

# Spiritual care in palliative care: working towards an EAPC Task Force

Spiritual care is frequently overlooked in palliative care. A new Task Force will be launched at the next European Association for Palliative Care (EAPC) Congress to tackle the issue, as **Steve Nolan**, **Philip Saltmarsh** and **Carlo Leget** explain

The WHO defines palliative care as ‘an approach that improves the quality of life of patients and their families facing the problem[s] associated with life-threatening illness, through the prevention and relief of suffering’.<sup>1</sup> The definition specifies that palliative carers attempt to achieve this outcome through ‘early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’.<sup>1</sup> However, despite working with a definition that makes mention of the ‘spiritual’, despite the reports which state that many patients have spiritual needs,<sup>2-5</sup> and despite evidence that attending to such spiritual needs directly benefits patients,<sup>6-8</sup> many healthcare professionals would feel hard-pressed to describe their assessment and treatment of spiritual problems as ‘impeccable’.

The aspiration embodied by the WHO’s definition is contradicted by the evidence,

since healthcare professionals report difficulty in addressing their patients’ spiritual issues.<sup>9</sup> As one experienced British palliative nurse expresses it, ‘I ... sometimes find it difficult to offer spiritual help and support to my patients and their families. I am not sure what my role is, and fear invading a private part of their lives. I hold back and offer only the rudiments of spiritual care. I am relieved when I am told that they are either non-practising or have their own minister or priest. I have also made the mistake of thinking that religion and spiritual care are one and the same ... I understand that if my patients’ spiritual needs are not met, this can have an effect on their pain and suffering.’<sup>10</sup>

## Rationale and process

Recognising this disjunction between understanding and practice, a Dutch delegate at the 2009 European Association for Palliative Care (EAPC) Congress in Vienna proposed a task force on spiritual care in palliative care (SCPC). On 15–17 October 2010, in the Netherlands, 13 palliative care professionals from various backgrounds and eight countries (Belgium, England, Georgia, Germany, Italy, the Netherlands, Norway and Switzerland) attended a conference supported by the EAPC and by Agora (the Dutch national centre for palliative care), and funded by a grant from the Dutch Ministry of Health, Welfare and Sport (see Box 1). Facilitated by Reverend Joep van de Geer, Dr Carlo Leget and Marijke Wulp, the conference was aimed at establishing a basis upon which a future Task Force on SCPC might develop within the EAPC.

Before the conference, delegates were asked to complete a questionnaire intended to

## Key points

- The WHO definition of palliative care includes the treatment of spiritual problems; however, healthcare professionals report difficulty in meeting the spiritual needs of patients.
- To improve the spiritual care of patients at the end of life, a European Association for Palliative Care (EAPC) Task Force on spiritual care in palliative care (SCPC) has been proposed.
- Thirteen delegates from eight European countries held a conference in October 2010 to prepare the work of the future Task Force. They drafted a common definition of spirituality, key areas of work and a mission statement.
- The EAPC Task Force on SCPC will be launched at the 12th EAPC Congress in Lisbon in May 2011.

### Box 1. The delegates at the October 2010 conference in the Netherlands

- Belgium: Katrien Cornette, Mieke Vermanderen
- England: Steve Nolan, Philip Saltmarsh
- Germany: Traugott Roser
- Georgia: Tamari Rukhadze
- Italy: Laura Campanello, Arnaldo Pangrazzi
- The Netherlands: Joep van de Geer, Carlo Leget, Marijke Wulp
- Norway: Ingebrigt Røen
- Switzerland: Urs Winter-Pfändler

clarify the status of SCPC in each delegate's home country (see Box 2). The responses were circulated as preparatory reading.

The conference began with a review of the challenges to further developing SCPC. It became immediately apparent that the lack of an agreed definition was a difficulty that significantly affected all areas of discussion, including, for instance, competences, education, research and funding. Delegates also recognised that the specifics of any agreed definition would have political implications; in particular, its power to legitimise which forms of care may appropriately be regarded as 'spiritual'. Consequently, after careful consideration of how SCPC could be conceptualised, delegates began work in two subgroups: one set to work on defining spiritual care, while the other began to formulate a mission statement for the proposed Task Force.

### Towards a European-appropriate definition of spirituality

Europe is a diverse continent; accordingly, spiritual care therein manifests itself in many different forms. From the Orthodox east to the Roman Catholic south and across the increasingly secular north, regional patterns of religiosity are shaped according to the particularities of history and geography. For this reason, and despite the excellent work currently emerging in the USA from the National Consensus Project for Quality Palliative Care,<sup>11,12</sup> the conference thought it was important to begin to clarify a European-appropriate understanding of SCPC.

