Integration spiritual care in health care: lessons from the Ars Moriendi tradition

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1. A first orientation
God in the Netherlands

“A large majority of the Dutch (82%) never or almost never visits a church and only 14% of them believes in a personal God. For many Dutch people Christianity has become an unknown or exotic world.”
Professional: only the functional is meaningful

- Diagnostic reduction
- Reframing en ‘disowning’
- Control in order to treat
- Excusion of unwanted connotations
Societal: the homo oeconomicus in charge

- **self-actualization**
  - morality, creativity, spontaneity, acceptance, experience purpose, meaning and inner potential

- **self-esteem**
  - confidence, achievement, respect of others, the need to be a unique individual

- **love and belonging**
  - friendship, family, intimacy, sense of connection

- **safety and security**
  - health, employment, property, family and social stability

- **physiological needs**
  - breathing, food, water, shelter, clothing, sleep
Cultural: spirituality is a private affair

*Homo clausus*

... contains the expectation that each human life should have a meaning for itself alone. If one cannot find that meaning one complains about the meaningless of one’s existence. (...) Meaning is a *social* category.
Spiritual care in health care: where are we now?

- Workable definitions (US, EAPC, ICC)
- Growing networks: EAPC, GNSAH
- Good overviews and literature reviews
- Growing amount of publications
- Increased attention on international conferences

But: hardly evidence-based research
Global Network for Spirituality and Health
EAPC Taskforce on Spiritual Care in Palliative Care

The EAPC Taskforce on Spiritual Care in Palliative Care will help developing spiritual care in an European context. We are deeply convinced that we can learn much from each other and achieve great things in an open minded atmosphere. We intend to contribute using experience in discussing and building bridges where delicate end-of-life issues in secular and/or multi-cultural society divide people.

Latest news: At the recent research congress in Dublin, June 2016, the Implementation subgroup of the Spiritual Care Taskforce presented the sociodemographic data from the survey they conducted in April-May 2016 which explored palliative care professionals’ understandings of spiritual care. Read the presentation here

Read the blog: Spiritual care in palliative care: Lost case

Countries that participate in the Taskforce Spiritual Care

Countries that participate in the EAPC Taskforce Spiritual Care

Member Countries: 35
EAPC Working Definition 2010

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
2. Value based considerations and attitudes (ethics)
3. Religious considerations and foundations
2. Developing Spiritual care as an interdisciplinary field of studies
1. The gap between paradigms

- Randomized Controlled Trial
- 200 years of literature: 5 studies selected, insufficient evidence
- Effectiveness *versus* meaning
Action theory

To care =

- To produce, make
  (goal oriented, effective, efficient)
- To act
  (freedom, originality, uncertainty)
- To express
  (meaning, connectedness, value)
Explaining *versus* understanding

- (para) Medical sciences
- Social sciences
- Arts and Humanities

<table>
<thead>
<tr>
<th>Causality</th>
<th>Effectiveness</th>
<th>Efficiency</th>
<th>Quantitative</th>
<th>Univocity</th>
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<th>Meaning</th>
<th>Value</th>
<th>Expression</th>
<th>Qualitative</th>
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2. The lack of a connecting framework


Cobb et al (2012)

- Spirituality is seen as “a feature and capacity of the system as a whole in which people express and experience spirituality individually, through others and through ‘objects’ that effect and mediate spirituality in the world.”

- “The model therefore aims to represent the spirituality of patients and provide an adequate account of how it relates to the internal and external reality of the person including mental phenomena (eg, beliefs), personal and social experiences (eg, illness), and practices and behaviours (eg, meditation).”
3. The gap between disciplines

<table>
<thead>
<tr>
<th>Medicine</th>
<th>Humanities/ Chaplaincy</th>
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<tbody>
<tr>
<td>• Good opportunities for research funding</td>
<td>• Problematic research funding</td>
</tr>
<tr>
<td>• Large scale – human resources, infrastructure (KNMG: 50.000)</td>
<td>• Small scale – human resources (VGVZ: 1.000)</td>
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<tr>
<td>• Strong research tradition</td>
<td>• Underdeveloped tradition</td>
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<tr>
<td>• Research facilities and journals</td>
<td>• Lack of journals</td>
</tr>
<tr>
<td>• Strong position in society</td>
<td>• Marginal position in society</td>
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<td>(urgency, recognition)</td>
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<tr>
<td>• Dominant position in science</td>
<td>• Marginal position in science (not ‘science’)</td>
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<tr>
<td>(‘scientific’)</td>
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3. The gap between disciplines

Who are the delegates?

