

1^{er} colloque d'experts internationaux en soins palliatifs

1st international palliative care experts symposium

Integration of Spirituality in Palliative Care: who needs it?

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no link of interests declared by the speaker

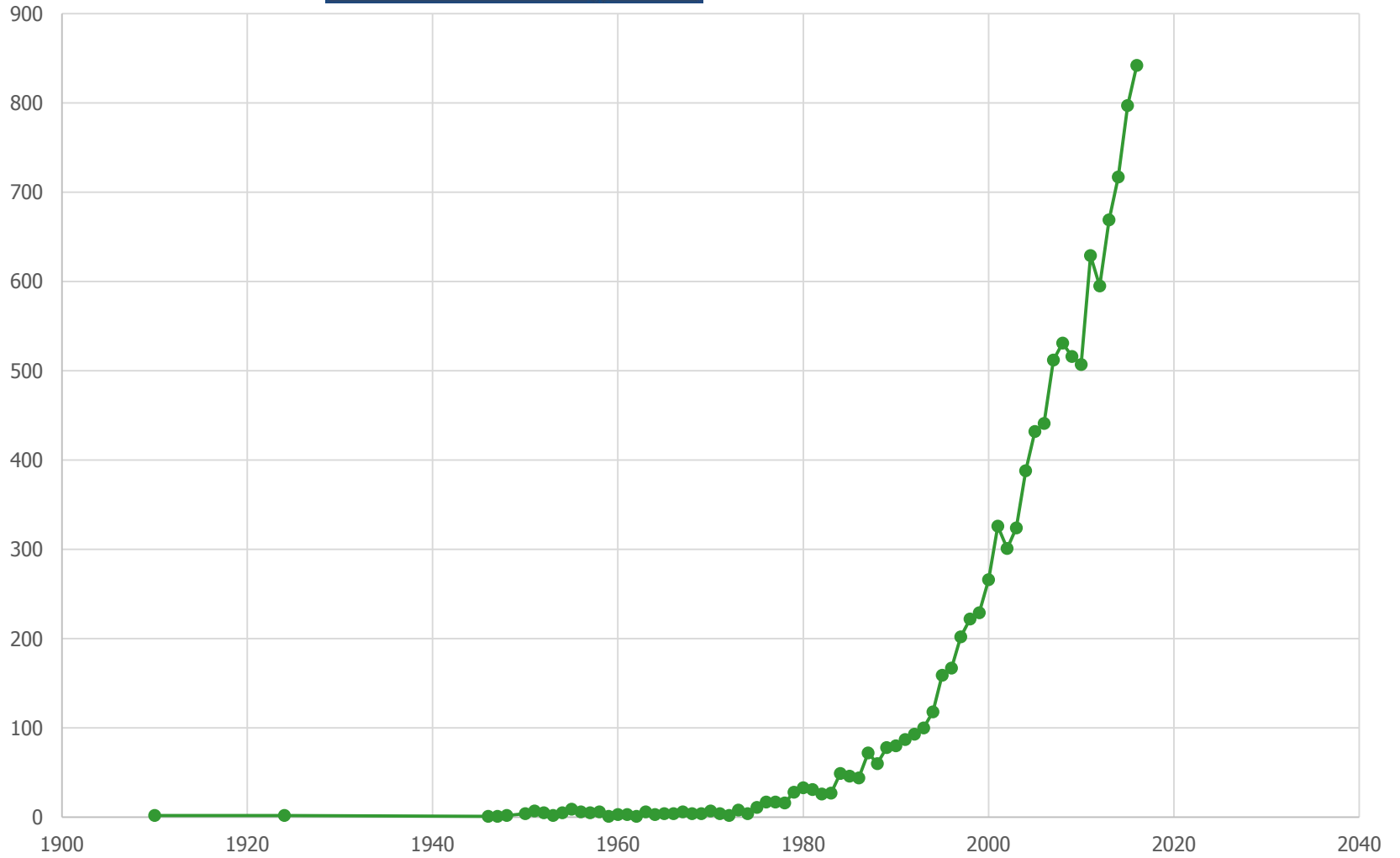
0 (Prologue)

For those of you without
patience...

WHO Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and **spiritual**.

PubMed “spiritual”



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Who needs what?

High five (Christiaan Rhodius)



(...)

“I took every chance, and fought for what I’m worth.” Also this time she will take every chance for treatment if there is one. But at the same time there is a voice in her that says that it has been enough. And there are more voices to be heard inside her. The fear of what is about to come. Having to let go of her daughters with whom she has become a trinity after her divorce. The different ways of processing things which characterizes each of them. The frictions this can bring about. Her role as a mother who wants to care and continue caring. The big support she has received from the casemanager of Bardo Hospice. The necessity to think about the preferred place of dying. Dying, that you do not want, but that you have to.

