Assistance to the Elderly and Palliative Care

Notes on the Workshop of the XXI General Assembly

Pontifical Academy for Life

Session I
Clinical Care for the Elderly at the End of Life

The workshop began with a presentation from H.E. Msgr. Ignacio Carrasco de Paula, President of the Pontifical Academy for Life, entitled “The Challenges of Assisting the Elderly at the End of Life.” In modern-day culture, we do not always find adequate means to face the specificity of the problems that the elderly encounter. In first place, then, the “social” value of the elderly must be recognized. This has their “ontological” value as an ineludible premise: existing as a person, as someone who deserves to be loved unconditionally. Love and care for the elderly have, as for every human being, their proper place within the family. Along with this place within the family, there should also be, however, concrete expression of this care within the entire community, according to the principle of subsidiarity. The elderly also manifest the truth of the human person as ens indigens, an anthropological paradigm welcomed by palliative care as its essential core. In light of this, palliative care is to be understood not only as “easing of pain” but as a manifestation of love. Palliative care is not a type of philanthropic “charity” or concession, but is an expression of that which is truly human.

Dr. Armando Garcia Querol, Co-founder of Hospice San Camilo (Buenos Aires, Argentina), then presented on the theme of “Elderly at the End of Life Due to Chronic Degenerative Illnesses.” The patient can live through the deterioration associated with the final stages of chronic illnesses in a dignified manner when science and
medicine are utilized in such a way that takes into account the unique nature proper to the individual patient. Medical planning for the elderly is specific. They require above all an adequate analysis of the risks and benefits of each treatment, considering the way in which the pathology in question will act in relationship to important changes linked to the aging process itself (deterioration of hearing and vision, loss of liver and renal functionality, skin conditions such as sores and difficulty in healing, dental problems and dysphagia, ...). Treatment must be within a framework that takes into account the presence of multiple comorbidity. There also exist conditions proper to advanced age (dementia, delirium, constipation, falls, fragility, depression) that can be present simultaneously. Palliative care can bring important benefits to the treatment of these symptoms as well to the patient’s overall physical and social stabilization, alleviating thus at the same time the stress upon the family members committed to the long-term care of the patient.

Professor Joan Panke, Palliative Care Nurse Practitioner at MedStar Washington Hospital Center (Washington, DC, USA), made the third presentation, on the theme of “Nursing Care for the Terminally Ill Elderly.” The work of the nurse, according to Prof. Panke, combines the science of nursing and the art of giving care. For this reason, the personal relationship with the patient lies at the heart of the profession. One learns how to build this relationship through practical work experience, as current educational models do not always adequately address this issue. Further, and notwithstanding the diversity of expressions that the profession takes throughout the world, human nature and respect for human dignity are foundational principles that hold universal value in the nursing profession.

Prof. Paolo Preziosi, Professor Emeritus of Pharmacology at the Catholic University of the Sacred Heart (Rome, Italy), then spoke upon the theme of “Use and Abuse of Analgesics in Palliative Care.” Treatment for the alleviation of pain has always been a clinically complex and ethically controversial aspect of palliative care. This is due to factors such as the collateral effects of such medication as well as the possibility of their abuse. Greater caution is required when these medications are utilized in the treatment of the elderly. These medications can cause respiratory depression, particularly if used along with sedatives, or with the presence of pulmonary illness. In the United States, between 1999 and 2010, deaths linked to the abuse of prescription pain medication quadrupled.

