THE DOCTOR'S ROLE IN END-OF-LIFE MEDICINE

Fuat S. Oduncu

Division of Hematology and Oncology Klinikum der Ludwig-Maximilians-Universität München Medizinische Klinik, Munich, Germany

Abstract

Due to legislations on euthanasia and its current practice in the Netherlands and Belgium and Luxembourg, issues of end-of-life medicine have become very vital in many European countries. Here, the author rejects medical killing (euthanasia and physician-assisted suicide) as due care and proposes the delivery of palliative care in end-of-life medicine, which calls for a holistically oriented concept where physicians act as companions to the terminally ill and dying patients. Modern palliative care includes both the delivery of competent palliative skills and a virtuous attitude of compassionate caring about the terminally ill patient as an autonomous person.

Introduction

Medical doctors in industrialized countries are increasingly faced with decisions about end-of-life issues. This is a consequence of increasing population ageing and considerable advances in medical technology in the fields of life-sustaining and life-prolonging treatments. Moreover, the bioethical principle of respect for the patient's autonomy (Beauchamp and Childress 2001, Oduncu 2007) is being strongly stressed in the physician-patient encounter so that patients with incurable terminal diseases increasingly demand the premature termination of their lives.

Legalizations of euthanasia (EUT) in the Netherlands (2002), in Belgium (2002) and in Luxembourg (2008) have stimulated highly controversial international debates on the issues of premature ending of life in the terminally ill and dying. According to the Dutch and Belgian euthanasia laws, physicians who take action to hasten their patients' deaths are exempted from criminal liability, provided the due care criteria of intolerable and incurable suffering and of voluntary request are being satisfied, which are explicitly defined in the corresponding legal texts. Apart from the European context, the so-called *Death with Dignity Act*, which took effect in 1997 in the State of Oregon (USA), permits the legal practice of physician-assisted suicide (PAS) under certain conditions.

The German Association for Palliative Medicine (Deutsche Gesellschaft für Palliativmedizin – DGP)

In 2002, the *Working Group on Ethics of the German Association for Palliative Medicine* has conducted a survey among its physician members in order to evaluate *attitudes* towards different end-of-life medical practices, such as EUT, PAS, and terminal sedation (TS) (Müller-Busch et al. 2003, 2004). The proportions of the respondents who were opposed to legalizing different forms of premature termination of life were: 90% opposed to EUT, 75% to PAS, 94% to PAS for psychiatric patients. Terminal sedation was accepted by 94% of the members. The main decisional bases drawn on for the answers were personal ethical values, professional experience with palliative care, knowledge of alternative approaches, knowledge of ethical guidelines and of the national legal frame. In sharp contrast to similar surveys conducted in other countries, only a minority of 9.6% of the DGP physicians supported the legalization of EUT. Palliative care needs to be stronger established and promoted within the German health care system in order to improve the quality of end-of-life situations which subsequently is expected to lead to decreasing requests for EUT by terminally ill patients.

The concept of palliative care

In accordance with the definitions of the European Association of Palliative Care (EAPC) and the WHO, good palliative care should be the active care of patients whose disease is not responsive to curative treatment (Materstvedt et al. 2003). Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. Thegoal of palliative care is achievement of the best quality of life for patients and their families. Palliative care affirms life and regards dying as a normal process, neither hastens nor postpones death, provides relief from pain and other distressing symptoms, integrates the psychological and the spiritual aspects of care, offers a support system to help patients live as actively as possible until death, offers a support system to help the family cope during the patient's illness and in their own bereavement. This holistic concept of care is derived from Ciceley Saunders' concept of 'total care' as the corresponding answer to her concept of 'total pain'.

The need for 'caring for' increasingly evolved as a consequence of the increasing depersonalization of medical care in hospitals. The holistic approach demands that physicians become more attentive to a personal relationship with the patient and his/her relational background. 'Caring for' involves sympathy with the patient's total situation, i.e. with the patient's quality of life, rather than with his mere disease. A caring solicitude for the individual patient has now become integral and essential e.g. in palliative terminal care. 'Caring for' starts with simple issues: listening to patients with personal attentiveness, considering the values and concerns of the patient, being attentive both to the physical and the emotional components of illness, and offering maximum understanding, freedom and comfort to the individual patient (Oduncu 2003a, 2003b, 2005a, 2005b, 2006a, 2006b, 2007).

Principles of the German Medical Association concerning terminal medical care

'The duty of the physician is to preserve life, protect and restore health, relieve suffering and be there for the dying until death, while respecting the patient's right of self-determination' (Bundesärztekammer 2004). In 1998 and again in 2004 an 2008, the Bundesärztekammer, i.e. the German Medical Association, completely revised and published the new Principles Concerning Terminal Medical Care.

Here it is explicitly stated that, irrespective of the objective of medical treatment, a doctor is always obliged to provide so-called 'basic care'. This includes, inter alia: dignified accommodation, personal attention, personal hygiene, the alleviation of pain, of respiratory distress and of nausea, and the stilling of hunger and thirst. The nature and scope of treatment are the responsibility of the doctor. In this context, the doctor must respect the patient's will.

The doctor's duty vis-à-vis the dying is to help the dying in such a way that they are able to die with dignity. In addition to palliative care, this help includes emotional support and the provision of basic care. The medical obligation to preserve life does not apply under all circumstances. There are situations in which otherwise appropriate diagnostic and therapeutic measures are no longer indicated and limitation can be necessary. Palliative medical care comes to the fore in these instances. However, active euthanasia is punishable by law, even if it occurs at the request of the patient. The participation of a doctor in suicide contradicts medical ethics and may be punishable by law. Measures to prolong life may be dispensed with or discontinued in compliance with the will of the patient, if they would only delay the onset of death and the progression of the illness can no longer be stopped. Furthermore, the alleviation of suffering in the dying can be prioritized in such a way that the possibility of unavoidably shortening life may be accepted. But deliberately shortening life through measures that induce or accelerate death is impermissible and punishable by law.