It is a cacaphony of voices. A choir in which everytime another voice is is singing the lead. Confusing, but certainly not unusual for people in her situation, I tell her. If we succeed in seeing the plurality of voices as a choir, it might result in the possibility to give every voice attention when it sings the lead. In our conversation, together we listen to the different voices.
(...)



Olsman E et al. A singing choir:
Understanding the dynamics of hope,
hopelessness, and despair in palliative care
patients. A longitudinal qualitative study.
Palliat Support Care. 2015

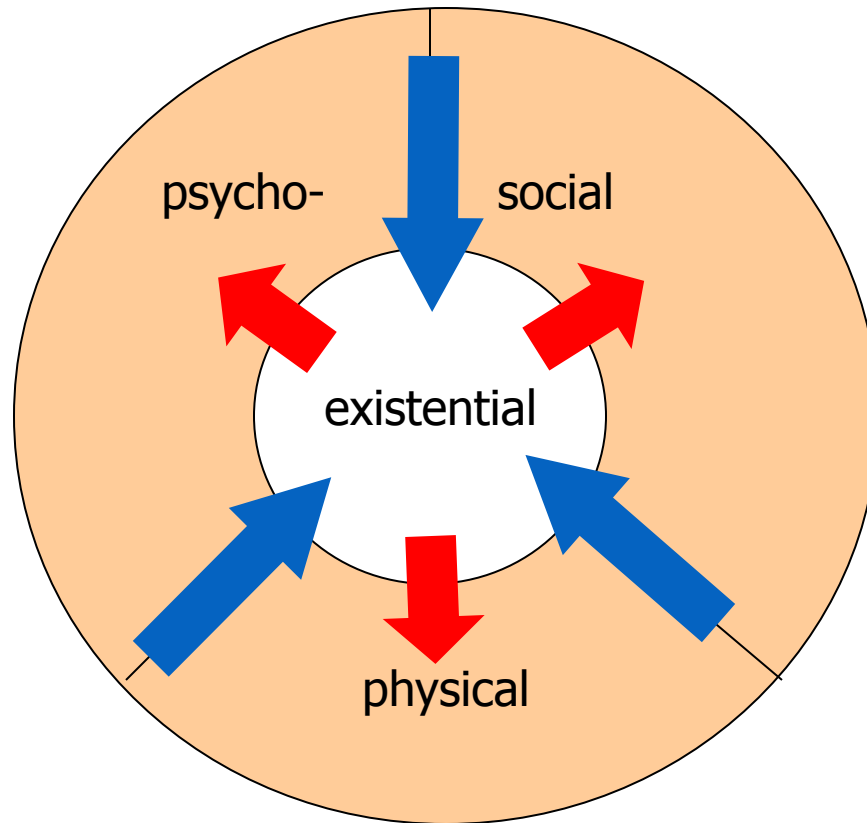
EAPC Working Definition 2010

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

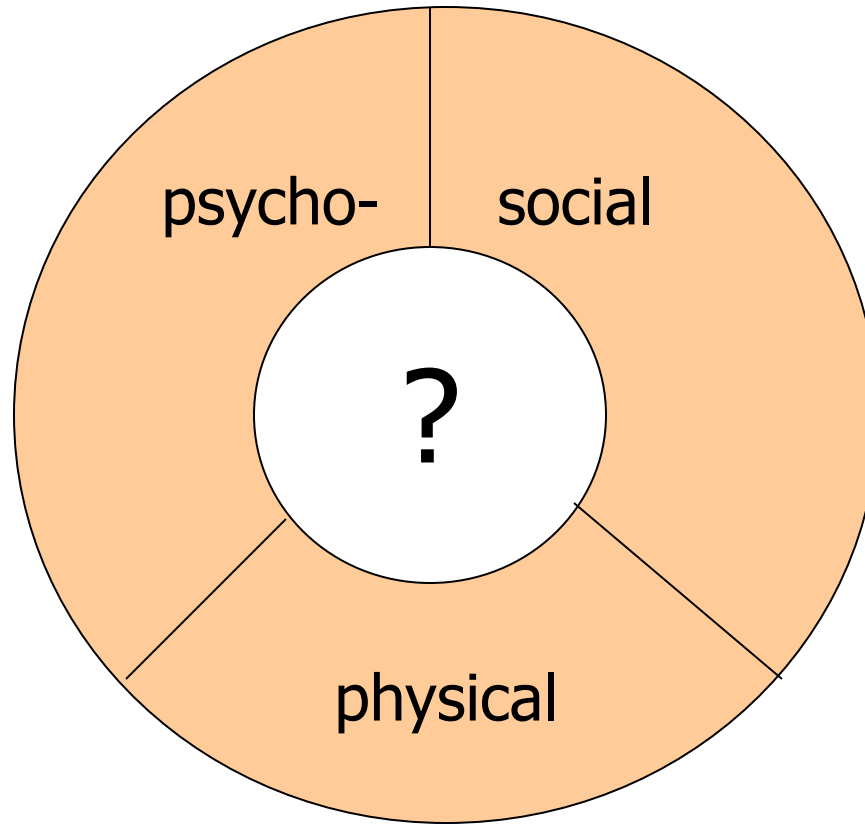
What is the position of spirituality?