In closing the first session, Prof. Daniel Sulmasy, Associate Director of the Maclean Center for Clinical Medical Ethics at the University of Chicago (USA), presented upon “The Process of Clinical Decision-Making for the Elderly at the End of Life.” Though the ethical principles in question remain unchanged, the clinical decision making process at the end of life must also take into account the particular circumstances present when death nears. There is the duty to safeguard life that forms the basis of every concrete decision, though this should be done without an undue or unreasonably excessive preoccupation for prolonging life. Medical action is an ethical endeavor where dignity and finite nature of the human person meet. Therefore, clinical decisions must always take into account the specificities proper to each individual case. This is possible without falling into relativism. Different from the negative articulation of the norm that prohibits the taking of life, which
carries with it a fixed absolute value, the positive duty to safeguard life requires at times concrete decisions and a clinical judgement that is the fruit of prudence. The duty of those assisting in this care is not only that of helping to make the decisions regarding which treatments to undertake or not, but to both care for the person and seek an environment in which the person may grow in a holistic sense.

**Session II**

**Ethical-Anthropological Perspectives**

The second session began with a presentation from Prof. Pierre Boitte, Professor of Medical Ethics at the Catholic University of Lille (France), on the theme of “The Central Role of ‘Relationships’: The Elderly, Healthcare Worker, Family and Society.” The expression of relationality in the medical field has definitely undergone changes due to the increase of technology used in medical care. Palliative care has mostly been unaffected by these changes, with relationality retaining its importance within patient care and thus stemming the tide of euthanasia/medically assisted suicide, which is often invoked in the name of individual autonomy. The physical and spiritual suffering of illness can often lead to the depersonalization of the patient as well as the family. In response to this, the reality of being in relationship can reduce this isolation and allow the patient to be welcomed in the fullness of his or her personal reality. In so doing, possible reductionist tendencies associated at times with technology can be avoided; thus allowing the possibility to make sense out of that which is essentially incomprehensible. The value of relationship can be grasped only if medicine returns to providing care and not merely technical interventions. This dimension of care must be present not only in individual relationships, but also at the institutional and societal level.

Prof. Adriana Turruziani, Chair of the Hospice “Villa Speranza” at the Catholic University of the Sacred Heart (Rome, Italy), then made a presentation entitled, “Beyond Verbal Communication in the Care of the Elderly Patient.” Prof. Turruziani highlighted the central role of communication in preserving quality of life and a sense of identity. Furthermore, nonverbal communication has the capacity to reveal deeply held sentiments of the person. In care for the elderly, whose ability to communicate verbally can be affected by a weakened cognitive state or proximity to death, nonverbal communication allows for a real and dynamic relationship. The patient can communicate his or her needs and wishes through facial expressions, body movements, posture and eye movements. It is particularly important for the team that is assisting to be able to recognize nonverbal signs associated with the presence of pain. Visual and tactile communication are fundamental as well for the health care worker in giving care and comfort. Attention must be given as well to the nonverbal communication of family members and others who are giving care to the patient, as the stresses involved can at times affect their ability to attend to the needs of the patient.

Prof. David Roy, Director of the Research Center “Ethics and Aging” at the University of Montreal (Canada), then presented “Ethics and Palliative Care for the Elderly.” The human being, by his or her very nature, resists death and its dominion, even in its most fragile and vulnerable state, in such a way that no medical act
can negate. Today, loneliness of abandonment are the most characteristic of life experiences of the elderly. When seeking to approach the situation from an ethical perspective, one must keep in mind the complexities involved. Many times, abstract principles do not suffice for an adequate consideration of these situations, nor are the modes of reasoning built upon these principles. Ethics must always take into account the particularities and judgements related thereto, as the more general norms and foundational premises are assumed and rarely reflected upon in the moment of practical judgement. Prof. Roy considered at least two of these assumptions present in contemporary palliative medicine: (1) the pretense of “taming” human suffering by pharmacologically controlling it until induced death; and (2) the pretense of controlling human death. In this context, specific questions can be considered, such as ending treatment and euthanasia. Situations may be considered here as well in which the elderly are victims of dehumanization and discrimination—even unto imposing a “duty to die” upon them—excluding them from those entitled to remain within human society.