- 2012 Trondheim
- 2009 Vienna
- 2007 Budapest
- 2006 Venice
- 2004 Stresa
- 1992 Brussels
- 1990 Paris

- Chaplains
- Nurses
- Physicians
4. The gap between theory and practice

- Research into spiritual care from an academic perspective and theoretical interest
- Focus on quantitative research, psychometric tools, outcomes, generalizability
- Search for evidence based knowledge and tools (instruments for screening, etc)

- Practice of spiritual care from a caring perspective and practical interest
- Focus on qualitative research (if so), reflection on one’s unique setting and practice
- Search for understanding the phenomenon and human & professional qualities needed to address this dimension
5. The gap between ‘church’ and society

• Rise of viewing ‘spirituality’ as something separated from (non)religious traditions
• Separation between chaplains and (non)religious institutions (‘independent chaplaincy’)
• Loss of content (traditions, rites, rituals, metaphors, myths, narratives, etc)
• Separation from traditional networks
3. Retrieving the Ars Moriendi tradition
Rotterdam, two palliative care units in two nursing homes:

Antonius Binnenweg

Antonius IJsselmonde
An old lady

‘Space’ in the care giver

• listening: with an open mind
• answering: returning the question ‘opened up’

‘Space’ in the patient

• experience and emotions
• opening up new perspectives
Inner space

_(metaphor)_

A state of mind that enables one to be aware of one’s actual thoughts and feelings without being overthrown or swept away by them.
Inner space

- Simple and easy to recognize (body)
- Formal (≠ inner peace)
- Open to different spiritual traditions
- Process oriented
- Also addressing the caregiver
- At the crossroads of psychology, spirituality, ethics

Opening up and discovering new horizons
Inner space

... of the care-giver

... of the patient

... of the relatives
Five choices

1) Loss of faith
2) Despair
3) Impatience
4) Complacency
5) Avarice

1) Faith
2) Hope
3) Patience
4) Humility
5) Love
Who am I and what do I really want?

How do I deal with suffering?

How can I say goodbye?

How do I look back on my life?

What can I hope for?
Doing - undergoing

Holding on - letting go

Remembering - forgetting

Knowing - believing

Oneself - the other

Inner space

Relations

Guilt

Suffering

Hope

Autonomy
1. Autonomy: oneself – the other

P. Ricoeur
1. Autonomy: **oneself** – the other

- Strong sense of I-centered autonomy
- Neoliberal climate
- Individualism
- Less social connections
- Little to no respect for authorities (Church, politicians, physicians)
- Maximum (negative) freedom of citizens
2. Suffering: doing – undergoing

- activism
- apathy

- physical
- spiritual
- psycho-
- social
2. Suffering: **doing** – undergoing

- Activism
- Control
- Transparency
- Medical Specialties
- Technological revolution
- Low tolerance for suffering
- Control over life, control over death
3. Relations: holding on – letting go

- body, image of self
- possessions position
- loved ones
3. Relations: **holding on** – letting go

- Life expectancy: women 82+ years, men 77.5 years
- Conservation of youth
- Conservation of the good things in life
- No familiarity with decline and dying
- Holding on or throwing away
- Problems with loss (letting go)
- Replacement instead of repair
- Materialism
4. Guilt: remembering – forgetting

Holding on to the good (but no fixation)  
Letting go of the bad (but no denial)

feeling guilty  
guilt
4. Guilt: remembering – forgetting

- Remembering (guilt) does not bring much
- Guilt is not ‘healthy’: let go of morality
- To live is to make mistakes: forgetting, self-development
- Authenticity more important than responsibility
- Subjectivism: ‘my truth versus your truth’
- Happiness as ‘feeling good or being lucky’
- Pragmatism
5. Hope: knowing – believing

- Knowing
  - Agnosticism
    - No
  - Openness
    - ?

- Believing
  - Subjective
  - Objective
    - (‘knowing’)
5. Hope: **knowing** – believing

- Disenchantment of the world: rituals, symbols, metaphors
- Empirical foundation of all knowledge: measuring = knowing
- ‘What’s the *use* of religion?’
- Subjectivation of the spiritual
- Privatization of belief

“In God we trust. All others must bring data”.

W. Edwards Deming
Doing - undergoing

Inner space

Holding on - letting go

Remembering - forgetting

Knowing - believing

Oneself - the other

Autonomy

Relations

Suffering

Guilt

Hope
Five ways of using the model

• **Framework for reflection**: patients and families
• **Training**: all healthcare professionals
• **Spiritual history taking**: health care professionals with an education in spiritual care
• **Spiritual assessment**: chaplains
• **Communication**: patient files and transfer
Ars moriendi as a cultural challenge