic care
- Spiritual care
- Dignity in care
- Person-centred care
- Relationship/family centred care
- Compassionate care
- Integrated care
- Evidenced based care



#### **Public Inquiry**

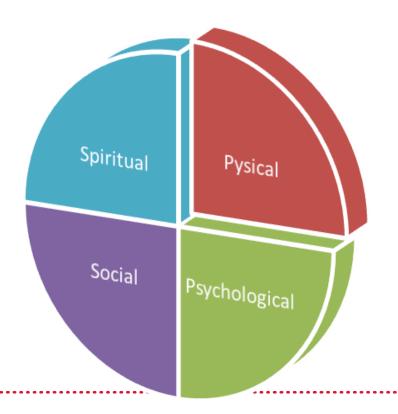


#### " Putting the patient first

The patients must be the first priority in all of what the NHS does. Within available resources, they must receive effective services for caring, compassionate committed staff, working within a common culture, and they must be protected from avoidable harm and any deprivation of their basic rights p85"

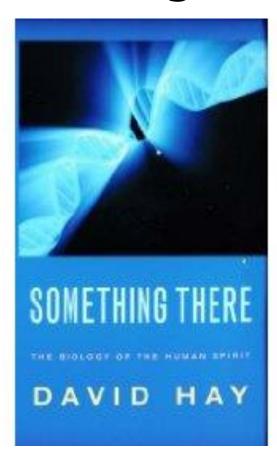


### Standard representation of holistic care





### Something there?



#### Hardy 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



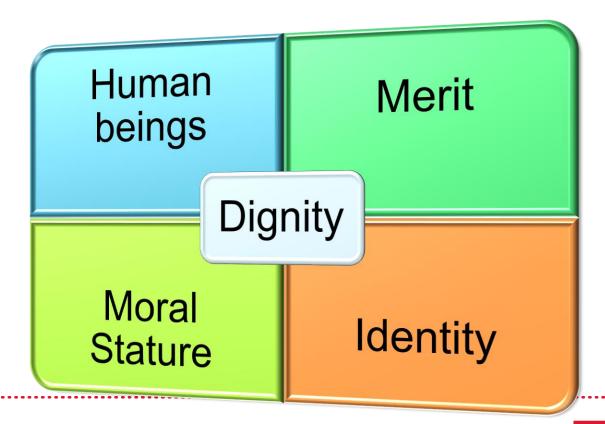
### Introduction to the Dignity Government Initiatives

- □ Dignity in Care Campaign aims to **stimulate a national debate** around dignity in care and create a care system where there is zero tolerance of abuse and disrespect of older people. (Launched in November 2006)
- ☐ It is led by Government in partnership with many organizations.
- ☐ Lays out the **national expectations** of what a care service that respects dignity should value.
- ☐ Introduced **Dignity Champions** Scheme.
- ☐ Focuses on ten **Dignity Challenges**.

