Pontifical Academy For Life Webinar Session 1: State of the art Palliative Care
February 9, 2022

Summary

Introduction – Ostgathe (President EAPC)

Ostgathe began with the assertion that palliative care is in a state of crisis. Globally 86% of those in need of palliative care do not receive adequate care or do not receive care at all. Assisted suicide is unfortunately becoming a normal part of life as a result of passed legislation and expansions on initial legislation. He argued that regulations are a reality and we must adapt with a focus on the principles of palliative care. Finally, he concluded by describing the important connection between palliative care and the pandemic.

State of the art from international perspectives

Africa - Emmanuel Luyrika, African Palliative Care Association (Uganda)

Dr. Luyrika presented on palliative care development and delivery in Africa. He is the executive director of the African Palliative Care Association (APCA) whose mission is to ensure palliative and comprehensive chronic care is understood and integrated into health systems across Africa. He discussed how before the COVID-19 pandemic, palliative care services were insufficient to meet the demand, but the situation was improving especially in Eastern Africa. The healthcare systems in Africa were unprepared for COVID-19. Many hospices resorted to telemedicine and lockdowns limited access to palliative care services for patients resulting in many patients dying in isolation with no access to palliative care. He spoke of the many initiatives APCA has done to mitigate these issues including mentorship and grants for hospitals as well as information for the public. He also discussed the large amounts of misinformation surrounding the pandemic. He concluded that Africa was already behind other continents in palliative care and COVID-19 brought new challenges, but APCA and partners have successfully innovated to meet these challenges. Finally he articulated that governments and providers must invest in palliative care to build resilient systems for contemporary challenges across Africa, but most especially support West Africa, Lusophone, and Francophone countries.

USA - Kathleen Benton, Hospice Savannah

Dr. Benton is the CEO of Hospice Savannah and she presented on the art of palliative care in 2022 in the USA. She discussed the challenges resulting from the pandemic such as isolation in skilled nursing facilities, healthcare worker burnout, the bureaucracy of healthcare, and high demand for palliative care across the board. She also discussed the lack of spiritual care and family visitation from COVID-19. COVID-19 made end of life conversations more difficult because family was often absent due to recommendations, PPE often inhibits connection between people, and staff has compassion fatigue. She explained that there is a shortage of

palliative care teams and especially palliative care physicians. There is also a funding issue in the US because palliative care does not match the other high volume high revenue areas of medicine; palliative care involves lengthy conversations and deep relationships that need a different revenue system. She explained her vision to improve palliative care which includes a daily team routine with collaborative thinking to minimize burnout and maximize productivity, as well as focus on early intervention and beginning conversations about death early, and expanding care from one tough conversation to all aspects of end of life care. She ended by stating that palliative care is in high demand and is no longer just a sub specialty in medicine.

Europe - Carlos Centeno, University of Navarra (Spain)

Centeno began by defining palliative care and its goals including to improve quality of life, relieve pain, and empower people and communities. He emphasized that palliative care should be available to everyone who needs it across the world and the importance of early intervention. He described the divide between the two sides of Europe: developed and developing. He described the need for palliative care in Europe as well as the shortcomings in terms of access to services and limited palliative care training for future doctors. Barriers include excessively restrictive regulations for opioid pain relief, the lack of specialization for palliative care professionals, as well as cultural and social barriers and general lack of awareness. The landscape in Europe is such that there are limited opportunities to specialize in palliative care, and this must be changed. Centeno stated that the magic number is two palliative care teams for 100,000 people, but many parts of Europe is nowhere close to that. Countries must promote palliative care education for all health professionals, revise laws to improve access to opioid pain relief, and provide palliative care through primary care centers and homes. Centeno concluded by saying that Europe is advanced in terms of the global landscape for palliative care, but it needs to improve especially in terms of education for professionals.

Palliative Care in Countries that have legalized medically assisted death

Belgium - Chris Gastmans, Catholic University of Leuven

Professor Gastmans discussed end-of-life care in Belgium, in which euthanasia was legalized in 2002. He began with the idea that euthanasia support largely draws on the idea of extreme individual autonomy and its failure to incorporate the relational embeddedness of human beings. End-of-life care necessarily involves the patient, family, caregivers, and society at large and these decisions develop over time and require dialogue. He explained that the Belgian Euthanasia Act and its minimal requirement for physicians to simply mention the different palliative care possibilities. He articulated the urgent need to inform citizens about all medical decisions at the end of their life and the effects of withholding life sustaining treatments. There must be competent end of life care available to all those in need, and pain alleviation must be emphasized. Gastmans discussed the ability for conscientious objection, but the obstacles that come with that such as emotional distress for physicians who want to fulfill the requests of their

patients. He also discussed societal challenges such as the modern conception of euthanasia as a normal and "good death" which is individual, planned, and swift. He described the slippery slope of euthansia legislation because once the barrier to legislation is passed, euthanasia becomes normalized very easily. Professor Gastmans concluded that a strong voice is needed to work against the normalization of euthanasia and health care professionals are the people in the best position to intervene in the media in an authentic way based on their professional experience.

Belgium - Jonah Menten, University Hospital of Leuven

Professor Menten discussed the legal and ethical landscape of palliative care and euthanasia in Belgium. He discussed the growing prevalence of laws regarding euthanasia and the fact that discussion is going on across the world. In Belgium, palliative care is available and free to all, but is often delayed until the final end. He explained the large public support for the Euthanasia Act in Belgium and the place of Catholic hospitals who have been pressured to make euthanasia possible. He discussed the lack of palliative care in the core curriculum for students studying to become healthcare providers. The ethical committee at his hospital implemented a system of requirements on top of the legal criteria in which every euthansia request is discussed with the palliative care team and regular treating team, euthanasia procedures are only performed during normal working hours, treating head physician must report on the procedure, and the caring team must complete a posthoc reflection afterwards. Furthermore, he worked to educate people about palliative care by providing books and manuals in their language to educate people on eliminating physical and spiritual pain. He discussed the options of physicians who do not want to perform euthansia as well as the dilemma they may encounter with patient, family, or societal pressure as Catholic hospitals have been attacked in the media if they refuse to perform euthanasia. The general public is largely in favor of the act and euthanasia is even considered a right, but only 2.5% of deaths are the result of euthanasia so there is a divide between public perception and actual decisions upon death. He concluded that expert palliative care controls almost all symptoms, but some patients still prefer euthanasia which creates potential moral dilemmas for physicians.

Canada - Noël Simard, Bishop of Valleyfield

Simard discussed the state of palliative care and medical aid in dying (MAID) in Canada. Simard began with the legal background and development of euthanasia laws which have developed to allow euthanasia for mental as well as physical ailments. Simard argued that this development threatens more and more the sanctity of human life. Canadian civil leaders have always declared that euthanasia legislation is not an action against the development of palliative care and there has been legislation as well as Catholic efforts to provide and promote palliative care. The Canadian Conference of Catholic Bishops reaffirmed that palliative care is not just a health care service, but it is the most humane movement and response to the needs of the seriously ill. The number of hospice facilities which refuse to offer MAID has become much

smaller as the government has threatened to reduce their funding. There is a real lack of commitment in expanding palliative care in Canada and therefore it is largely inaccessible. Simard concluded that it appears that as access to euthanasia is expanded, the less palliative care is sustained and it is becoming more difficult to reverse the present Canadian tendency to favor MAID. The idea of absolute personal autonomy, the confusion of it being medical care rather than an act of killing, and the distinction between legal and moral dimensions are all major challenges.

(Summary by Elizabeth Miller)