GIVINGCARE
Empowering Caregivers

A2.2 – Educative resources for teachers

Title: Ethics, Religion, Culture and Spirituality

Module: End of Life Care

Sub-Module: **Ethics, Religion, Culture and Spirituality**

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

This project has been funded with support from the European Commission. This publication [communication] reflects the views only of the author, and the Commission cannot be held responsible for any use which may be made of the information contained therein. Project Nº.: 2020-1-PT01-KA203-078360

Introduction

Module	End of Life Care
Sub-module	Ethics, Religion, Culture and Spirituality
Lesson nr.	#1
Duration (minutes)	
Date	To be defined

Lesson Outcomes

Identifying the ethical and legal aspects and implications of caregivers action in end of life care

Topics

Law, Ethics and Justice: regulation and jurisprudence

BioEdge bioethics news from around the world

Monday, June 26, 2017

An urgent need for palliative care as the world turns grey

by Michael Cook | 17 Jun 2017 | 5 comments

Law, Ethics and Justice

Main landmarks

1947 – Nuremberg Code

Law, Ethics and Justice

1947 – Nuremberg Code

The judgment by the war crimes tribunal at Nuremberg laid down 10 standards to which physicians must conform when carrying out experiments on human subjects in a new code that is now accepted worldwide. This judgment established a new standard of ethical medical behaviour for the post World War II human rights era. Amongst other requirements, this document enunciates the requirement of voluntary informed consent of the human subject. The principle of voluntary informed consent protects the right of the individual to control his own body. This code also recognizes that the risk must be weighed against the expected benefit, and that unnecessary pain and suffering must be avoided. This code recognizes that doctors should avoid actions that injure human patients. The principles established by this code for medical practice now have been extended into general codes of medical ethics.

Law, Ethics and Justice

1947 – Nuremberg Code

1. The voluntary consent of the human subject is absolutely essential. This means that the person involved should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, overreaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision. This latter element requires that before the acceptance of an affirmative decision by the experimental subject there should be made known to him the nature, duration, and purpose of the experiment; the method and means by which it is to be conducted; all inconveniences and hazards reasonably to be expected; and the effects upon his health or person which may possibly come from his participation in the experiment. The duty and responsibility for ascertaining the quality of the consent rests upon each individual who initiates, directs, or engages in the experiment. It is a personal duty and responsibility which may not be delegated to another with impunity.

Law, Ethics and Justice

1947 – Nuremberg Code

2. The experiment should be such as to yield fruitful results for the good of society, unprocurable by other methods or means of study, and not random and unnecessary in nature.

3. The experiment should be so designed and based on the results of animal experimentation and a knowledge of the natural history of the disease or other problem under study that the anticipated results justify the performance of the experiment.

4. The experiment should be so conducted as to avoid all unnecessary physical and mental suffering and injury.

5. No experiment should be conducted where there is an a priori reason to believe that death or disabling injury will occur; except, perhaps, in those experiments where the experimental physicians also serve as subjects.

Law, Ethics and Justice

1947 – Nuremberg Code

6. The degree of risk to be taken should never exceed that determined by the humanitarian importance of the problem to be solved by the experiment.
7. Proper preparations should be made and adequate facilities provided to protect the experimental subject against even remote possibilities of injury, disability or death.
8. The experiment should be conducted only by scientifically qualified persons. The highest degree of skill and care should be required through all stages of the experiment of those who conduct or engage in the experiment.
9. During the course of the experiment the human subject should be at liberty to bring the experiment to an end if he has reached the physical or mental state where continuation of the experiment seems to him to be impossible.
10.During the course of the experiment the scientist in charge must be prepared to terminate the experiment at any stage, if he has probable cause to believe, in the exercise of the good faith, superior skill and careful judgment required of him, that a continuation of the experiment is like

Law, Ethics and Justice

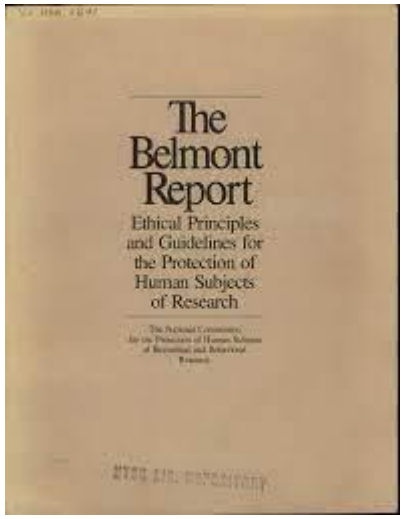
Law, Ethics and Justice

all of our human choices not only have consequences that are short term on the ecosystem and all life systems and societies, but also have long-term consequences for the future, some of which are predictable, others not. His bioethics, further elucidated in his second book, Global Bioethics