Prof. Carlos Centeno Cortes, Director of the Palliative Unit, Clinica Universidad de Navarra (Spain), then spoke upon “Advance Care Planning.” The notion of “Advanced Care Planning” has to do with the relational process through which a treatment plan is designed, taking into account the future evolution of the illness. This approach is particularly suited for terminal illnesses. The planning process for the care to be given, which can also be documented, is fundamentally different from a living will or an expression of prior consent to treatment. These latter documents emphasize the legal value of the decision expressed and the forms of treatments not to undertake. Advanced care planning, however, emphasizes the relational process preceding the decision and treatments to undergo. Many studies illustrate the limitations of legal documents such as living wills and expressions of prior consent while also noting the benefits of the process of a treatment plan. In the process of forming the treatment plan the patient is afforded a more appropriate participation in his or her treatment while at the same time experiencing less anxiety linked to the progression. The principle roadblock to prior planning of care is perhaps the prevalent attitude of giving of minimal information to the patient. This decisional process also has a heightened ethical value for those in clinical medical professionals involved, in the sense that it allows the patient to have the experience of being truly accompanied through the final stages of life.

Prof. Chris Gastmans of the Center for Biomedical Ethics and Law, Catholic University of Leuven (Belgium), then spoke upon “Worrying Tendencies in the Care of Elderly Patients with Dementia.” The practice of euthanasia upon persons affected by dementia has seen a continual increase, along with the issuance of prior directives in this regard. The desire for euthanasia seems to be linked to the loss of a sense of one’s autonomy, the subsequent “dependence” on others that comes along with dementia and the related debasement of one’s own personal dignity. Empirical studies seem to show, however, that in countries where euthanasia is accepted, as for example in Holland, more than 50% of doctors indicate they are not ready to euthanize patients with dementia and view prior directives consenting to euthanasia as invalid. A better course of action would be to meet and come together with the
family of the patient. There are many cultural elements that do not allow for the licit practice of euthanasia within medicine and society at large: the recognition of the intrinsic and thus inviolable dignity of the human person; the recognition of the value of that autonomy formed in relationships, meaning thus that it cannot be considered abstractly as some sort of requirement pertaining solely to the individual; a quality of life that takes into account the personal perspective of the patient and that is not confused with the perspectives that other people have regarding the patient; and the ideal of “caring” as forming part of our anthropological structure and thus for this being an ethical duty.

Rev. Prof. Leocir Pessini, Superior General of the Camillians and Professor of Bioethics at the University of São Paulo (Brazil), concluded the session with his presentation upon “Ethical Guidelines for ‘Good Accompaniment.’” They myth of eternal youth and the possibility of immortality expounded within contemporary scientific culture pose an ideological challenge that is particularly frustrating for the medical health care field dealing with the elderly. A more wise consideration of the issue, on the contrary, welcomes vulnerability and mortality as aspects of the human condition. From this awareness also proceeds recognition of solidarity as a personal and professional value, as well as a true social virtue. In this perspective, each period of human existence is seen thus as an opportunity. From these premises the fundamental principles of caring for the elderly patients with dementia flow: welcoming the person in his or her entirety, uniqueness and dignity, vulnerability and care as the poles of relationship; discovering solidarity through communication that is also able to respect the presence of suffering. In this way, care becomes not only an ethical and legal duty, but also a beautiful and good endeavor to carry forth to realization.

**Session III**

**Socio-Cultural Perspective**

The session opened with a presentation by Rev. Armando Augiero, President of the CVS International Confederation, Rome (Italy) on the theme of “Elderly at the End of Life: Spiritual Aspects.” The elderly today, according to Rev. Augiero, receive much counsel regarding care for the body though not for the soul. Existentially speaking, there are thus important questions to consider: what does it mean to be elderly; how to face fragility and abandonment, as well as what kind of outlook there is for the elderly. Emptiness is an ailment that is particular to this time and one that cannot help but be accentuated in the elderly. Antidepressant medication is not the solution, but the reconstruction of one’s own mode of looking at one’s self and interpreting the world. Emblematic here are saints such as Luigi Novarese, known for his exploration of spiritual resources within the limitations posed by physical suffering. The Good Samaritan of the XXI century must care for the broken spirit above all, which has great needs. These profound needs are religious (prayer, turning to God...), existential (speaking of the meaning of life and suffering, of life after death), and above all for interior peace and the ability to work for the good by giving themselves in some way to others.

