Spiritual Care in Palliative Care

Developments in Europe

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Carlo Leget PhD
Tilburg University, Tilburg
University of Humanistic Studies, Utrecht
Board member & Chair Taskforce Spiritual Care EAPC
EAPC Definition of palliative care

• Palliative care is the active, total care of the patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of social, psychological and spiritual problems is paramount.

• Palliative care is interdisciplinary in its approach and encompasses the patient, the family and the community in its scope. In a sense, palliative care is to offer the most basic concept of care – that of providing for the needs of the patient wherever he or she is cared for, either at home or in the hospital.

• Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death.
The aim of the **European Association for Palliative Care** (1988) is to promote palliative care in Europe and to act as a focus for all of those who work, or have an interest, in the field of palliative care at the scientific, clinical and social levels.
Setting up a taskforce

**Importance:** building a network, working together in research and exchange of information

- **May 2009** Vienna: plans for a taskforce
- **October 2010** Werkhoven (NL): small conference 14 people, 8 countries
- **May 2011** Lisbon: 34 people, 14 countries
**EAPC taskforce on Spiritual Care in Palliative Care**

Available in a few weeks: the first European questionnaire for setting research priorities in spiritual care in palliative care. Please let us know your view and help us develop this area by responding to this initiative.

**Summary**

The WHO definition of palliative care includes taking care of the spiritual (care) needs of patients. It is essential that the spiritual (care) needs of patients, family and carers in all settings are adequately met. There is much discussion about the definition of spirituality. Based on the 2009 Consensus Conference in the US, at the invited conference in October 2010 this taskforce has agreed upon the following working definition and comment:

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 regarding 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 relation to oneself, family, friends, work, things nature, art and culture, ethics and morals, and life itself)
3. Religious considerations and foundations (belief, beliefs and practices, the relationship with God or the ultimate)

**Aims & objectives**

The mission of the Taskforce is to encourage all members of the EAPC to support spiritual care in palliative care through:

1. Recognition
2. Research
3. Education
4. Implementation
5. Funding/resources

**Short term aims and objectives: 2011-2013**

1. Recognition
   - To promote representation of the SC dimension in the EAPC board
   - To write articles about SC and aim to have these accepted in leading journals
   - To encourage national and international meetings on spiritual care in palliative care (ISCPC)
Lucy Selman, co-coordinator (UK)
Ian Stirling, co-coordinator (UK)
Hanne Bess Boelsbjerg (DK)
Christian Busch (DK)
Katrien Cornette (BE)
Birgit Holritz-Rasmussen (S)
Sigrid Helene Kjørven Haug (N)
Urska Lunder (Slov)
Tamari Rukhadze (Georg)
Peter Speck (UK)
Mieke Vermandere (BE)
Urs Winter-Pfändler (Swi)
Teresa Young (UK)
Education

Traugott Roser, co-coordinator (D)
Andrew Goodhead, co-coordinator (UK)
Catherine Baldry (UK)
Benito Enric (Spain)
Karen Groves (UK)
Anne Hirsch (N)
Steve Nolan (UK)
Ingebrigt Røen (N)
Philip Saltmarsh (UK)
Sandra Schaap (NL)
Tanja Stiehl (D)
Etje Verhagen (NL)
Ruurd van de Water (NL)
Implementation

Laura Campanello, co-coordinator (It)
Cinzia Martini, co-coordinator (It)
Maria Teresa Garçia- Baquero Merino (Spain)
Joep van de Geer (NL)
Piotr Krakowiak (P)
Carlo Leget (NL)
Bella Vivat (UK)
Marijke Wulp (NL)
Setting up a taskforce

- Belgium
- Germany
- Italy
- Netherlands
- Norway
- UK
- Switzerland
- Georgia

Making an inventory: 10 questions
1. What does the spiritual/religious map of your country look like, and what specific cultural particularities should be taken to heart with regard to SCPC?

1. Division: Catholic versus free thinkers (B)
2. Growing number of Muslims and patchwork spirituality (Ger)
3. Majority of Catholics (It)
4. Those who do not belong to any denomination (It)
5. Church declining, Muslims growing, personal systems (NL)
6. Religion as a private subject (Nor)
7. No common language about spirituality (UK)
8. Spiritual care integrated in NHS (Scot)
9. Post-Christian, financially threatened (UK)
10. Christianity dominant: RC & Swiss reformed (Swit)
2. What are the main problems and obstacles for further development of SCPC in your country?