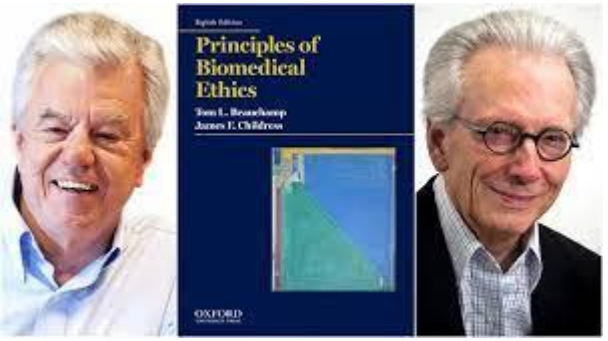
Van Potter

Law, Ethics and Justice

1948



1964



Introduction

Module	End of Life Care
Sub-module	Ethics, Religion, Culture and Spirituality
Lesson nr.	#2
Duration (minutes)	
Date	To be defined

Lesson Outcomes

Identifying the ethical and legal aspects and implications of caregivers action in end of life care

Topics

The Rights to Life and Health
Informed consent in adults, minors and adults with reduced legal capacity
The duty of information and the duty of secrecy

The Rights to Life and Health

Informed consent in adults, minors and adults with reduced legal capacity

Conditions for informed consent (Beauchamp, Childress):

I - Initial elements (prerequisites)
1 - competence (to understand and decide)
2 – voluntariness (to decide)
II – Informational elements
3 – exposure (of material information)
4 – recommendation (of a plan)
5 – understanding (from 3 and 4)
III - Elements of consent
6 – decision (in favor of a plan)
7 – authorization (of the selected plan)

The Rights to Life and Health

Informed consent in adults, minors and adults with reduced legal capacity

Advance Care Planning

The Rights to Life and Health

Informed consent in adults, minors and adults with reduced legal capacity

The Rights to Life and Health

Informed consent in adults, minors and adults with reduced legal capacity

https://www.advancecareplanning.org.au/resources/love-is-not-enough

The Rights to Life and Health

The **duty of information** and the duty of secrecy

People will not decide if they don’t have the information about their clinical situation.

Informed Consent

The Rights to Life and Health

The duty of information and the **duty of secrecy**

Professional secrecy:

Natural - Required by the nature of the information

Promised - There is a promise not to reveal the information

Trusted - The communication is made under the agreement, tacit or express, not to disclose it

The Rights to Life and Health

The duty of information and the **duty of secrecy**

What information?

Is it subject to professional secrecy?

What can and cannot be revealed?

Under all circumstances?

The Rights to Life and Health

The duty of information and the **duty of secrecy**

Protect the person from invasion of intimacy

Ensure the confidentiality of collected data

Right to confidentiality (the person decides the information to be shared or, if necessary, the decision is made in the best interest)

Duty to collaborate with justice does not overlap with the duty of professional secrecy, possibility of excusing duty

The Rights to Life and Health

The duty of information and the duty of secrecy

Who should keep it confidential?

Doctors
Health Care Assistants
Health Technicians
Informal caregivers
Students

Everyone involved in the therapeutic process!

The Rights to Life and Health

The duty of information and the duty of secrecy

When can professional secrecy be broken?

In situation imposed by law
Authorized by the Clarified Interested Party
Requested by legal representatives
For a just cause

Introduction

Module	End of Life Care
Sub-module	Ethics, Religion, Culture and Spirituality
Lesson nr.	#3
Duration (minutes)	
Date	To be defined

Lesson Outcomes

Identifying the ethical and legal aspects and implications of caregivers action in end of life care

Topics

Bioethics

1. General questions regarding bioethics
2. Withholding and withdrawing treatment
3. Persistent Vegetative State
4. Euthanasia

INDIVIDUAL AND INTEGRATED CARE PLAN

… aims at the process through which it is described and operated, in an easily accessible and intelligible way, how treatments are articulated with the support of the patient and family.

It is the product of the convergence between the goals of care and the best way to operationalize them in space and time, knowing the interlocutors and the inherent responsibilities.

Termos e Conceitos na Relação Clínica
Words and Concepts in Clinical Relation
António H. Carneiro[1], Rui Carneiro[1], Catarina Simões[2]

Medicina Interna, revista da SPMI, VOL.25 | N.º 3 | JUL/SET 2018

INDIVIDUAL AND INTEGRATED CARE PLAN

Uses anticipatory care principles (crisis plan)

Planning is centered on the patient as an individual, based on their intrinsic value as a human being with historical and unrepeatable relevance, reflects their preferences and diversity and projects into the future (short or long term), the needs anticipated, taken care of and addressed by a team interdisciplinary.

Termos e Conceitos na Relação Clínica
Words and Concepts in Clinical Relation
António H. Carneiro[1], Rui Carneiro[1], Catarina Simões[2]

Medicina Interna, revista da SPMI, VOL.25 | N.º 3 | JUL/SET 2018

INDIVIDUAL AND INTEGRATED CARE PLAN

The treatment and support implemented are flexible, require regular reassessment of effectiveness / effectiveness and adjust to the change in the patient / family's state, sensitive to new needs.