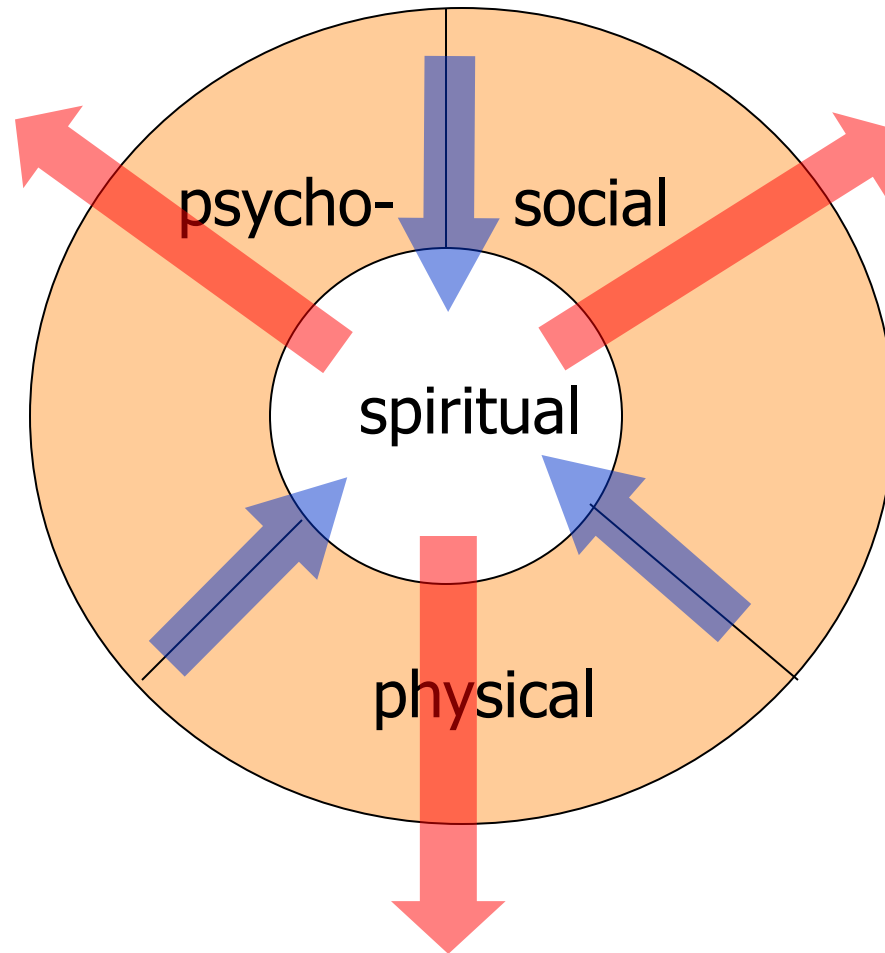
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What does need mean?

What is the question?
(need, problem, desire, etc)



Resonating with the unspeakable



What do patients and informal caregivers need?

Selman, L. E., Brighton, L. J., Sinclair, S., Karvinen, I., Egan, R., Speck, P., ... & Puchalski, C. (2018). Patients' and caregivers' needs, experiences, preferences and research priorities in spiritual care: A focus group study across nine countries. *Palliative Medicine*, 32(1), 216-230.

- Canada, UK, Finland, Belgium, Republic Korea, USA, Kenya, South-Africa, Poland.
- 74 Patients and 71 informal caregivers in 22 focus groups
- 2/3 Christian

Preferred spiritual care providers

- Wide range, including specialists (e.g. chaplains) and non-specialists
- Nurses and health care assistants have most contact and familiarity, but physicians are central to illness and treatment
- Spiritual Care a responsibility of all staff

What does good spiritual care look like?