Notwithstanding the obvious cultural and historical differences, delegates considered the North American 'consensus definition of spirituality' to be an important development.



Despite the fact that spiritual needs are part of the WHO definition of palliative care, spiritual issues are still poorly addressed

### Box 2. Pre-conference questionnaire

#### The countries: background information and perception of the field and its problems

- What does the spiritual/religious map of your country look like, and what specific cultural particularities should be taken to heart with regard to spiritual care in palliative care (SCPC)?
- What are the main problems and obstacles for further development of SCPC in your country?

#### Concepts, models and instruments

- How is SCPC framed in your country in terms of its definition and leading concepts, and what problems can be seen on this level?
- Have any instruments been developed for SCPC in your country?

#### Organising palliative care

- How is the interdisciplinary collaboration of professionals in SCPC in your country?
- Are there forms of national communication or cooperation within your country in the field of SCPC?

#### Science and research

- What research is done in your country on SCPC?
- What disciplines are involved? What strengths and weaknesses are to be reported?

#### The road to Lisbon: plans and commitments

- What are the most urgent needs for the further development of SCPC?
- How can an international SCPC Task Force help, and what contributions are we willing to make?

It reads: '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'.<sup>12</sup>

### *Adjustments to the North American consensus definition*

It was thought that this definition could form a foundation from which delegates could begin to formulate a new European understanding. However, delegates agreed that several phrases needed adjusting for the European context.

- The phrase 'Spirituality is the aspect of humanity' implies that spirituality is but one more component of being human, rather than that which infuses every aspect of human experience – the 'more' in Aristotle's holism, where 'the whole is more than the sum of its parts'.<sup>13</sup>
- The phrase 'the way individuals seek' reinforces an overly individualistic approach to human spirituality, and glosses over the fact that the individual spirit is born into, and thrives within, a community.
- The phrase 'seek and express meaning and purpose' seems to limit spirituality to a concern with meaning-making, and leaves it open to being understood as a purely conscious process, whereas much meaning-making is unconscious.

Delegates were also keen to acknowledge the importance of including transcendence in any definition of spirituality, on the understanding that transcendence, while still a disputed technical term, conveys the sense that human beings experience themselves as more than just physical beings. The term is open to being interpreted as psychological transcendence, and/or as implying transcendence in a more traditionally religious sense.

### *Proposed European definition*

This is the definition of spirituality proposed by delegates: '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.'

### *Comments*

Delegates thought it was important to stress that 'spirituality' is difficult to define because of its multidimensional nature, and that the spiritual field encompasses:

- Existential questions (concerning, for example, identity, meaning, suffering and death, guilt and shame, reconciliation and forgiveness, freedom and responsibility, hope and despair, love and joy)
- Value-based considerations and attitudes (that is, the things most important to each person, such as relations to oneself, family, friends, work, things, nature, art and culture, ethics and morals, and life itself)
- Religious considerations and foundations (faith, beliefs and practices, one's relationship with God or the ultimate).

### **Key areas of work and mission statement**

Delegates acknowledged that the diversity in the understanding and provision of SCPC across the countries represented is a strength, as it creates a common pool of rich resources from which practitioners can draw. However, delegates also recognised that diversity presents a challenge to the goal of developing a common aim that might address the various needs of EAPC members. It is important, therefore, that the Task Force sets clear and achievable aims that embrace diversity, but that will also focus on promoting SCPC, without being distracted by the enormous range of possibilities the area presents.

Delegates identified and prioritised four key areas of work.

- Service improvement – the primary objective of the Task Force will be to improve care for terminally ill patients by improving the delivery of spiritual care. In view of the difficult present financial climate, the delegates recognise that service improvement needs to be achieved through the critical review of current resources.
- Strategic planning – this is essential to ensure equity of care across organisations and countries, regardless of where the terminally ill person is cared for.

