

Pontifical Academy For Life Webinar Session 2: Key Issues in Palliative Care  
February 10, 2022

Summary

**Palliative Sedation - Marco Maltoni, University of Bologna (Italy)**

Dr. Maltoni began by describing and defining palliative sedation as a therapy of last resort for terminally ill patients with severe refractory symptoms (symptoms that persist despite all treatments). He explained that the goal of palliative sedation is not to end life, and thus it is very different from euthanasia. Research shows that palliative sedation does not shorten the life of patients when, and if, it is proportionally used to relieve refractory symptoms. Maltoni emphasized the fact that the decision of palliative sedation and the decision to withdraw nutrition and hydration are separate. Finally he concluded by making clear the distinction between palliative sedation and euthanasia. They are different in intention, action, and outcome with euthanasia using lethal injection to end the patient's life and palliative sedation sedating the patient to alleviate refractory symptoms. Palliative sedation has no negative impact if used correctly.

**Advance directives/Advance care planning- Stephan Sham, Ketteler Hospital Offenbach (Germany)**

Dr. Sham began by stating that in low income countries, patients often do not receive the palliative care they need and patients in middle and high income countries often receive overburdensome and ineffective treatment at the end of their life. Advance directives and advance care planning help solve this issue by giving people the opportunity to discuss and potentially decide what kind of treatment they want at the end of their life. He explained that Advance directives are documents stating the treatment people want at the end of their life. He also stated that research shows that advance directives do not always reflect what patients, their families, and physicians actually end up wanting at the end of life. Advance care planning (ACP) is a communicative process as opposed to a written document, but it may end up in a written document such as an advance directive. He explained that ACP can begin at any time after diagnosis. ACP at its best is a continuing process that includes surrogate based decision making and has the patient-physician relationship as a core element. Dr. Sham concluded by emphasizing the importance of ACP for all patients and that physicians must take on the responsibility to initiate these conversations with patients and their families.

**Palliative care in neurodegenerative setting- Neil Scolding, University of Bristol (United Kingdom)**

Dr. Scolding discussed palliative care in the context of neurodegenerative diseases which are diseases of the brain and spinal cord. He spoke of the four most common neurodegenerative diseases: motor neurone disease, multiple sclerosis, Parkinson's disease, and Alzheimer's

disease. While these diseases have many differences, they all are relentlessly progressive, are incurable, often have an unknown cause, and they have few, if any, treatments to even slow the course. These diseases bring long term physical, psychosocial, and spiritual suffering as well as complex medical/ethical decisions such as end of life decisions. Dr. Scolding explained that the question of hastening death has grown more prominent over time and neurological disease is a major cause of choosing assisted suicide because of limited access to palliative care and issues like incontinence. Research has shown that incontinence is a major reason people request assisted suicide because they find it to be the same or worse than death. He articulated that palliative care education must be improved because neurologists often lack palliative skills and palliative care itself must be improved to mitigate major problems such as incontinence and become more widely available.

### **Round Table: Palliative Care everywhere and for everyone**

#### **Geriatrics - Xavier Gomez, Universitat Central de Catalunya (Spain)**

Dr. Gomez spoke about palliative care and geriatrics. He explained the conceptual shift that has taken place within the field of palliative care in that palliative care is not just for cancer patients, but all people with chronic or serious conditions. He described the many gaps that exist in palliative care caused by many factors including poverty level, age, gender, and dementia. There is a major challenge in developing comprehensive psychosocial and spiritual support as a part of palliative care. Dr. Gomez described the spiritual and psychosocial program his organization has created and dispersed to healthcare providers to meet this challenge in Spain. He further discussed the need for more palliative care education as well as the need to change social perspectives on end of life care. He concluded by stating that the most vulnerable, specifically those with advanced chronic conditions and psychosocial needs, are in great need of better access to palliative care.

#### **Pediatrics - Julia Downing, International Children's Palliative Care Network (UK)**

Dr. Downing discussed palliative care in pediatrics, and began by stating that all children who need palliative care should have access to it. She explained that this care must include care of the child's body, mind, and spirit as well as for the child's family. Children are often forgotten in palliative care considerations, but 7% of those needing palliative care are children, and over half of these children are in Africa. She described challenges to pediatric palliative care including uneven distribution of services, children often presenting with illness late, the lack of awareness, as well as the lack of technical skills and expertise. Furthermore, there is a major lack of recognition of the need for palliative care for children, a lack of policy surrounding it, and a lack of integration into greater healthcare systems. She argued that we need to change the dialogue around pediatric palliative care. Palliative care for children is not giving up on them as some people perceive, but rather it is life and helping children live with as little pain as possible.

She concluded that there is great need for education in the area of palliative care for children and we must work to provide all children across the world the palliative care they need.

**Religion and Spirituality - Tullio Proserpio, IRCCS Foundation, National Cancer Institute of Milan (Italy)**

Father Proserpio began his discussion of religion and spirituality in the context of palliative care by underlining the importance of accompaniment. Good relationships are the crucial thing that brings people trust and hope. Technology and medicine are unable to accompany people, only others can do that. Modern palliative care must consider the person as more than just the physical; they must be considered in their entirety as a person as well as their relationships. Father Proserpio described the crucial place of psychologists, social workers, and religious directors in the palliative care team. He emphasized the need for an interdisciplinary approach to palliative care. He stated that there must be greater provision at the state and local levels for spiritual direction within palliative care. He concluded that spirituality and religion promotes health, and spiritual care can help achieve the goal of health.

**Poverty situations - Matías Najún, Hospice Buen Samaritano (Argentina)**

Doctor Najún discussed poverty and palliative care. He stated that 76% of people who need palliative care live in low and middle income countries where palliative care services are very limited. Thus, poor people are essentially left out of the services offered by medical professionals. He articulated our duty to care for the poor and treat them as people and not simply a diagnosis. He stated that research on poor people at the end of life is limited, but we know that they are much less likely to receive palliative care services such as drugs. Doctor Najún explained that being poor multiplies the suffering and pain of the poor because they do not have the support systems or resources like wealthy people have. He concluded that we must work to regain the confidence of these people who are so often cast out of health resources and promote education so that people understand their right to pain relief and care.