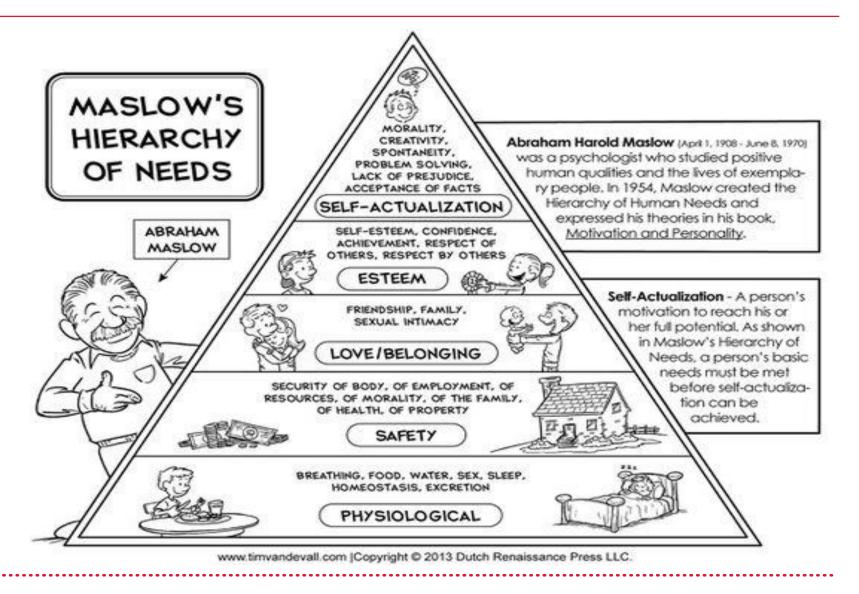
#### 10 Dignity Do's

Abuse	Have a zero tolerance of all forms of abuse.
Respect	Support people with same respect you would want for yourself or a member of your family.
Privacy	Respect people's right to privacy.
Autonomy	Maintain the maximum possible level of independence, choice and control.
Person-centered Care	Treat each person as an individual by offering a personalised service.
Self-esteem	Assist people to maintain confidence and a positive self-esteem.
Loneliness & Isolation	Act to alleviate people's loneliness and isolation.
Communication	Listen and support people to express their needs and wants.
Complaints	Ensure people feel able to complain without fear of retribution.
Care Partners	Engage with family members and carers as care partners.

### Model of Dignity – Adapted from Dignity and Older Europeans (2004)









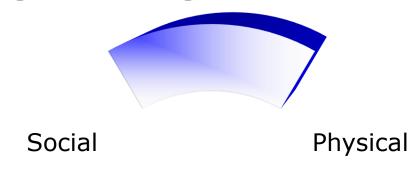
## Fenton's and Mitchell's definition (2002 p 21)

Dignity is a state of physical, emotional and spiritual comfort, with each individual valued for his or her uniqueness and his or her individuality celebrated. Dignity is promoted when individuals are enabled to do the best within their capabilities, exercise control, make choices and feel involved in the decision-making that underpins their care.

Fenton, E, Mitchell, T. (2002) Growing old with dignity: a concept analysis Nursing Older People 14 (2) 16 - 21



### Spiritual and dignity preserving nursing care







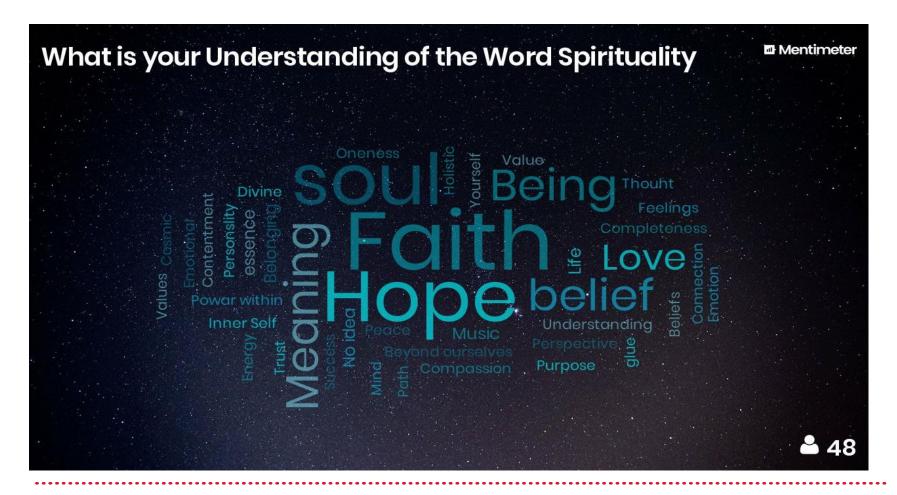
#### **Question 2**

 What is your understanding of the word spirituality?

https://www.menti.com



#### Responses from a recent public lecture





#### Patients' perceptions

"Well that's what I thought when I got this letter you know. Well I thought well again were back to religion!"

(A older lady receiving Palliative Care)

"Spirituality I think it is personal, it depends on what the individual believes for example my mother believes spirituality to be psychic, ghosts and people coming back from the dead. Where as I think it to be what religion you believe in your own aspects towards god or however it is that you worship."

(A young lady receiving medial care in an Acute Trust)



#### **Ghosts and Ghouls**







### Nurses perceptions

"I think it's different to every person, to me spirituality is what makes me feel what makes me! The emotional side, the essence of living! It makes somebody feel whole. It's the sparkle. Yeah it's just Je ne sais quoi! I don't know?"

