Making Sense of Spirituality in end of life care

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Learning Outcomes

• Reflect upon one's own understanding of the terms spirituality and spiritual care

• Discuss the role of health care professionals in the provision of spiritual care

• Identify any barriers that may prevent health care professionals from engaging with spiritual issues

• Explore the skills required by health care professionals for effective spiritual care
Response

- 4054 respondents
- Approximately 10% of RCN membership
- Members from all 3 countries (Scotland, Northern Ireland, Wales) participated
- All 9 English regions involved
- Biggest response to the survey South East 17.0%
Demographic profile

- 41% respondents from NHS hospitals
- All health sectors included
- 25.4% Staff nurses
- Only 0.3% HCA/HCSW
- 0.9% students
- All main specialities/branches of nursing represented
- Age range - < 20 years - > 60 years represented largest age groups
  40 – 59 years 74% of all respondents
- Males 12% and females 88%
- 92.1% identified themselves as White and 4.3% of respondents classified themselves against National Census Criteria – 3.1% not stated
Spirituality and nursing

10.1 I believe that spirituality and spiritual care are fundamental aspects of nursing

- Strongly Disagree: 2.3%
- Disagree: 4%
- Uncertain: 10.3%
- Agree: 40.4%
- Strongly Agree: 43%

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Spirituality and quality of care

10.8 I believe that providing spiritual care enhances the overall quality of nursing care

- Strongly Disagree: 2.1%
- Disagree: 2.1%
- Uncertain: 5.7%
- Agree: 34%
- Strongly Agree: 56%

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Historical Overview

• Health care, Religion and spirituality were integrated

• The notion of vocation, devotion and self-sacrifice were essential traits.
Contemporary Developments

• Established spirituality as a fundamental concept

• Macro approach to conceptual and theoretical development

• Micro-application within branches and specialities

• Engaging with and transferring theoretical constructs into practice
I would like to read to you a scenario titled Spiritual Care – a Case to answer?

Afterwards I will explain why this critical incident sparked my interest in the area of spirituality and spiritual care.
Challenges

**Conceptual** - Consideration must be given to how people define, perceive and understand the nature of spirituality.

**Organisational** - People, places and process are central to understanding spirituality and the provision of 'spiritual care' and assessment.

**Practical** - The practical implications of assessing, planning, evaluating an individual's spiritual needs.

**Ethical** - The ethical issues and potential dilemmas that may be encountered when supporting individuals with their spiritual needs.
A scheme in which new hospital patients have their "religious and spiritual care needs" assessed has been condemned by the National Secular Society.

Southampton University Hospitals NHS Trust said people would be asked whether they had "any faith needs that can be supported during their stay". But the National Secular Society, which defends the rights of non-believers, said the move "misused NHS resources".

“How on earth have we reached the stage that you can't even go to hospital for treatment without having religion foisted on you like this?”

Terry Sanderson
National Secular Society President
Recent Criticisms

“But hiding it behind these themes represents an attempt to create a space for religious sensibilities in health care, while making it possible to deny such a space has been created. For this reason we need a debate on the propriety of peddling spirituality in health care.”

Paley (2009 p 26)

Reflection

• What is your understanding of the word spirituality?

• Write down any thoughts, words, feelings, images that come into mind as you think about the word.
Feedback

- Perhaps several things came to mind:
  - A belief in God
  - A belief affecting your life and how it relates to other people
  - Something not necessarily religious
  - A belief, concept, purpose and meaning
  - Faith/peace with oneself, A source of strength
  - Feelings of security/to be loved
  - Philosophy of life, death and religion
  - Self esteem, inner self, inner strength
  - Searching, coping, hope
  - An idealism, a striving to be good, a trusting relationship

Narayanasamy (1991p3)
Have things Changed?

- Beliefs affecting one’s life and how it relates to others.
- Something not necessarily religious.
- Purpose and meaning in life
- A source of strength.
- At peace with oneself.
- Inner peace.
- A feeling of security.
- Love and to be loved.
- Self-esteem
- Inner self
- Inner strength
- Searching
- Coping
- Hope and security.
- Trusting relationship
- Connectedness

- *Narayanasamy (2001 p 3)*
Why the interest in spirituality?