- Essential is a human connection
- Putting the patient first, going the extra mile, integrated into care
- Attributes of a good spiritual care provider: being genuine and non-judgmental, giving hope while being honest, not proselytizing



Crisis

Accompaniment

Attention_t

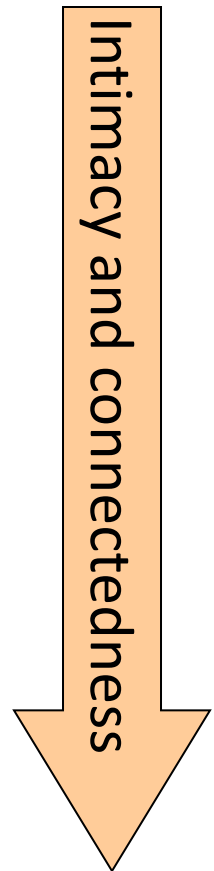
Attention

1. How do you make sense of what is happening to you?
2. What sources of strength do you look to when life is difficult?
3. Would you find it helpful to talk to someone who could help you explore the issues of spirituality/faith?

The Mount Vernon Cancer Network

“I cannot sit around the table with my children next sunday”

Physical	Description of reality
Psycho-	Experience and emotions
Social	Connection with identity and life story
Spiritual	Sources, inspiration



How can I say
goodbye?

How do I deal
with suffering?

How do I look
back on my life?

Who am I
and what do I
really want?



What can
I hope
for?

Leget C. Art of living, art of dying. Spiritual care for a good death. London and Philadelphia: Jessica Kingsley Publishers; 2017.

III

Who needs it?

Silence (Sander de Hosson)



‘When I ask the nurse to call the family and schedule a meeting for later today, I start to feel cold. A strange feeling in my stomach. How for heavens sake to tell someone who is barely 20 years old that he is going to die?’

Although sometimes I have conversations like this several times in one week, it is impossible that they become a routine. I have learned from earlier conversations. One of the biggest mistakes I have made was to keep on talking. For yes, that is what I have done. Endlessly. About treatments, about chemotherapy, about radiations, about choices between all this, and about everything that is not yet important for a patient on that moment.

The best one can do is bringing the message quickly and clearly. As a rule only three sentences are needed. Because it is that one sentence, or as a matter of fact that one word about which everything revolves: „You will die”.

Everything said in addition during those first moments in which the death sentence is declared, is useless and meaningless. Because perhaps it seems completely silent in the room, the heads in front of me fill themselves with a deafening noise, the noise of total panic. How arrogant to think that this can be changed with a few words from my side. Words that are not suitable in such moments. Madness cannot be grasped in words. (...)

I prepare myself. I start. I will always continue to remember well how insecure I will sound. With a stuttering voice I tell about the scan in a sentence that ends in the diagnose lung cancer. Then I tell him that the disease cannot be cured. I tell him that finally he will die.

And then I stop talking. There is a complete silence. Perhaps for minutes, at least this is how it feels. Minutes in which no one says anything. In which he will zoom out. And will look away. Over the fields and trees. In which his mother will wrap an arm around him. I don't think I will ever see an image of greater horror in my career than this one image.'