Senior Nurse working in Palliative Care



#### Social Worker

"I certainly don't see spirituality as belonging to a religion; I don't see it as that. And I think that probably because I don't have a practising faith at the moment. Working at the hospice and seeing people die and it just makes me doubt the existence of a forgiving merciful God. So I can't see it doesn't fit comfortably spirituality and religion to me. The chaplain and I have lots of interesting conversations and discussions, which he always wins. Because he's got lots of information and experience from the religious point of view! So you come away from these conversations feeling very dissatisfied. So it's certainly not there! It sort of experiences I think to me, things that things that you know I find meaningful, think awe the wow factor!"



#### Chaplain

"My current understanding is that it's three-fold! The meaning purpose aspect which is most often talked about is only part of spirituality and I would say that equally at least relationships and I still struggle to find the right word a sense of transcendence awe, wonder, mystery are also important parts of spirituality and spiritual care."



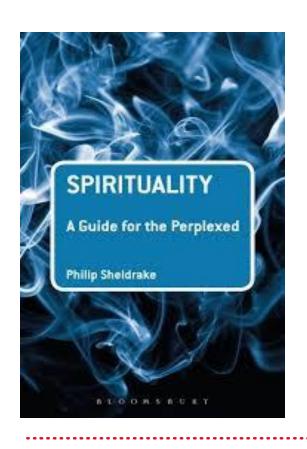
### McSherry (2009) Definition of Spirituality

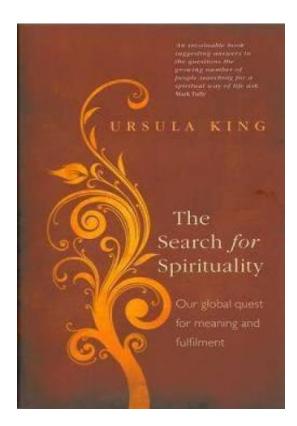
Spirituality is universal, deeply personal and individual; it goes beyond formal notions of ritual or religious practice to encompass the unique capacity of each individual. It is at the core and essence of who we are, that spark which permeates the entire fabric of the person and demands that we are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

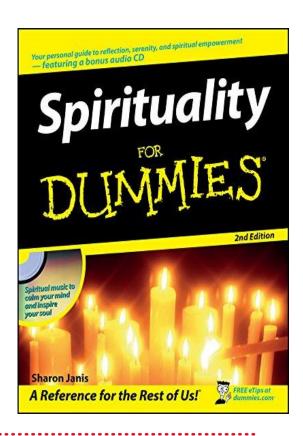
McSherry, W. Smith, J (2012 p 118) Spiritual Care In McSherry, W., McSherry, R., Watson, R. (Eds) (2012) Care in Nursing Principles values and skills Oxford University

Press, Oxford

#### A couple of useful guides









#### Distinguishing Religion and Spirituality

Adapted from (Koenig et al 2001 p 18)



**Spiritual** 



- 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

Koenig H G., McCullough M E., Larson D B (2001) Handbook of Religion and Health Oxford University Press Oxford



#### Sheldrake (2014 p1)

"It seems that, as human beings, we are persistently driven by goals beyond mere material satisfaction to seek deeper level of meaning and fulfilment."



### Sheldrake (2014) 4 typologies (Types of spirituality)

Ascetical The mystical Spirituality The prophetical The practical



### Sheldrake (2014) 4 typologies (Types of spirituality)

- Ascetical: liberation from material preoccupations and a deepened moral behaviour (p14. Discipline and non religious practice of meditation, mindfulness (p168)
- **Mystical:** a quest for an immediate consciousness of , or sense of a deep connection with, God or the ultimate depths of existence... way of 'knowing' that transcends purely rational analysis (p15)
- **Practical:** promotes the everyday world as the main context for following a spiritual path (pp15-16)
- **Prophetic:** while equally focused on the everyday world, goes beyond the practical service of our fellow humans in favour of social critique and commitment to social justice as a spiritual task. (p16) Finally the critical-prophetic 'type' is arguably detectable in some discussions of spirituality in relation to renewed vision of human care in the health professions...(p168).