• National Legislation/Guidance

• Codes of Ethics and Professional Conduct

• Educational preparedness

• Changing society
Patients’ Charter

• NHS staff will respect your privacy and dignity. They will be sensitive to, and respect, your religious, spiritual and cultural needs at all times.

• (Department of Health (2001 pg 29) *Your Guide to the NHS.* DOH London.)
Priority 5 (pg. 24)
An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.
(2014 Pg. 52) Discussions regarding the patient’s spiritual needs were held with patients who were capable of participating in such discussions (52%, n=3,391):

Yes 21% (715)
No 79% (2,676)
Nurse suspended for prayer offer
Competences

- All nurses must carry out comprehensive, systematic nursing assessments that take account of relevant physical, social, cultural, psychological, spiritual, genetic and environmental factors, in partnership with service users and others through interaction, observation and measurement.

- Nursing and Midwifery Council (2010 p 45) Standards for pre-registration nursing programmes NMC London.
Definitions

• “A quality that goes beyond religious affiliation, that strives for inspirations, reverence, awe, meaning and purpose even in those who do not believe in any good (God). The spiritual dimension tries to be in harmony with the universe, strives for answers about the infinite, and comes into focus when the person faces emotional stress, physical illness or death.”

• Murray & Zentner (1989 p259)
Analogy and Symbolism
Football Explained

• Football = Whole Person

• Patches = Different Dimension of our being

• Black = Physical, Psychosocial

• White = less tangible, values, creeds, cultural aspects

• Thread = unifying force of spirituality

• Air = life force
• Adapted from McSherry & Draper (1998)
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
Overview of the study

• Method – qualitative grounded theory
• Data collection interviews were conducted between March 2001 – July 2003
• 53 Participant – Nursing (24) Chaplaincy (7) Social work (1) Occupational Therapy (1), Physiotherapy (2) Patients (14), Public (4)
• Location – area I hospice and area II & III Large Acute Trust
Findings

Subcategories:
- Definitions of spirituality
- Diverse perceptions of spirituality
- Provision of spiritual care
- Socialisation of the spirit
- Drivers
Patients’ perceptions

“I have not a clue. I really don’t know what it means. To me it is just about religion. I don’t know how you describe it quite honestly. That’s why when you rung up I thought to myself, I don’t know what I am going to say to you because I don’t know what it means”
(Patient Acute Trust)

“Never has interested me even illness it’s never interested me has religion. It has done nothing for me.”
(Patient Palliative Care)
Patients’ perceptions

“Well that’s what I thought when I got this letter you know. Well I thought well again were back to religion!”
(Patient 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.”
(Patient 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?”

Nurse Palliative Care
“I do actually think about spirituality. I couldn’t define spirituality. I think spirituality is something which is for me it’s like a thread if you like or stronger than a thread. It’s like you get rivers of stone underground. I forget what you call them (strata). It’s like that really that runs through all of our lives really. Well that’s what I think spirituality is! What that means for each individual. It does have to be some sort of bases of - it’s like a common denominator”.

Nurse Acute Trust
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.
# A taxonomy of Spirituality

## DESCRIPTORS

<table>
<thead>
<tr>
<th>Theistic: belief in a supreme being, cosmological arguments not necessarily a ‘God’ but deity.</th>
<th>Religious: affiliation – belief in a God, undertaking certain religious practices, customs and rituals</th>
<th>Language: Individuals may use certain language when defining spirituality such as inner strength, inner peace.</th>
<th>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.</th>
<th>Phenomenological: one learns about life by living and learning from a variety of situations and experience both positive and negative</th>
<th>Existential: a semantic philosophy of life and being, finding meaning, purpose and fulfilment in all of life’s events.</th>
<th>Quality of Life: although quality of life is not explicit in definitions it is implicit.</th>
<th>Mystical: relationship between the transcendent, interpersonal, transpersonal, life after death.</th>
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</table>

## CONSIDERATION

The order or sequencing of the descriptors present in the taxonomy are individually determined depending upon one's 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 forms of spirituality the ‘old’ and the ‘post modern’. The old = religious and theist while the ‘The post-modern’ = Phenomenological and existentially focused.
Language of spirituality

• Seeks to be universal

• All inclusive

• Acknowledges individuality

• Suggest spirituality comes into focus at time of need?