It embodies the model of Follow-up and Support Medicine.In this understanding, the PIIC is an obstacle to therapeutic obstinacy and an essential instrument to optimize patient-centered care and triangulated in the relational value of request, solicitude and empathy.

Termos e Conceitos na Relação Clínica
Words and Concepts in Clinical Relation

António H. Carneiro[1], Rui Carneiro[1], Catarina Simões[2]

Medicina Interna, revista da SPMI, VOL.25 | N.º 3 | JUL/SET 2018

INDIVIDUAL AND INTEGRATED CARE PLAN

Decision Making*:*

Difficult
Difficulty added when:

Incompetent patient / vulnerable adult

Evolution of the disease is little-known

INDIVIDUAL AND INTEGRATED CARE PLAN

Decision Making / *Ethical Deliberation Process*:

Deliberation: discussion of values
Deliberate = make prudent decisions
Prudence = end of the act of deliberation, finding intermediate courses that you consider great
Deliberation - rational analysis of situations (concrete circumstances and foreseeable consequences) to find an optimal, less bad solution, choosing for possible courses of action

Barbosa, 2010

Decision Making / *Ethical Deliberation Process:*

Deliberation = procedure that seeks to enrich the analysis in order to increase prudence in decision making

Purpose = to improve the quality of clinical decision making, correct assessment of values, optimizing conflict resolution of values (intermediate courses that try to integrate the greatest number of conflicting values)

Barbosa, 2010

Ethical Deliberation Process (Diego Gracia):

Careful and reflective analysis of the main factors involved

It intends to analyze the problems in all their complexity:

Principles and values involved
Circumstances
Consequences
Analyze all courses of action
Different result of dilemmas…

Ethical Deliberation Process (Diego Gracia):

Listen attentively

Effort to understand the situation

Analysis of implied values

Rational arguing about courses of action

Legal context

Ethical Deliberation Process (Diego Gracia):

Food and hydration

Conspiracy of silence

Death caused at the request of the self - Euthanasia

Ethical Deliberation Process (Diego Gracia):

Food and hydration

"Eating and drinking are essential to life“
Very delicate theme
Total loss of the oral route…not always
Importance of mouth care
Ensure that the patient is comfortable (with or without artificial feeding)

Ethical Deliberation Process

Silence Conspiracy

We are faced with a Conspiracy of Silence situation when one or several members of a group, in this case the family, block communication

There is a communication break

Ethical Deliberation Process

Silence Conspiracy

Signs that can predict a future Conspiracy of Silence situation:

Very close patient/family relationship,

Dependent

Overly protective attitude towards family members

When family infantilizes the patient

Ethical Deliberation Process

Silence Conspiracy

Signs that can predict a future Conspiracy of Silence situation:

Family with little dialogue, little sharing of feelings and tendency to prevent the expression of emotions

Overuse of tranquility

Attempt to systematically prevent the patient from talking, especially about their concerns and fears

Ethical Deliberation Process

Silence Conspiracy

How to act?

Assure the family that they know the patient better than anyone else.

Try to find the reasons why the family does not want the patient to be informed

Helping the family to understand and identify the "costs" of not informing the patient about their situation

Ask to speak with the patient alone and ensure that the objective is to determine what they want to know and not to force them to know the reality of the situation if they do not want to.

Identifying signs of emotional distress in the family and/or patient

Ethical Deliberation Process

Euthanasia – ethical issues

Palliative Care promotion - preventing and reducing suffering and hopelessness at the end of life

People are afraid of unnecessary prolonging of life

Risks of legalizing euthanasia

Pressure on the vulnerable person,

Barrier to the development of CP

Opportunity to other social groups

Acceptance of the act of killing

Euthanasia

Kill on demand, the doctor intentionally kills the person by administering drugs upon request (voluntary) by a competent person. (EAPC)

Assisted Suicide

The doctor intentionally helps the person to commit suicide by providing drugs for self-administration, upon request (voluntary) from a competent person. (EAPC)

What happens in the world on this subject?

Introduction

Module	End of Life Care
Sub-module	Ethics, Religion, Culture and Spirituality
Lesson nr.	#4
Duration (minutes)	
Date	To be defined