Conceptual

1. Struggle for definition (B, UK, UK, Scot)
2. Lack of practical tools (UK)

Organizational

1. Availability competent spiritual caregivers (B, It, Scot)
2. (Coordinated) funding (B, Ger, NL, UK, Scot)
3. Spiritual care at home (B, NL, Scot)
2. What are the main problems and obstacles for further development of SCPC in your country?

Professional

1. Integration SC-givers in teams (B, NL, Nor, Scot)
2. Lack of sensitivity, understanding (It, NL, UK)
3. Marginal position of spiritual caregivers (NL, UK)
4. Education of health care professionals (UK)
5. Uncertainty of roles among professionals (UK)
6. Poor working relationships professional chaplaincy (Scot)
2. What are the main problems and obstacles for further development of SCPC in your country?

Political

1. Marketisation of public health service (Swit)
2. Legal basis healthcare chaplaincy (Swit)

Cultural/local

1. Association with death (B)
2. Communication (B, It)
3. Culture of action and control (B)
4. Dominance of one religion (It)
3. How is SCPC framed in your country in terms of definition, leading concepts, and what problems can be seen on this level?

„Spirituality can be understood as a person‘s inner attitude, the inner spirit or the personal search for meaning, that helps the person to deal with experiences in life and especially to face existential threats.‘

‘Spirituality concerns all that makes for an individual’s existence as a person with all that implies of our capacity as human beings for self transcendence, relationship, love desire and creativity, altruism, self sacrifice, faith and belief: it is the dynamic of integration towards a persons unique identity and integrity.’ (The Association of Hospice & Palliative Care Chaplains)
3. How is SCPC framed in your country in terms of definition, leading concepts, and what problems can be seen on this level?

Formal religion is a means of expressing an underlying spirituality, but spiritual belief, concerned with the search for the existential or ultimate meaning in life, is a broader concept and may not always be expressed in a religious way. It usually includes reference to a power other than self, often described as ‘God’, a ‘higher power’, or ‘forces of nature’. This power is generally seen to help a person to transcend immediate experience and to re-establish hope. (NICE 2004, 7.4, emphasis added)

‘Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred’ (Consensus VS)
3. How is SCPC framed in your country in terms of definition, leading concepts, and what problems can be seen on this level?

Accepted definitions within NHS Scotland (Guidelines, 2009):

- **Spiritual care** is usually given in one to one relationship, is completely person centred and makes no assumptions about personal conviction or life orientation.
- **Religious care** is given in the context of shared religious beliefs, values, liturgies and lifestyle of a faith community.
- Spiritual care is not necessarily religious. Religious care should always be spiritual.
3. How is SCPC framed in your country in terms of definition, leading concepts, and what problems can be seen on this level?

‘Human functioning in the field of philosophy of life, which also implies the questions of experiencing and giving meaning’. Spirituality is about all possible sources of inspiration – ranging from religious to everyday inspiration. For some people the most important is their emotional life (e.g. prayer, enjoying nature, literature, music, art) or activities (meditation, rituals or working for a good cause), others are more intellectually oriented (contemplation, study). Spirituality has impact on existence as a whole, is dynamic, and is more related with the source of a life attitude than a definable area of life. (Guideline, NL)
3. How is SCPC framed in your country in terms of definition, leading concepts, and what problems can be seen on this level?

The spiritual field has got three main dimensions.

1. Existential challenges, that is questions concerning identity, meaning, suffering and death, guilt and shame, freedom and responsibility, joy and courage.

2. Value based considerations and attitudes. Reflections on what is most important for each person, such as relations: Self, family, friends, work, things, nature, art and culture, moral standards and life itself.

3. Religious considerations and foundations. Faith or search for a higher power (Nor)
Some other questions:

4. Have there any instruments been developed for SCPC in your country?
5. How is the interdisciplinary collaboration of professionals in SCPC in your country?
6. Are there forms of national communication or cooperation within your country in the field of SCPC?
7. What research is done in your country on SCPC?
8. What are the disciplines involved and what strengths and weaknesses are to be reported?
9. What are the most urgent needs for further development of SCPC?

**Language and concepts**
- Consensus on a definition, conceptual attunement (B, NL)
- Spiritual is not the same as religious (Scot)
- Agreement on open understanding of spirituality (Ger, It)
- To have a broad common language (UK)
- Clarify the nature and scope of spiritual care (Scot)

**Improving care**
- Acceptance in the medical world (Ger)
- Implementation of SCPC in primary care (B)
- Integration in multidisciplinary teams (NL)
9. What are the most urgent needs for further development of SCPC?