• Dismisses or seeks to divorce the religious and theistic

• Subjective
Spiritual Needs

- The need for meaning and purpose
- The need for love and harmonious relationships
- The need for forgiveness
- The need for a source of hope and strength
- The need for trust
- The need for expression of personal beliefs/values
- The need for spiritual practices, expressions of concept of God or deity and creativity.

Narayanasamy (1991 pgs 7-8)
Meeting spiritual needs?

9. Do you feel that you are able to meet your patients’ spiritual needs?

- Always: 5.3%
- Sometimes: 92.2%
- Never: 2.5%

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Scenario Two

I would like you to read the scenario titled:

“Case study 2 titled Psychological and Spiritual”

• In pairs can you work through and discuss the questions presented.
Feedback
Spiritual care is not:

• Just about religious beliefs and practices
• About imposing your own beliefs and values on another
• Using your position to convert
• A specialist activity
• The sole responsibility of the Chaplain
Role of Health Care Professionals

• Systematic approach - Assess, plan, implement and evaluate.

• Individualised, person-centred care,

• Symptom control

• Listening and attending

• Support

• Facilitation - other agencies
Treatment

Scientific Proficient Technical Competence Detached Robotic Cold

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Care

Warm
Time
Presence
Valued
Accepted
Recognise the person

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Scientific and Artistic

Scientific
• Proficient
• Technical Competence
• Detached
• Robotic
• Cold

Artistic
• Warm
• Time
• Presence
• Valued
• Accepted
• Recognise the person

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Approaches to spiritual assessment

• Formal (active)

• Informal (passive)
Spiritual Assessment

Acronym

Narayanasamy, 1999, 2001 ASSET Model (Actioning spirituality and spiritual care education and training in nursing) ACCESS Model

A: Assessment
C: Communication
C: Cultural negotiation and compromise
E: Establishing respect and rapport
S: Sensitivity
S: Safety

Puchalski and Romer 2000 Acronym FICA

F: Faith or Beliefs
I: Importance and influence
C: Community
A: Address

Anandarajah and Hight 2001 Acronym HOPE

H: sources of hope, meaning, comfort, strength, peace, love and connection
O: Organised religion
P: Personal spirituality and practices
E: Effects on medical care and end-of-life issues
Barriers

• Physical - sense, loss of ability to communicate.

• Environmental - lack of privacy, quiet rooms.

• Psychological - fears taboos, our own insecurities, dementia

• Economic - not enough staff, time, money for resources

• Educational - lack of training insight into the concept
Skills Required

• **Self Awareness** - introspection - we need to reflect upon ourselves identifying our own personal and unique spirituality.

• **Counselling and interpersonal skills** - we need to be able to relate confidently to individuals.

• **Trust building** - establish a rapport and therapeutic relationship with patients.

• **Non judgmental (if this is possible)** be accepting and tolerant acknowledging we are a unique.

• **Education** - we need to develop our knowledge and understanding of the concepts of spirituality.

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Advancing Spirituality in Care

Integrated

Individuality

Inter/intra-disciplinary

Inclusivity

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Conclusion

• Spiritual health care is a complex and subjective, however it is central to the notion of holistic practice.

• There is no authoritative definition of the term spirituality.

• Spirituality requires awareness on the health care professionals part.

• Spirituality is not only to be associated with institutional religion since it consists of many components.

• Many health care professionals already possess many of the skills required to take the initiative in dealing with spiritual issues. What they lack is confidence and education.