Lesson Outcomes

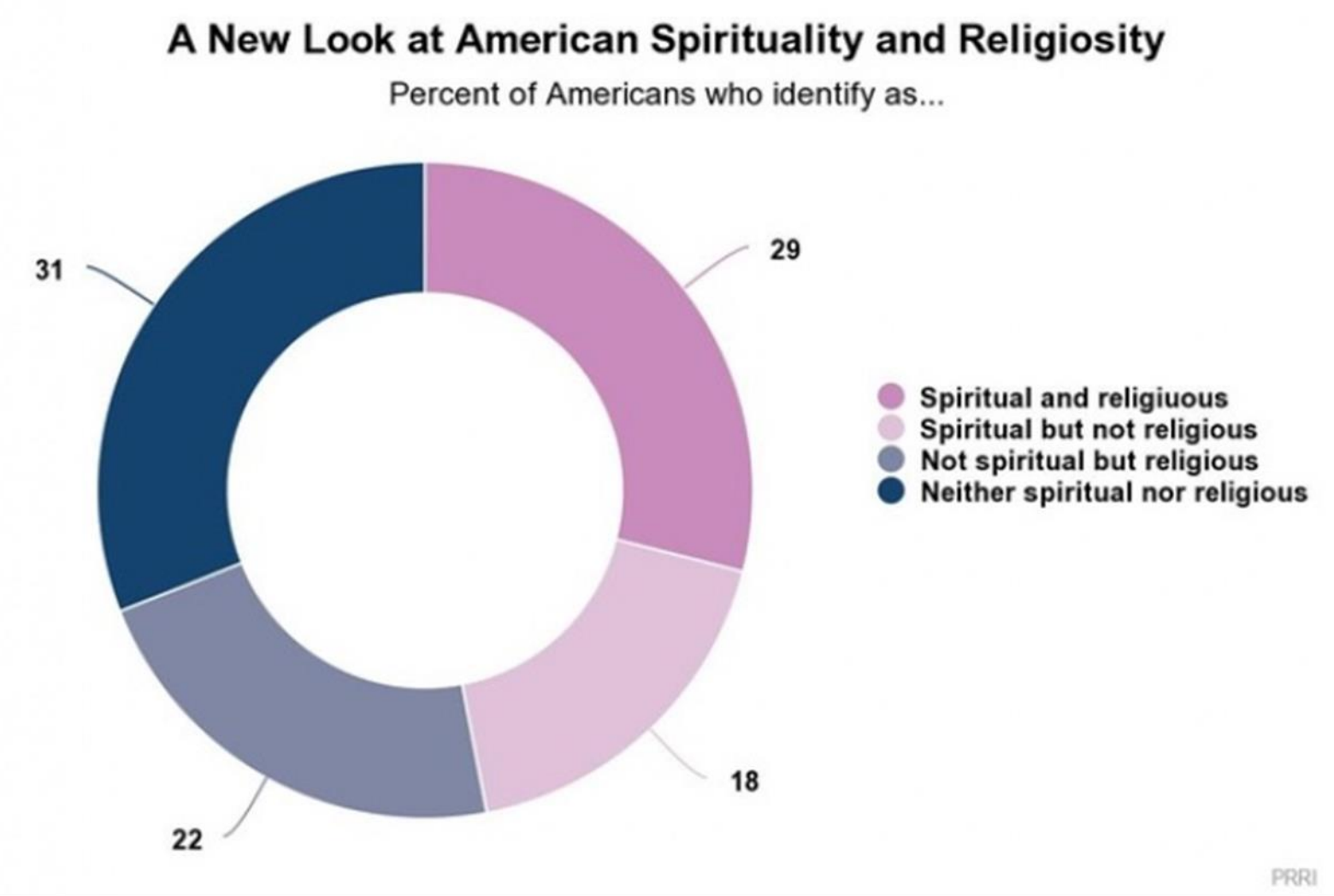
Understanding spirituality as a key aspect of caregiving

Topics

Spirituality

Spirituality as Part of Caregiving

Meaning and means of coping



Moses (2017). Public Religion Research Institute and Florida State University

NURSING THEORY AND CONCEPT DEVELOPMENT OR ANALYSIS

Towards clarification of the meaning of spirituality

Ruth A. Tanyi BSJ RN BSN MSN FNPCandidate
Registered Nurse, Orthopedics and Spine, Regions Hospital, Saint Paul, Minnesota, and Abbott Northwestern Hospital Minneapolis, Minnesota, USA

Submitted for publication 20 July 2001
Accepted for publication 31 May 2002

Withers et al., Int J Nurs Clin Pract 2017, 4: 234
https://doi.org/10.15344/2394-4978/2017/234

International Journal of Nursing & Clinical Practices
Concept Analysis Open Access

Spirituality: Concept Analysis

Alexandrea Withers[1], Kimberly Zuniga[1] and Sharon L. Van Sell[2*]
[1]*Graduate Nursing Program, Texas Woman's University, USA*
[2]*Professor, The Houston J. and Florence A. Doswell College of Nursing, Texas Woman's University, USA*

Abstract

Spirituality, a highly complex concept, was a very controversial subject. Since the human being served as a spiritual being, spirituality was present in all levels of care. The authors conducted a concept analysis using Walker and Avant's methodology to analyze the concept of spirituality to allow the reader to understand better how spirituality affected the advance practice nurse (APN). The authors' extensive dictionary search and literature review of spirituality led to recurring and defining attributes, antecedents, and consequences. The attributes of spirituality included a human being, belief, enlightenment, and a decision. The antecedents of spirituality were a higher being, self-reflection, spiritual awareness, and desire. The consequences of spirituality were a higher level of care, resilience, transcendence, open-mindedness, burnout, and persecution. A model, a borderline, and a contrary case demonstrated the influence of spirituality for the APN. The authors discussed spirituality's impact on advanced practice nursing and created a model for the concept of spirituality.