### **Box 3. Proposed mission statement of the future European Association for Palliative Care (EAPC) Task Force on spiritual care in palliative care (SCPC)**

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. The mission of the Task Force is to encourage all

members of the EAPC to support spiritual care in palliative care through:

- Recognition
- Research
- Education
- Implementation
- Funding/resources



**Table 1. Impact–feasibility diagram with examples of objectives**

	Difficult to achieve	Moderately easy to achieve	Easy to achieve
High-impact	For example, working at building a collaborative interdisciplinary network	For example, developing a core content for teaching spirituality to non-chaplaincy professionals	For example, exchanging training programmes
Medium-impact	For example, activating national forums for chaplains and pastoral staff working in palliative care	For example, translating existing EU guidelines, standards and competence profiles for spiritual care in palliative care	For example, collecting narratives of spiritual care from different EU backgrounds, and publishing them for teaching and research purposes
Low-impact	Under development	Under development	Under development

- Research – this should demonstrate that the human and economic ‘added value’ of SCPC must underpin strategic planning, and must feed into training and professional development.
- Education – at all levels of an organisation, from volunteers and unqualified support staff to specialist spiritual care providers such as chaplains, education is key to improving spiritual care.

From this, delegates proposed the mission statement reproduced in Box 3.

### Concrete objectives

Delegates formulated a set of concrete objectives for developing SCPC in the future. Each delegate was invited to formulate three urgent objectives; all the objectives were then plotted on a diagram with the aim of organising them according to their impact and feasibility (see Table 1).

High-impact objectives that would be easy to achieve included:

- The exchange of successful training programmes
- A domain on the EAPC website for the circulation of information, guidelines, standards, educational programmes and research projects
- A European manifesto promoting the inclusion of a spiritual caregiver in multidisciplinary palliative care teams
- The clarification of indicators for SCPC quality management.

High-impact objectives that would be moderately easy or difficult to achieve focused on research, training and education (see Table 1). One of those objectives is the building of collaborative interdisciplinary networks that might foster greater understanding of each discipline’s contribution to the holistic care of patients.

### Launch at the Lisbon Congress

It is planned for the EAPC Task Force on SCPC to be launched at the 12th EAPC Congress in Lisbon on 18–22 May 2011. Those interested in taking part in the Task Force are invited to contact the authors of this paper.

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#### Declaration of interest

The authors declare that there is no conflict of interest.

#### References

1. World Health Organization. WHO Definition of Palliative Care, 2002. [www.who.int/cancer/palliative/definition/en](http://www.who.int/cancer/palliative/definition/en) (last accessed 04/02/2011)
2. Grant E, Murray SA, Kendall M *et al*. Spiritual issues and needs: Perspectives from patients with advanced cancer and nonmalignant disease. A qualitative study. *Palliat Support Care* 2004; **2**: 371–378.
3. Holmes SM, Rabow MW, Dibble SL. Screening the soul: communication regarding spiritual concerns among primary care physicians and seriously ill patients approaching the end of life. *Am J Hosp Palliat Care* 2006; **23**: 25–33.
4. Murray SA, Kendall M, Boyd K, Worth A, Benton TF. Exploring the spiritual needs of people dying of lung cancer or heart failure: a prospective qualitative interview study of patients and their carers. *Palliat Med* 2004; **18**: 39–45.
5. Moadel A, Morgan C, Fatone A *et al*. Seeking meaning and hope: self-reported spiritual and existential needs among an ethnically-diverse cancer patient population. *Psychooncology* 1999; **8**: 378–385.
6. Chibnall JT, Videen SD, Duckro PN *et al*. Psychosocial-spiritual correlates of death distress in patients with life-threatening medical conditions. *Palliat Med* 2002; **16**: 331–338.
7. McClain CS, Rosenfeld B, Breitbart W. Effect of spiritual well-being on end-of-life despair in terminally-ill cancer patients. *Lancet* 2003; **361**: 1603–1607.
8. Fisch MJ, Titzer ML, Kristeller JL *et al*. Assessment of quality of life in outpatients with advanced cancer: the accuracy of clinical estimations and the relevance of spiritual well-being – a Hoosier Oncology Group Study. *J Clin Oncol* 2003; **21**: 2754–2759.
9. Dein S. The role of health professionals in spiritual care: attitudes, practices and interventions. *European Journal of Palliative Care* 2009; **16**: 296–300.
10. Nolan S. Personal communication, 2010. Princess Alice Hospice, Esher, UK.
11. National Consensus Project for Quality Palliative Care, 2011. [www.nationalconsensusproject.org](http://www.nationalconsensusproject.org) (last accessed 04/02/2011).
12. Puchalski C, Ferrell B, Virani R *et al*. Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. *J Palliat Med* 2009; **12**: 885–904.
13. Aristotle. *Metaphysics*, Book H, 1045a10.

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