#### Puchalski et al 2014 p 646

Volume 17, Number 6, 2014 © Mary Ann Liebert, Inc. DOI: 10.1089/jpm.2014.9427 Special Reports

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

> Christina M. Puchalski, MD, MS, FACP, Robert Vitillo, MSW, ACSW,2 Sharon K. Hull, MD, MPH,3 and Nancy Reller

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.

LTHOUGH THE CLOSE CONNECTION between spirituality A 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 recog-nize the role of spirituality in patient care, particularly in palliative care. Since that time, the professional literature reflects growing interest in and debate about this topic. 2-6 Recent years have witnessed extensive growth in research on the ways in which spirituality can support health in the ontexts of medicine, nursing, ethics, social work, and psy-chology. This has been especially true in the field of palliative care. Data indicate that a focus on spirituality improves patients' health outcomes, including quality of life. <sup>10–22</sup> Conversely, negative spiritual and religious beliefs can cause distress and increase the burdens of illness. 23,24

Given that global health outcomes are influenced by health care access, and considering increases in patient dissatisf ac-

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 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. <sup>25,26</sup> For example, a large Canadian study reported that 96.8% of patients identified "receiving health care that is respectful and compas sionate" as being very or extremely important.<sup>27</sup>

Palliative care, built on the biopsychosocial-spiritual model of care, has long recognized the critical role of spirition and clinician burnout, addressing spirituality is both tuality 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."

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.



George Washington Imstitute for Spirituality and Health, The George Washington University School of Medicine and Health Sciences (George Washington University, Washington, DC. Carlas International Delegation to be United Nations, Geneva, Switzerland. Department of Community and Family Medicine, Dale University School of Medicine, Durham, North Carolina. "Sojourn Communications, McLean, Virginia.

#### In summary - so what is spirituality?

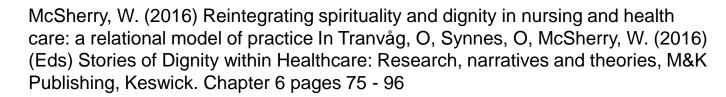
**Existentialism:** the way individuals derive and find meaning, purpose and fulfilment in life.

**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.





#### 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



### Extract from the award-winning short film:

#### What do you see?

 Film produced by Amanda Waring based on the poem 'Crabbit Old Women' by Phylis McCormack.  https://www.youtube. com/watch?v=MTcopj 6dYWQ

For more information about the poem see:

http://en.wikipedia.org/wiki/Crabbit\_Old\_Woman



# "We get treatment in the hospital and care in the hospice"



### Treatment

Scientific

**Proficient** 

**Technical Competence** 

Detached

Robotic

Cold



# Care or more precisely caring

Warm

Time

Presence

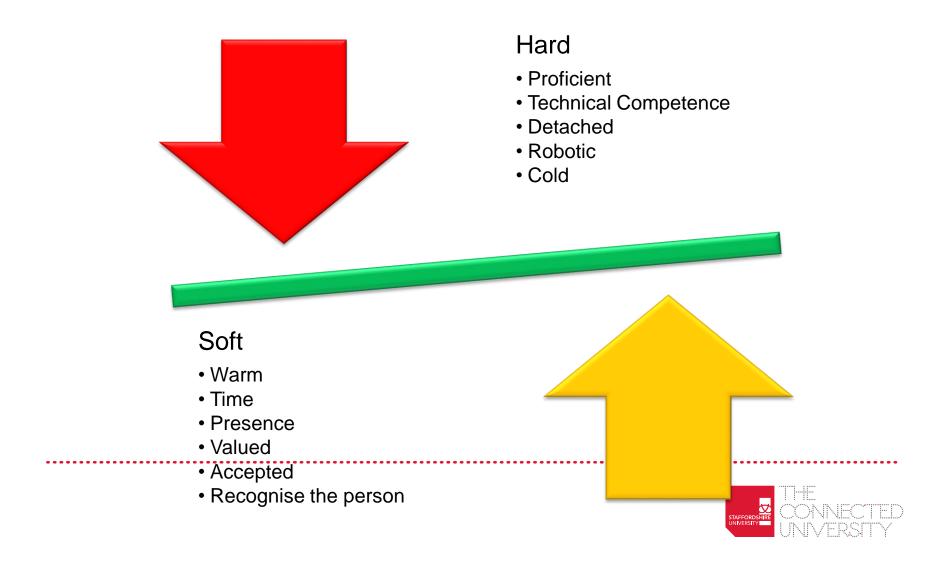
Valued

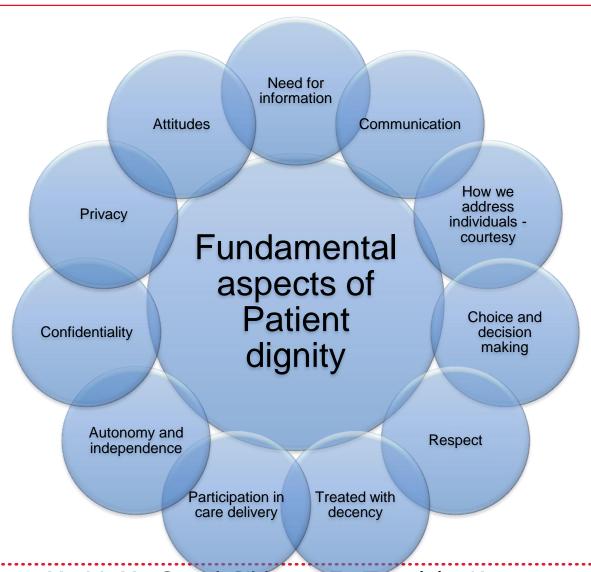
Accepted

Recognise the person



## Hard and Soft Nurse





Adapted from Matiti, M., Cotrel-Gibbons, E., Teasdale, K. (2007) Promoting patient dignity in healthcare settings. *Nursing Standard*. 21 (45) 46-52.



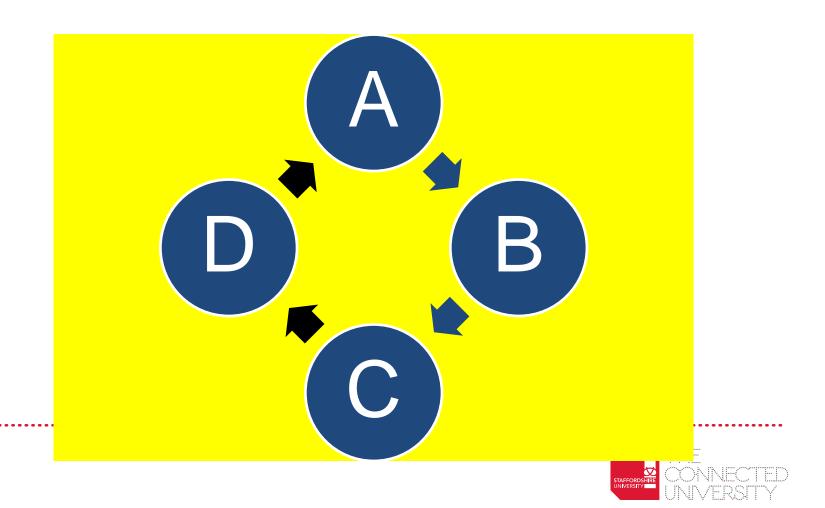
# Harvey Chochinov, O.M, M.D., PhD, FRCPC

University of Manitoba
Director, Manitoba Palliative
Care Research Unit
Cancer Care Manitoba