Publication History:

Received: January 27, 2017
Accepted: April 10, 2017
Published: April 12, 2017

Keywords:

Advance practice nurse, Care, Concept analysis, Spirituality

Table 1 Definitions of spirit

Spirit
The animating or vital principle in man...
The breath of life...
Incorporeal or immaterial being...
The soul of a person...
The disembodied soul of a deceased person...
A supernatural, incorporate, rational being or personality usually regarded as imperceptible at ordinary times to the human senses...
The spirit of God...
The disposition, feeling, or frame of mind with which something is done...
A person considered in relation to his character or disposition...
The prevailing tone or tendency of a particular period of time...
The immaterial intelligent or sentiment element or part of a person...
The emotional part of a man...
Liveliness, vivacity, or animation in persons...
Vital power or energy...
Vigour or animation of mind...
Strong alcoholic liquor...
To infuse spirit, life, ardour, or energy into a person...
To invest with a spirit or animating principle...
To instigate or promote...

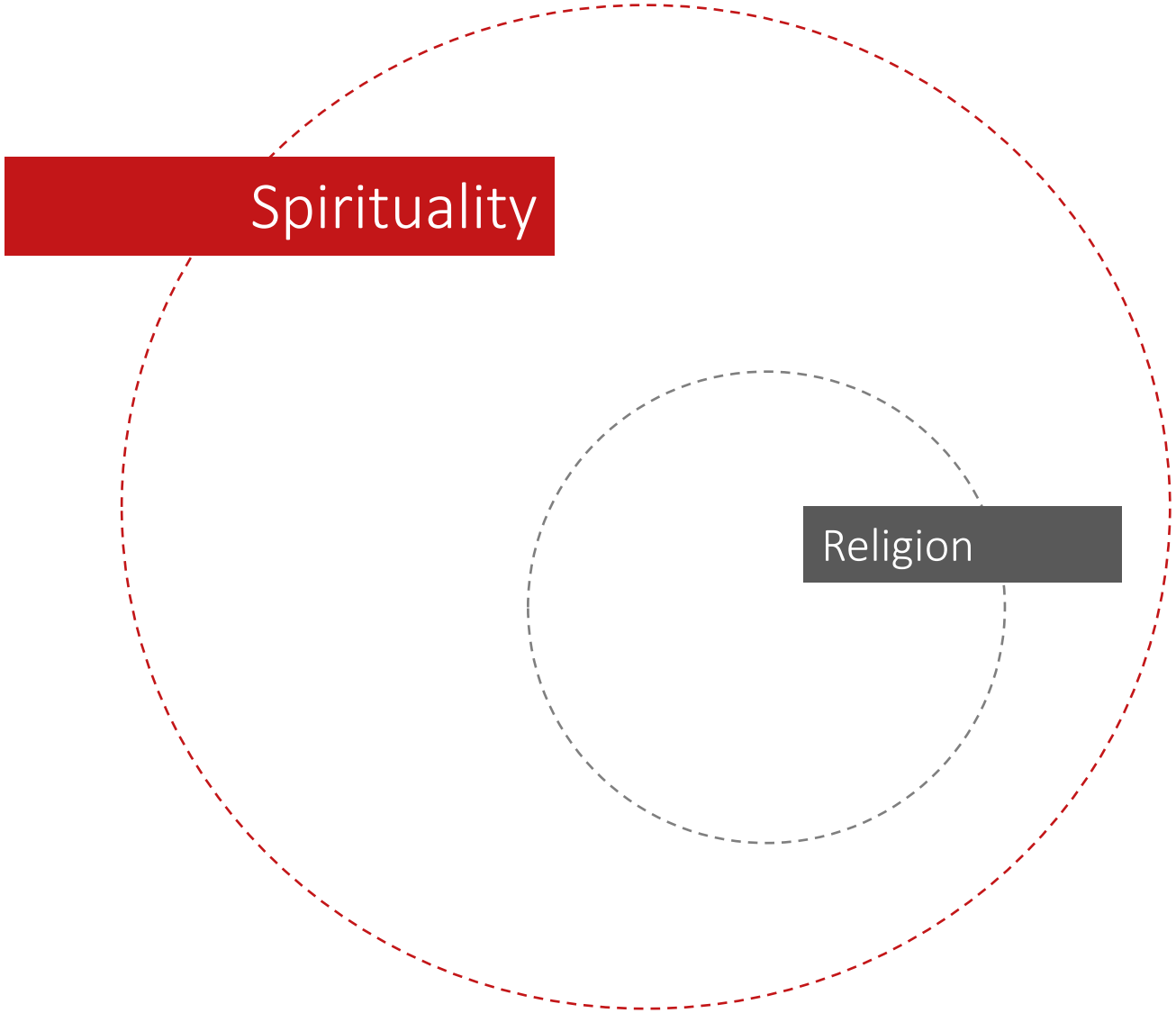
Source: The Oxford English Dictionary (2nd ed.) (1989, pp. 251–255).

