Harmonisation and Dissemination of Best Practice - Educating and alleviating the concerns of Health Care Professionals on the proper practice of End of Life Care

Short-form Title: EndCare

PROJECT BRIEF

Background to the Project Proposal

Bioethics has existed as a field for over five decades and begun as a field of moral inquiry into the life sciences, in time focussing more and more on health related issues. Whilst the core moral debates are more of a question of conflict of values, there are areas of agreement, which from time to time need promulgation. In fact Bioethics has not proposed a universal theory for end-of-life decisions. Many still pursue debates over euthanasia (or physician-assisted death). However the moral proposals of many religions including Christian and Muslim are quite consistent and have pre-dated bioethics in providing significant moral guidance – a guidance which remains in many countries whose normative values are conservative – rather elusive.

It is now being considered a 'duty' of bioethics to guide health care into proper management where agreement exists on moral levels which take into consideration the normative values of the society where implementation is considered. Moreover there is a need not merely to provide courses to those who choose to have a better understanding of the field, but to *target* populations, such as physicians and nurses dealing with patients who have reached an 'end of life' stage. It seems however that this goal is not being reached.

Therefore one finds that although, for example, Catholic doctrine speaks clearly about the unreasonable use of extraordinary and disproportionate measures at the end of life, the appropriate use of increased doses of pain relief, even to the point where this can hasten death, by invoking the principle of double effect and making a distinction between killing and allowing someone to die, many health care professionals prefer to take a more conservative approach, even when knowing that undue suffering may be caused.

The reasons for this may range from fear of litigation by relatives, to an unclear understanding of one's own moral values (assuming that these are based on the individual's normative values.) Recent events have also highlighted the importance of artificial nutrition and hydration at the end of life to provide comfort. Conversely one does not take this guidance as 'under ordinary circumstances' and many forget that

even hydration can be a source of discomfort and that people who die at home die comfortably and without hydration intravenous lines.

This Erasmus + project aimed to emphasise education as the ideal vehicle to develop an understanding of the fears and limits of end of life decisions and to develop a suitable and generally acceptable curriculum at a political level based on a common understanding across the European Community.

Current understanding

The following salient points are in agreement with Catholic, Islamic and Judaic doctrine on End of Life Care:

1. Health Care professions cannot treat patients without their consent.
2. When patients cannot give consent the family's wishes should be taken into consideration.
3. Increased doses of pain relief can be given according to a recognised standard of care even if this hastens death. Death is here seen as the inevitable outcome. This is not considered euthanasia as it follows the Principle of Double Effect where a foreseen harm can be accepted once it is indirect and not intended.
4. Patients are only obliged to receive ordinary care. That which patients deem extraordinary can be refused. It is important to note that extraordinary care is not a measure of the state of the art of the procedure but is determined by the patient. For one patient it may merely be not dying in hospital.
5. There is a difference between killing and allowing someone to die.
6. One need not give treatment which is considered futile.

There have been ample scholarly works and texts in this regard and yet they remain elusive especially in the light of recent events and allocutions which allude to artificial nutrition and hydration. This has caused even more confusion among health care professionals. This is aggravated by the fact that until recently ethics was not formally taught in many courses and a conversion of moral theory into practice was not always feasible and understood by the bed-side. Whilst there are many peoples trained in palliative care who provide good end of life care, there are many physicians and health care professionals who deal with dying patients but are not appropriately trained in palliation and what constitutes futile treatment.

Whilst it is acknowledged that changing practice is not simple, it is also recognised that one needs to start with a proper recognition of the problem: that there is inappropriate application of moral theory at the end of life. What can at first sights appear as passive euthanasia is in fact not euthanasia and this has been recognised by religious institutions, which put a great significance on the normative values of countries, as well.

The partners in this project were experts in the field and range from a variety of institutions ranging from Medicine, Bioethics, Institutions with a religious leaning (such as Islamic thought, and the Pontifical Academy for life), to International and local political institutions such as UNESCO and the Departments of Health.

Methodology

The methods to attain the project's aims were defined by a series of meeting of experts to promulgate existent doctrine and moral theory and understand what has led to these areas being abandoned, with the resultant lack of appropriate care for patients, and indeed with the health professional thinking that s/he is actually following a doctrinal moral standard.

These workshops will helped design scientific questionnaires directed at health professional with a view of establishing current practice and understanding their concerns, following which an appropriate curriculum incorporating identified best practice was developed to train health professionals and such information was disseminated to stakeholders and during seminars and conferences. The work is ongoing.

In this regard, the project held summer schools on a yearly basis aimed to develop and test a curriculum for centres to identify needs and develop pathways to change. The concept of a 'Hidden Curriculum' addressing the needs of health care professionals, whilst discussing with them appropriate means of reaching all those involved in health care at end of life, from primary through to tertiary health care, was focused on in order to address ground root needs. These varied from communication skills courses, need for training in palliative care, need for knowledge of law and ethical issues, especially those relating to different beliefs, conflict resolution, spirituality not only as a means of religious belief but also from an existential perspective, dealing with stress and debriefing etc. The curriculum will thus vary from ward to ward or from institution to institution.

The final stage of the project involved the establishment and implementation of a plan of action at a political level (both internally, within the professional environment, and at a national policy level). This stage, the result of local summer schools, entailed working closely with the relevant leaders so that change can be implemented without controversy, in the recognition that society may perceive such changes as verging on the practice of euthanasia and/or that they are being adopted due to an over-arching positive economic impact. Such issues must, therefore, be addressed and resolved, with the support and conviction of socio-religious leaders being considered of utmost importance. This also gave rise to the idea of another project (EndCare 2) which ought to focus on the community (education of public, dying at home, end of life curricula for General Practitioners and nurses, etc).

In particular, while it is acknowledged that there are legitimate concerns on the economic impact of keeping people alive through extraordinary and disproportionate means, proper and morally appropriate health care at the end of life was identified as needing to be the over-riding consideration of the project. Indeed, a positive economic outcome should be viewed as a direct result of proper end of life practice which avoids not seeing death as a final outcome and which avoids efforts to keep people alive as much as possible, to the extent of risking sending them into unconscious states which can last several days. In this regard a proper understanding of the biological nature of dying is important along with the psychological and social impact of these extraordinary measures.

Project Aims

The purpose of this project was therefore to:

1. Provide a new appraisal of where we are with the moral teachings of various normative values by bringing together expert scholars in this field of study.
2. Understand why health care professionals fear using appropriate moral care pathways at the end of life.
3. Provide a basis for teaching and educating the general public and health care professionals in this regard.
4. Clearly define and identify that care that might normally be considered as 'ordinary care', such as artificial nutrition and hydration', can easily become disproportionate and extraordinary due to the discomfort caused to patients, not recognising that the patient's dignity and comfort should be the goal of any treatment at this stage of life; the clear purpose of the health care professional should be to treat *the patient* and not one's own (unclear) conscience and/or the fear of s lack of understand on the part of relatives.

Specific outcomes included:

1. The design of a curriculum for Health Care Professionals providing treatment at end of life.
2. A publication which will include various positions comparing and contrasting the end of life moral positions of the diverse cultures and religions within the European Community and the various ethnic groupings within.
3. A pathway to implement training and change at primary and secondary care level.
4. A pathway to implement change at a political level for Advance Care Planning in countries where such planning does not exist.
5. The commencement of 'summer schools' at the University of Malta to train physicians and nurses in End of Life moral theory and practice.

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