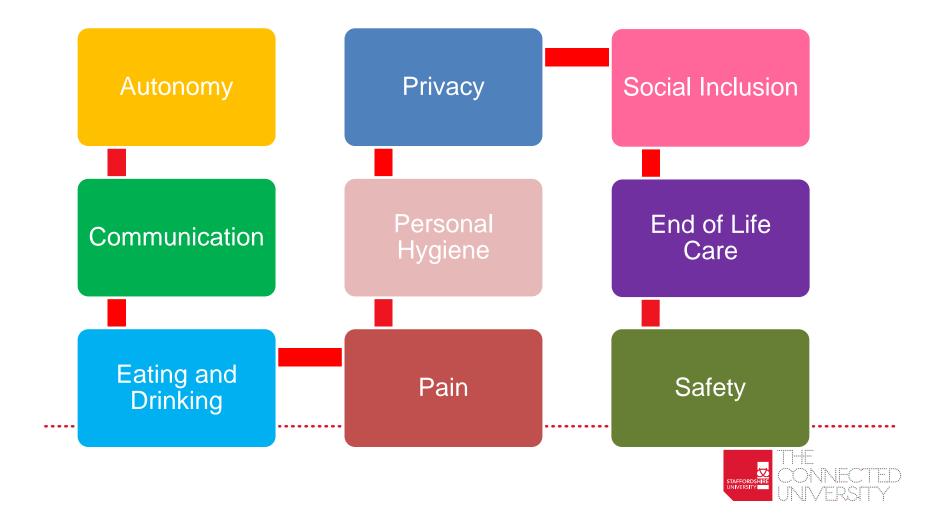
Chochinov, H, M. (2007) Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care. British Medical Journal 335, 184-187.



# Dignity conserving care



## **Dignity Domains**



## Dignity in Care Indicator Tool

2011 privacy and dignity survey with date CQUIN Jan12 V4 (3936 - A	ctivated, Traditional).pdf - Adobe Reader
File Edit View Window Help	
□    □    □    □    □    □    □	5.4% 🔻 🖟 🔻 Tools Sign Comment
Yes, sometimes	Yes, minimal disturbance
☐ No	□ No
Q20. Have staff enquired about your religious and spiritual beliefs?	If YES, what was the cause of this noise?
Yes No	
Don't know/ Can't remember	
Q21. Have you been given sufficient support to practice your religious or spiritual beliefs?	
I do not want or need to practice my religious or spiritual beliefs whilst in hospital	
Yes, always	
Yes, to some extent	
∐ No	
Don't know / Can't remember	
Q22. How clean were the ward bathrooms and toilets that you used?	
U Very clean	
Fairly clean	✓



### Conclusion

- Continue in our drive to re-establish and safeguard, our core values and principles of caring
- •Spirituality and dignity remind us to focus our attention on the individual the person, not the medical condition or treatment
- •Institutions and organisations and indeed wider society must value the contribution of our health and social care workforce
- •There must be a open, honest and transparent culture where integrity, honesty and sensitivity flourish

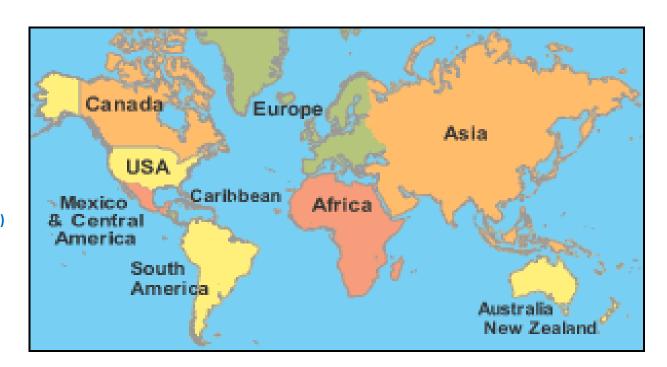


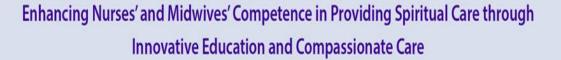
# The EPICC Journey: Overview of the Project and Outputs

**Professor Wilfred McSherry** 

### Countries represented

- United Kingdom:
- England, Scotland, Wales, (Northern Ireland)
- Croatia
- Czech Republic
- Norway
- Netherlands
- Poland
- Turkey
- Ireland
- Malta
- Denmark
- Germany/Austria
- Belgium
- Ukraine
- Greece
- Spain (mainland + Gran Canaria)
- Portugal
- Lithuania
- Sweden
- China
- Malaysia
- Thailand
- Palestine
- New Zealand







### What have we developed

- Established the EPICC Network (Launch 1 & 2 July Cardiff)
- Developed a Gold Standard Matrix for Spiritual Care Education and Adoption Toolkit
- Developed a Website and online repository





Cultural context

in which it is used

Terminology

Last accessed 18/02/19.