Table 3 Definitions of spirituality

Spirituality
The body of spiritual or ecclesiastical persons; That which has a spiritual character; The quality or condition of being spiritual; An immaterial or incorporeal thing or substance; The fact or condition of being spirit or of consisting of an incorporeal essence.

Source: The Oxford English Dictionary, 2nd edn., (1989, pp. 259).

MEANING
PURPOSE
RELATION


Spirituality
Religion

GIVINGCARE
Empowering Caregivers

SPIRITUAL CARE?

1st skill

Reflect and Open your mind

PERGAMON

Available online at www.sciencedirect.com

SCIENCE DIRECT®

International Journal of Nursing Studies 41 (2004) 151–161

INTERNATIONAL JOURNAL OF NURSING STUDIES

www.elsevier.com/locate/ijnurstu

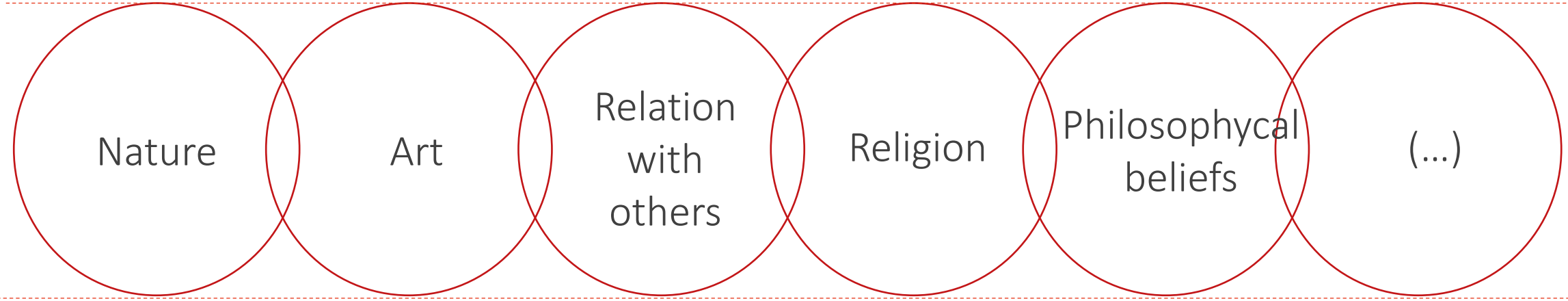
The language of spirituality: an emerging taxonomy

Wilfred McSherry[a,*], Keith Cash[b]

[a] *School of Nursing, Social Work, and Applied Health Studies, The University of Hull, Milner Hall Room M208, Cottingham Road, Hull HU6 7RX, UK*

[b] *Centre for the Analysis of Nursing Practice, Leeds Metropolitan University, Calverley Street, Leeds LS1 3HE, UK*

Received 28 November 2002; received in revised form 6 June 2003; accepted 9 June 2003


Nature
Art
Relation with others
Religion
Philosophycal beliefs
(…)

Placing Religion and Spirituality in End-of-Life Care

Timothy P. Daaleman, DO

Larry VandeCreek, DMin

teraction between religious belief and attitudes toward death has produced controversial results that generally do not support this assumption.[8]

GIVINGCARE
Empowering Caregivers

EXERCISE

Table 2. Attributes Rated as Important by More Than 70% of All Participants

Attributes	Participants Who Agreed That Attribute Is Very Important at End of Life, %			
	Patients (n = 340)	Bereaved Family Members (n = 332)	Physicians (n = 361)	Other Care Providers (n = 429)
Be kept clean	99	99	99	99
Name a decision maker	98	98	98	99
Have a nurse with whom one feels comfortable	97	98	91	98
Know what to expect about one's physical condition	96	93	88	94
Have someone who will listen	95	98	99	99
Maintain one's dignity	95	98	99	99
Trust one's physician	94	97	99	97
Have financial affairs in order	94	94	91	90
Be free of pain	93	95	99	97
Maintain sense of humor	93	87	79	85
Say goodbye to important people	90	92	95	99
Be free of shortness of breath	90	87	93	87
Be free of anxiety	90	91	90	90
Have physician with whom one can discuss fears	90	91	94	93
Have physician who knows one as a whole person	88	92	92	95
Resolve unfinished business with family or friends	86	85	87	97
Have physical touch	86	94	90	97
Know that one's physician is comfortable talking about death and dying	86	85	93	97
Share time with close friends	85	91	91	96
Believe family is prepared for one's death	85	88	83	90
Feel prepared to die	84	81	79	87
Presence of family	81	95	95	96
Treatment preferences in writing	81	85	73	90
Not die alone	75	93	84	88
Remember personal accomplishments	74	80	78	91
Receive care from personal physician	73	77	82	82

