Saturday, January 21, 2017, 14:01

Euthanasia debate stems from our failure to deal with end-of-life care, says bioethics expert

'Something is going wrong with end-of-life care'

"We need to understand that a patient can be relieved of pain and that there is no evidence that pain relief hastens death."

*The introduction of euthanasia would show a failure of humanity to deal with dying people, says bioethics expert **Pierre Mallia**. He spoke to **Simonne Pace** about a research project with a profoundly important aim: to make the end of life comfortable and pain free for everyone.*

A drive to amend the law and introduce new medical guidelines could pave the way for better end-of-life care being offered in Malta, which would include a greater acceptance of death, more effective pain relief and the avoidance of over-treatment for suffering patients.

This development should come before any further discussion takes place about euthanasia, according to Pierre Mallia, who is coordinating an EU-funded research project whose aim is to find out why end-of-life care is not working well in Malta and to improve it by putting the patient first.

The Erasmus project, called EndCare, kicked off last October. It is being undertaken by the universities of Malta, Dublin and L'Aquila, together with experts from the UK and France. The coordinator is Prof. Mallia, a professor of family medicine, bioethics and patients' rights, and chairman of the Bioethics Consultative Committee within the Health Ministry.

Prof. Mallia believes strongly that patients should have the right to effective pain relief and to decide what treatment is too burdensome for them. They should also be helped to plan ahead for good end-of-life care.

So far, studies carried out as part of the project have shown that these cardinal rights are not being implemented by healthcare professionals. They feel they are not adequately trained to speak to family members about advanced-care planning, which includes keeping patients comfortable and pain free when they're close to death.

"We need to recognise when death is imminent (within a year) so that people have time to make advanced-care plans and discuss them with doctors. When death is recognised as being very close (a few days), these plans are triggered into action," Prof. Mallia said.

Pierre Mallia. Photo: Chris Sant Fournier

"Only in this way can we move from cure to care. Patients ought to have rights to refuse life-prolonging treatments, such as advanced artificial ventilation, if they feel it is disproportionate for them."

Patients, he insists, need not suffer in death. "I speak to people who tell me: "I'd rather die!" I tell them you don't need to die in pain. If the pain is uncontrollable, if need be, we can sedate them and death will follow its natural course. They will die in their sleep.

"So it's not supposed to be a controversial topic. Unfortunately, something somewhere is going wrong with end-of-life care."

And he says he can identify where it's going wrong: not all hospital wards, for example, recognise that death is imminent, so they keep giving treatment. There is no advanced-care planning, where patients are told that the intention will be to keep them comfortable and pain free. Nor are patients told there are some medications they can refuse.

Health professionals need to morally feel that they're not doing anything wrong if they refuse to give life-prolonging treatments when unnecessary

Prof. Mallia recounted the personal experience of a friend whose daughter was dying. On the verge of her death, her father "stopped the doctor's hand".

"A doctor or health professional, in good faith for their profession and love for the patient, sees end-of-life care as a big challenge. The research project speaks about the need to learn – as we did in the old days when we didn't have such advanced medical technology – that we're all going to die. What we are really afraid of is how we will die. We don't want to die alone or abandoned, but most of all, nobody wants to die in pain," Prof. Mallia said.

The research has also clearly identified the need for clearer laws in the area. "Having a legal framework would be a great step forward.

"Health professionals need to morally feel that they're not doing anything wrong if they refuse to give life-prolonging treatments when unnecessary. This would reassure them immensely."

The law, as it stands today, does not allow euthanasia, but it doesn't specifically outline that a doctor has the right not to give futile treatment to a dying patient, he pointed out.

He is now hopeful that the current laws will be clarified as a result of the recommendations expected from the Attorney General's office, and that Parliament's Family Affairs Committee will be willing to have the amendments included in a new Charter for Patients' Rights.

Prof. Mallia has also prepared a draft consensus statement with the Faculties of Law, Theology, Medicine and Health Sciences focusing on the present situation with the law and moral teaching on end-of-life care.

Another result of the project will be the drafting of 'curricula' for the education of medical professionals. Health professionals need to be trained how to talk to patients and relatives about death and what to do when it's imminent.

"Palliative care is a speciality in its own right. An improvement in certain wards in hospitals is needed, as well as more education on end-of-life care. This can be done by the medical profession, together with the help of the legal profession and religious institutions – which is why, as part of the project, we developed what we're calling a curriculum.

"This curriculum is not about training in palliative care. Nor does it try to offer moral instructions to help professions. Its main aim is to bring those working in end-of-life care together to identify what their needs are. It's a learning process."

The intent, he adds, is not to "reinvent the wheel".

"Moral guidelines are already in place, and most religions, including the Catholic faith, are in the avant-garde of end-of-life. We have to accept that death is an inevitable outcome. We need to understand that a patient can be relieved of pain and that there is no evidence that pain relief hastens death. Even if it does, it is accepted and shouldn't be considered as active euthanasia.

"A lack of knowledge sheds a bad light on end-of-life. This is why we are faced with a situation where people, including medical students, feel that in certain cases euthanasia can be given."

He clarifies that the project is not about euthanasia but on proper end-of-life care. "I think euthanasia would show a failure of humanity to deal with dying people."

Still, he expresses gratitude to ALS sufferer Joe Magro, who is pushing for euthanasia to be accepted in the law. "When I come across cases such as this motor neurone disease patient, it pains me to feel that society has failed these people. Therefore, they come to a point where they request euthanasia.

"This debate has been useful. Mr Magro had the courage to speak out. Luckily, it coincided with the start of this research project, so far from condemning this person, I have great admiration for him not because I agree with him but because he stimulated further debate."

When death arrives, medicine does not need to continue. It's morally wrong to keep insisting

But before Malta discusses euthanasia, Prof. Mallia believes that we should first get it right in terms of end-of-life care.

"I like to use the analogy of the divorce issue. We introduced divorce because it is present in many countries. I don't think this is the true reason. I think divorce was introduced because people weren't satisfied with the annulment issue.

"Although divorce wasn't as big an issue as euthanasia, it was a failure of society to address marital problems. Were euthanasia to be introduced, I would see it as a failure of society to address end-of-life care."

He also feels that the Church needs to be on board. It would be useless having doctors trained in palliative care on the one hand and patients' relatives questioning their work on the other, he argues.

“We hope to make people understand that we are treating the patient. Pain relief does not kill. Even if it shortens life by a few hours, it’s morally accepted. It would be immoral to let a patient suffer. Some people go through the agony of death. I’ve seen patients experience it. It’s not pleasant.

“There comes a point where we have to stop trying to cure and start to care. We believe in life, so let us teach people what they’re allowed.

“Death is part of life. We are born and we die. When death arrives, medicine does not need to continue. It’s morally wrong to keep insisting.”

The project

After collecting information through surveys and “a meeting of minds”, the project proceeded to bring together the common rules of the countries and cultures under study, including Malta.

Moral guidelines were found to be quite uniform, but it was felt that people would feel more secure under a legal framework.

The next stages involve developing educational “curricula” for healthcare professionals, the public and for those who help patients and families at the end of life, in particular religious leaders.

There will then follow the phase of implementation through summer schools held every year.

Among other outcomes of the project will be publications in academic and learned journals and a book with collected papers by the experts involved, as well as talks and further studies.

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