**Spiritual Care Education Standard Core Spiritual Care Competencies for** Undergraduate Nursing/Midwifery Students

Throughout the EPICC Spiritual Care Education Standard, the terms 'person and individual' is used. These terms refer to the 'patient', 'client', 'service user', 'pregnant woman', 'carer', 'family member', 'relative', 'care recipient' and so on, depending on the country in which the Standard is used, along with the local

NHS Scotland (2010). Spiritual Care Matters: An introductory resource for all NHS Scotland staff. Retrieved from https://www.nes.scot.nhs.uk/media/3723/spiritualcaremattersfinal.pdf.

Co-funded by the Erasmus+ programme of the European Union

Is aware of the importance of spirituality on health and wellbeing.

INTERPERSONAL SPIRITUALITY

**COMPETENCIES** 

INTRAPERSONAL SPIRITUALITY

the lifespan for oneself and others. persons' - Understands the impact of one's own values and beliefs in providing spiritual care.

KNOWLEDGE (COGNITIVE)

Understands the concept of spirituality.

Can explain the impact of spirituality on

a person's health and well-being across

Understands the ways that persons'

 Recognises the uniqueness of persons' spirituality

and resources.

SKILLS (FUNCTIONAL)

Reflects meaningfully upon one's own

values and beliefs and recognises that

these may be different from other

Takes care of oneself.

ATTITUDE (BEHAVIOURAL)

- Willing to explore one's own and

individuals' personal, religious and

- Is open and respectful to persons'

diverse expressions of spirituality.

- Is trustworthy, approachable and

- Has a willingness to deal with

- Shows compassion and presence.

- Shows willingness to collaborate with

and refer to others (professional/non-

- Is welcoming and accepting and shows

humility and trustworthiness in seeking

empathy, openness, professional

additional spiritual support.

professional).

emotions.

spiritual beliefs.

Assesses spiritual needs and

resources using appropriate

formal or informal approaches,

and plans spiritual care,

SPIRITUAL CARE:

**EVALUATION** 

INTERVENTION AND

and resources within a caring,

compassionate relationship.

- Is aware of different approaches to

Collaborates with other professionals

express their spirituality. respectful of persons' expressions of Engages with persons' EPICC has adopted the European Association for Palliative Care (EAPC)<sup>3</sup> definition of spirituality and an adapted version of its definition of spiritual care (to reflect wellbeing as well as illness), which were derived from international consensus work in palliative care. - Is aware of the different world/religious spirituality and different world/religious Interacts with, and responds sensitively spirituality, acknowledging Spirituality: "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." views and how these may impact upon to the person's spirituality. views. their unique spiritual and persons' responses to key life events. The spiritual field is multidimensional: cultural worldviews, beliefs L. 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). and practices. 2. Value-based considerations and attitudes (e.g., what is most important for each person, such as relations to oneself, family, friends, work, aspects of SPIRITUAL CARE: ASSESSMENT - Understands the concept of spiritual - Conducts and documents a spiritual - Is open, approachable and nonnature, art and culture, ethics and morals, and life itself) Religious considerations and foundations (e.g., faith, beliefs and practices, the relationship with God or the ultimate). assessment to identify spiritual needs iudgemental. AND PLANNING care.

<sup>&#</sup>x27;Care which recognises and responds to the human spirit when faced with life-changing events (such as birth, trauma, ill health, loss) or sadness, and can include the need for meaning, for self-worth, to express oneself, for faith support, perhaps for rites or prayer or sacrament, or simply for a sensitive listener. Spiritual care begins with encouraging human contact in compassionate relationship and moves in whatever direction need requires' (adapted from 4). The content and application of the EPICC Spiritual Care Education Standard should be considered within the cultural context and the language of the country

maintaining confidentiality and obtaining informed consent. Responds to spiritual needs

spiritual assessment. - Understands other professionals' roles in providing spiritual care. - Understands the concept of compassion and presence and its importance in spiritual care. - Knows how to respond appropriately to identified spiritual needs and resources. - Knows how to evaluate whether spiritual needs have been met.

<sup>-</sup> Be able to appropriately contain and deal with emotions. - Recognises personal limitations in spiritual care giving and refers to others as appropriate. - Evaluates and documents personal, professional and organisational aspects of spiritual care giving, and reassess appropriately