ORIGINAL CONTRIBUTION

Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers

Karen E. Steinhauser, PhD
Nicholas A. Christakis, MD, PhD, MPH
Elizabeth C. Clipp, PhD, MS, RN
Maya McNeilly, PhD
Lauren McIntyre, PhD
James A. Tulsky, MD

Context A clear understanding of what patients, families, and health care practitioners view as important at the end of life is integral to the success of improving care of dying patients. Empirical evidence defining such factors, however, is lacking.

Objective To determine the factors considered important at the end of life by patients, their families, physicians, and other care providers.

Design and Setting Cross-sectional, stratified random national survey conducted in March-August 1999.

http://jnep.sciedupress.com Journal of Nursing Education and Practice 2017, Vol. 7, No. 8

ORIGINAL RESEARCH

A qualitative study about palliative care patients' experiences of comfort: Implications for nursing diagnosis and interventions

Sara Pinto *[1,2], Sílvia Caldeira[3], José Carlos Martins[4,5]

[1] Instituto de Ciências Biomédicas Abel Salazar, University of Porto, Porto, Portugal
[2] Centro Hospitalar São João, Porto, Portugal
[3] Universidade Católica Portuguesa - Instituto de Ciências da Saúde – Lisboa, Portugal
[4] Medical-Surgical Unit, Escola Superior de Enfermagem de Coimbra, Portugal
[5] Department of Human Sciences and Health, Faculdade de Medicina da Universidade do Porto, Porto, Portugal