**Training**

- Looking to the question whether SCPC has to be organized by ‘experts’ (pastors, moral counselors), or by specially trained health caregivers (formation and training being obliged for the whole multidisciplinary team) (B, UK)
- Mandatory aspect of all professional trainings (Ger, UK)
- Develop accessible trainings (Scot)
- Cooperation and further education for professionals (Nor, UK)
- More space at conferences (Nor)
9. What are the most urgent needs for further development of SCPC?

**Research**
- Demonstrating that spiritual care adds to the quality of care (UK)
- Promoting research done by chaplains and spiritual care specialists (NL, Scot)
- Interfacing research traditions (theology – medicine) (Ger, NL)
- Developing helpful instruments (It)

**Organization**
- Financial resources for research and implementation (B, Ger, Scot)
- Acknowledgement by government and funding (B)
- Having qualified people (It)
- Increasing interfaith dialogue (It)
- Interprofessional cooperation (Swit)
- Contribute to the challenge of the churches (Swit)
- Responding to demographic situations (Swit)
Question

How to proceed?
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
3. Religious considerations and foundations
An example from the Netherlands:

a Dutch guideline for physicians and nurses...
Question 1: Does spiritual care fit in a guideline?

No:
- Last open space in health care
- Impossible: qualities caregiver play a key role
- Bad idea to adjust to medical model

Yes:
- Is as old as the Ten Commandments
- Makes SC visible in the system (formal)
- Gives us a common text (content)
Question 2: what should the guideline be called?

- Meaning
- Existential questions
- Slow questions
- Philosophy of life
- Spirituality
- Inner life
- Faith
- Belief system
- Religion
**Question 3:** How can spirituality be defined?

**Do we need a definition?**
- Yes, defining helps focusing
- No,
  - Impossible: cf. the arguments of incompatibility etc.
  - Not desirable: phenomenological approach is better for fine-tuning
  - Not necessary: we can do without
What do we know of someone?

- Spirituality
- Religiosity
- ‘Church going’ (institutional)
Question 4: what is the position of spirituality?
Question 5: how concrete must the guideline be?

1. Attention to different layers of meaning
2. Dealing with questions to which there is no answer (presence)
3. Attention to the spiritual proces (from normal process to crisis)
“I cannot sit around the table with my children next Sunday”

<table>
<thead>
<tr>
<th>Physical</th>
<th>Description of reality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psycho-</td>
<td>Experience and emotions</td>
</tr>
<tr>
<td>Social</td>
<td>Connection with identity and life story</td>
</tr>
<tr>
<td>Spiritual</td>
<td>Sources, inspiration</td>
</tr>
</tbody>
</table>

Intimacy and connectedness
Question 6: what is the question (need, problem, desire, etc)?
Resonating with the unspeakable
Crisis
Accompaniment
Attention
**Question 9: how do the professions relate to each other?**

<table>
<thead>
<tr>
<th></th>
<th>Physician and nurse</th>
<th>Psychologist and social worker</th>
<th>Chaplain and spiritual counsellor</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary focus and framework of reference</strong></td>
<td><strong>Physical</strong></td>
<td><strong>Psychosocial</strong></td>
<td><strong>Spiritual</strong></td>
</tr>
<tr>
<td><strong>A Attention</strong></td>
<td>Listening, Supporting, Acknowledging, Exploring</td>
<td>Listening, Supporting, Acknowledging, Exploring</td>
<td>Listening, Supporting, Acknowledging, Exploring, Interpreting</td>
</tr>
<tr>
<td><strong>B Accompaniment</strong></td>
<td>Signaling, accompanying, referring, mapping</td>
<td>Acknowledging, Accompanying, Referring (\rightarrow) mapping</td>
<td>Acknowledging, Accompanying, (\leftarrow) referring, mapping, interpreting, valuing</td>
</tr>
<tr>
<td><strong>C Crisis intervention</strong></td>
<td>Signaling and referring</td>
<td>Acknowledging, Accompanying, treating, referring (\rightarrow)</td>
<td>Acknowledging, Accompanying, sometimes: treating (\leftarrow) referring, interpreting, valuing</td>
</tr>
</tbody>
</table>

Representing and connecting
Question 10: how concrete must the instruments be?
Tools: levels

1. Screening (feel, strength, speak)
   • Every caregiver, no training

2. Spiritual history
   • Every caregiver, short training

3. Spiritual assessment (interpretative framework)
   • Certified chaplain
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13th WORLD CONGRESS OF THE EUROPEAN ASSOCIATION FOR PALLIATIVE CARE

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