Inner space

... of the care-giver

... of the patient

... of the relatives

...of the volunteers

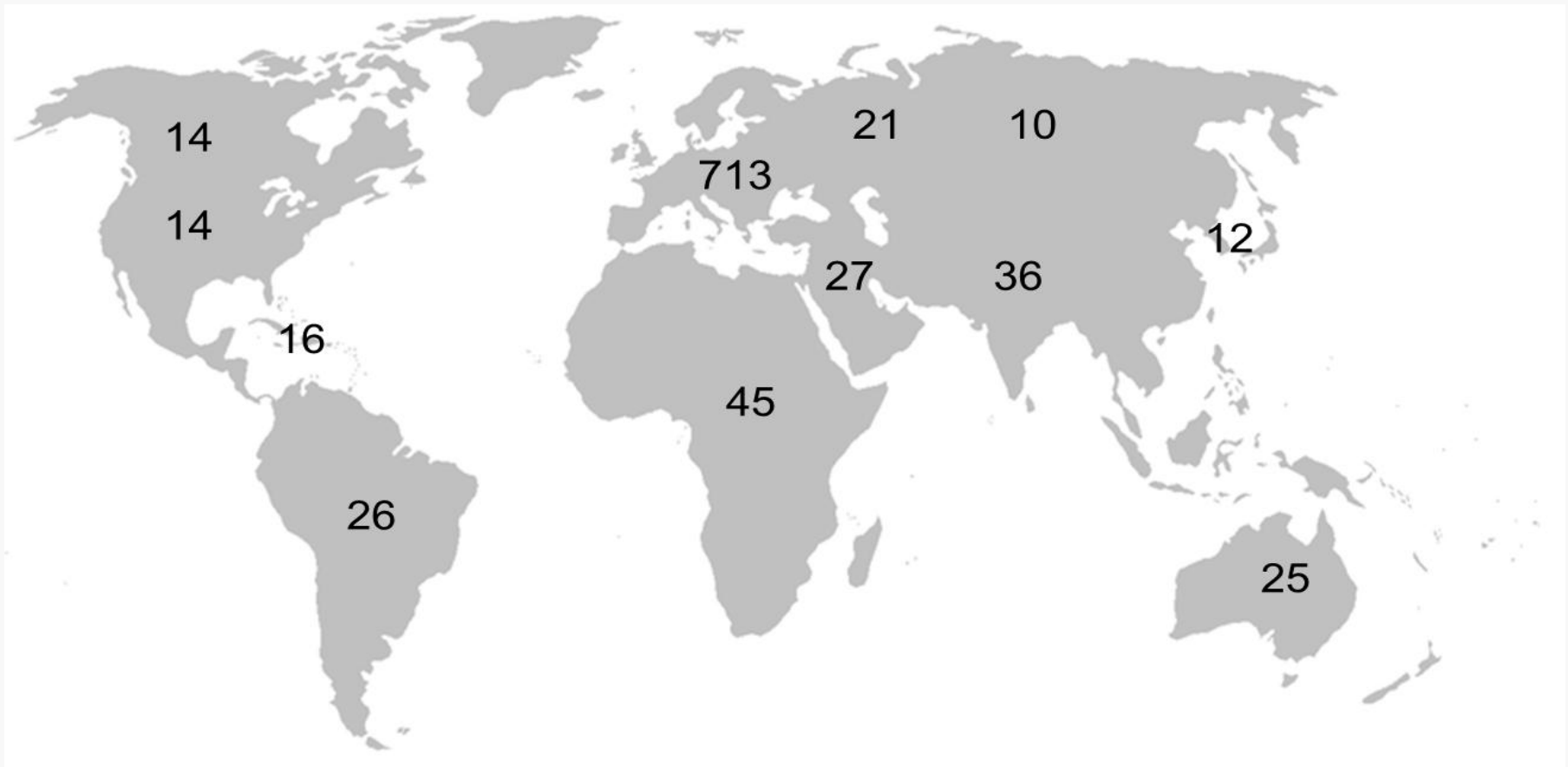


European survey 2012 (Selman/Young)

- Study design: cross-sectional online survey of clinicians and researchers in palliative care
- Delegates (n=6000) of EAPC Lisbon congress and national and international organisations invited to participate by email/bulletin between April and Sept 2012
- Survey developed by Taskforce's Research Subgroup
- **Choose and score 5 most important research priorities from list of 15**; sum score calculated and priorities ranked by sum score

Results: Geographical distribution

- 971 respondents from 87 countries



Ranking of research priorities

1. Evaluate **screening tools** used to identify patients with spiritual needs
2. Develop and evaluate **conversation models** for spiritual conversations with patients
3. Evaluate the **effectiveness** of spiritual care
4. Develop and evaluate **spiritual interventions** e.g. pastoral counselling, interventions by non-specialist spiritual care providers (doctors, nurses)
5. Determine the **prevalence** of spiritual distress among patients in different cultural and religious populations

- Choice of priorities independent of primary area of work and personal religious/spiritual affiliation

EAPC white paper on PC education: Core competencies in PC (EJPC 2/3 - 2013)

- Expert opinion on global core competencies for professional practice, irrespective of discipline
- Levels of education: three-tire framework
 - Palliative care approach (not specialised)
 - General palliative care (not main focus)
 - Specialist palliative care (main activity)
- Not covering the competencies for specialists

5. Meet the patient's spiritual needs

Palliative care professionals should be able to:

5a: Demonstrate the reflective capacity to consider the importance of spiritual and existential dimensions in their own lives

5b: Integrate the patients' and families' spiritual, existential and religious needs in the care plan, respecting their choice not to focus on this aspect of care if they so wish

5c: Provide opportunities for patients and families to express the spiritual and/or existential dimensions of their lives in a supportive and respectful manner

5d: Be conscious of the boundaries that may need to be respected in terms of cultural taboos, values and choices.



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