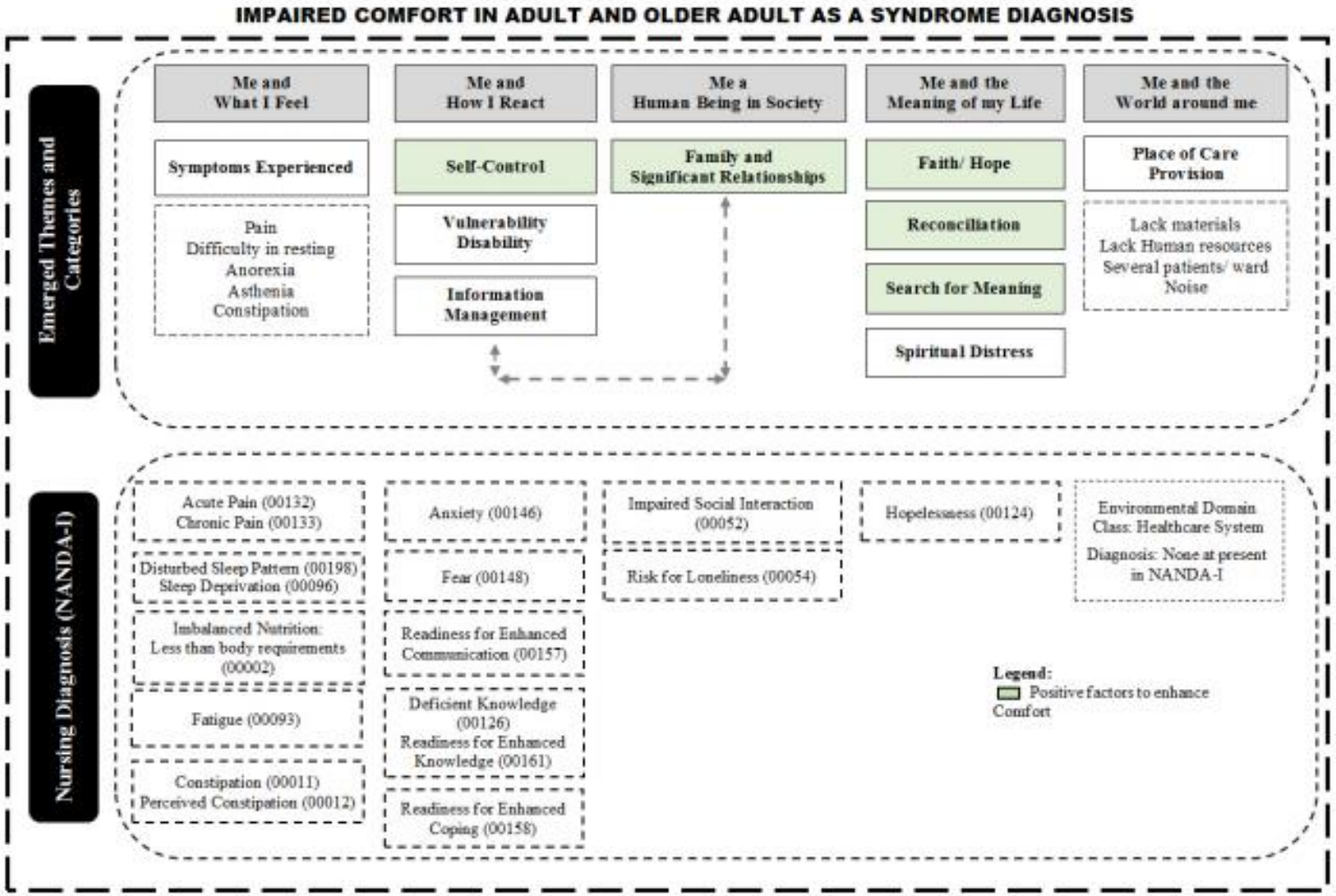


Figure 1. Impaired Comfort as a Syndrome Diagnosis: Themes, Categories and Nursing Diagnosis (Defining Characteristics)

JOURNAL OF PALLIATIVE MEDICINE
Volume 17, Number 5, 2014
© Mary Ann Liebert, Inc.
DOI: 10.1089/jpm.2013.0569

Palliative Care Reviews

Feature Editor: Vyjeyanthi S. Periyakoil

Evaluation of Spiritual Needs of Patients with Advanced Cancer in a Palliative Care Unit

Aleix Vilalta, PhD,[1] Joan Valls, MSc, PhD,[2] Josep Porta, MD, PhD,[3] and Juan Viñas, MD, PhD[4]

TABLE 2. DESCRIPTIVE STATISTICS FOR THE SPIRITUAL NEEDS ASSESSED

Spiritual needs	*Mean ± SD*[a]
To be recognized as a person until the end of life	8.6 ± 1.3
The need for truth	8.3 ± 2.7
To reinterpret life	6.2 ± 1.9
To look for a meaning to existence	5.7 ± 2.5
The need for hope	5.7 ± 3.5
To see life beyond the individual	5.2 ± 2.5
The need for religious expression	4.9 ± 2.5
The need for continuity and an afterlife	4.0 ± 2.0
The need for freedom and to be free	3.8 ± 3.4
To be free from blame and to forgive others	1.5 ± 2.0
To be reconciled and to feel forgiven	1.4 ± 2.2

[a]Original values range, 0–10.
SD, standard deviation.

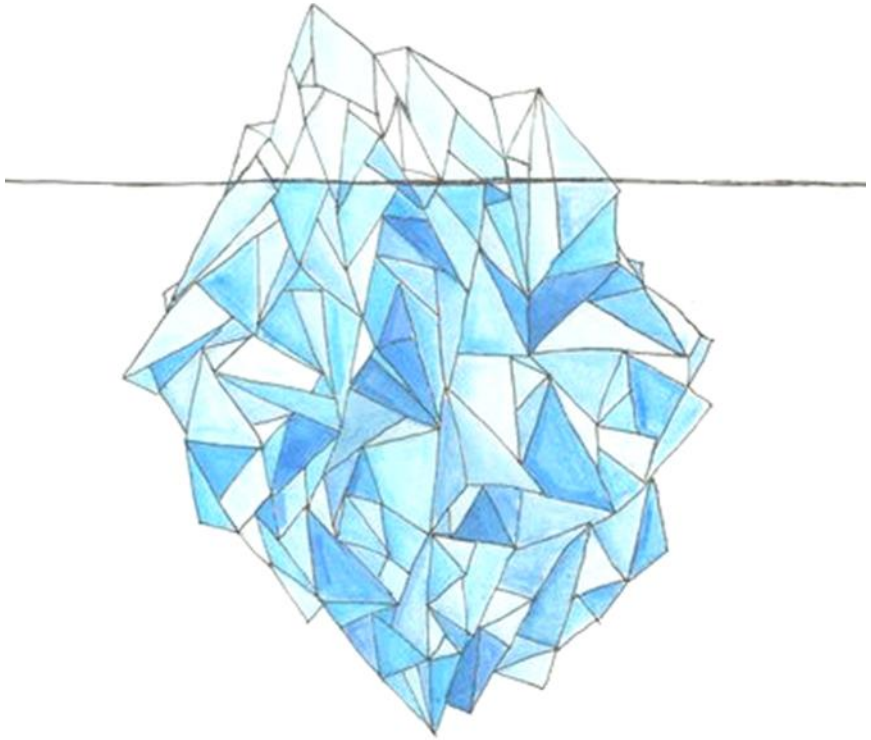
GIVINGCARE
Empowering Caregivers

SPIRITUAL NEEDS

Commentary

Bringing 'forgiveness' into the International Classification for Nursing Practice

Sílvia Caldeira, Maria Aparício, Sara Pinto and Rita Santos Silva



ASSESSMENT

- FICA
- SPIRIT


San Camilo
Humanizar

GIVINGCARE
Empowering Caregivers

Thank you!

Teachers's name

Teachers e-mail

Date of the session