Prof. John Keown, Rose F. Kennedy Professor of Christian Ethics, Georgetown University (Washington, DC, USA) then presented upon “Legal Issues at the End
of Life.” Along with the problem of euthanasia, there can also be legally relevant problems posed by the refusal of care. If generally on the one hand such refusals of care must be respected, then in some cases this may constitute suicide. The autonomy of the patient is to be respected, but within certain limits. Along with the issue of respecting the autonomy of the patient, within the realm of end of life decisions there is a certain discriminatory criteria of life that is diffused: in certain conditions life does not have sufficient value and this allows for (or obliges) the termination of that life. Discrimination based upon the quality of life is particularly worrisome with regard to the elderly and more so even for elderly persons diagnosed with dementia. The reality that this discrimination leads to a slippery slope for the elderly has been amply demonstrated. Increasingly widespread criteria for the cases of active or passive termination of life leads to an increase in those subjected to it, above all those whose quality of life is deemed to be unsatisfactory.

The Rev. Dr. Tomi Thomas, Director General of the Catholic Health Association of India (India), then presented upon the theme of “Pastoral Care and the Role of the Family.” The pastoral care of the elderly, above all for those affected by chronic illness or whose condition is greatly deteriorated, must often be given the possibility to have meaning where their sense of meaning seems lost. Family members of the elderly fulfill an important role, however, other volunteer caregivers of the local community can also intervene successfully to alleviate suffering and the sense of abandonment often experienced. Concrete needs and modes of assistance can often be particular to the specific socio-cultural context in question. Rev. Dr. Thomas noted in this regard that as women in India can have a more difficult social experience and generally more difficulty in obtaining available and accessible services, less than 2% of the population receive palliative care that adequately meets their needs. On the other hand, also in this country, the nuclear family increasingly finds itself farther and farther apart from one another. The woman is busy with work outside the home and the children migrate far from their place of origin. In this context thus, from the point of view of best responding to practical needs and local cultural sensibilities, palliative care as well as pastoral care is best given through home based services having teams and networks of volunteers from within the local community.

Prof. Marco Trabucchi, President of the Italian Association of Psychogeriatrics (Rome, Italy), then presented upon the question of “What Is Social Solidarity?” Prof. Trabucchi showed how the growing economic difficulties associated with the social and demographic changes cause many countries to limit the resources made available to assist and sustain the elderly. Consequently, this requires a change in the approach that society takes toward caring for the elderly, above all with regard to public assistance. It is necessary to promote medical research for the prevention of chronic illnesses and the disability associated thereto, but also to develop highly technically competent health care workers who serve the elderly with real compassion. Finally, it is necessary to promote an attitude of solidarity at the community level that supports families caring for their elderly, above all for the most difficult cases as in elderly persons with dementia.

Pope Francis, in his discourse to the participants of the General Assembly, spoke upon developing an attitude of authentic solidarity with the elderly. The Holy
Father recalled that “abandonment is the most serious ‘illness’ of the elderly, and also the greatest injustice they can be submitted to: those who have helped us grow must not be abandoned when they are in need of our help, our love and our tenderness.”

“All of medicine,” the Holy Father underlined, “has a special role within society as a witness to the honour that we owe to the elderly person and to each human being. Evidence and effectiveness cannot be the only criteria that govern physicians’ actions, nor can health system regulations and economic profits. A state cannot think about earning with medicine. On the contrary, there is no duty more important for a society than that of safeguarding the human person.”