All decisions must reflect the will of the patient. If the patient is unconscious, his presumed will is to be determined by his previous attitudes and declarations, his philosophy of life, his religious conviction. Relatives and intimates should be consulted in determining the presumed will of the patient. Advance directives (AD) are an indispensable guide for the action taken by the doctor. ADs are binding, insofar as they relate to the concrete treatment situation and there are no indications that the patient would no longer permit them to apply.

The German Principles Concerning Terminal Medical Care are generally very well accepted by the medical and nursing professions as well as by German society. The provision of competent

multidimensional palliative care plays a key role in the treatment of terminally ill patients and patients with infaust prognosis. Prolongation and preservation of life are then replaced by palliative medical and nursing care. The decision to change the treatment objective must reflect the will of the patient. The German approach seems to succeed very well in addressing relevant medical-ethical principles of patient's autonomy, beneficence and non-maleficence (Oduncu 2003a, Oduncu 2007).

'RAHME' (Arabic ,rahim'): caring with competence and compassion

As I mentioned above, euthanasia cannot be part of medical care. Historically, 'care' has a specific content that stresses both excellence (skills, professional competence) and virtue (attitude of being supportively there). The meaning of 'care' is twofold and can be traced back to the old Aramaic term 'RAHME' of ancient Mesopotamia, the former metropolis between the two rivers of Euphrates and Tigris. 'RAHME', which constitutes the Arabic term of 'rahim', encompasses (i) the notion of 'taking care of' the sick and (ii) the notion of 'caring for' the sick (Reich 1995). These two basic and different notions have been pointed out by Warren Reich's investigations on the concept of care: 'In the context of health care, the idea of care has two principle meanings: taking care of the sick person, which emphasizes the delivery of technical care, and caring for or caring about the sick person which suggests a virtue of devoting or concern for the other as a person' (Oduncu 2003a, 2003b, 2007).

Conclusions

The holistic concept of caring is precisely what is expressed by Ciceley Saunders' concept of 'total care', which responds to 'total pain'. 'Caring' or 'RAHME' can be expressed through acting as a companion to the patient until the very end of his/her life, as it is e.g. explicated in the preamble to the German Medical Association's Principles Concerning Terminal Medical Care. The German expression for terminal medical care is 'Sterbebegleitung', which means to be a companion to the dying, accompanying the dying on his way, neither shortening it nor prolonging it: 'The duty of a doctor is ... to relieve suffering and to accompany the dying until the end' (Oduncu 2003a). The caring disposition inclines the responsible physician to respect the patient as an autonomous agent and to recognize the patient's considered value judgments, even if they are contrary to what the physician expects.

'Caring for' is linked with covenant fidelity, which requires care directed to the person of the patient, i.e. to 'the patient as person'. Palliative care as the content and frame of the holistic caring of and caring for the terminal ill and dying is providing assistance to life; it helps make life richer and more enjoyable by removing hindering pain and mental inabilities. Palliative care is the only answer to be given to patients requesting a termination of their lives. Euthanasia should be removed from the medical stage, since it has never been part of it and should remain an illegal crime. However, when medically futile treatment is discontinued, the patient's life will end; but it is not the physician who ends life. It is the underlying disease, the patient's general condition that is the cause of death. In such instances of withdrawing treatment or in cases of withholding futile treatment, the physician cannot be made morally responsible for the patient's subsequent death. Hence, when a terminally ill patient is suffering and no longer benefiting from medical care, treatment should be ended in agreement with the patient's express or presumed will, but not the patient's life. When the treatment is ended, the patient can die in peace and dignity. Because of its aggressive interventionism and its inability to acquiesce, medicine could be instrumental in creating conditions that bring patients to request active euthanasia. Therefore, medicine must always be on its guard.

Doctors and nurses of today need to have both the 'professional competence' (care as skills) and the 'humane competence' (care as virtue), in order to provide the optimal instead of the maximal but incomplete care. Only these two competencies together will establish an attitude and a treatment with which the patient may personally feel not only being taken care of, but rather cared for, which results from a virtue of devotion or concern for the other as an autonomous human being.

Taking care for or about a terminally ill or dying patient is to promote this particular human being in all his/her dimensions and relations, or in short, to regard this patient as a human person. Nothing else is described by the Aramaic 'RAHME', which reveals the basic idea of the German 'Sorge', including the active dimension of 'taking care of' and the rather passive dimension of the 'caring for' attitude towards sick and needy fellow humans. 'RAHME' presents the spirit of integration between

the ancient intentionbased medicine and the present evidence-based medicine, resulting in a more fitting value-based medicine, which should be the new goal of present and future health care (Oduncu 2003a, 2003b, 2005a, 2005b, 2006a, 2006b, 2007).

In this sense, care ethics demands from caregivers 'total personal care' of the particular sick and needy human being within an intimate caring relationship, with the aim of promoting the physical and mental well being of the patient by providing good care. To achieve this, care ethics calls for the delivery and application of competent skilled care, which is inherently embedded in a virtuous attitude of compassionate caring about the patient as a person. The underlying anthropology of care ethics evokes in caregivers honest feelings of solidarity, responsibility and attentiveness due to a Levinasian facing of the vulnerable and dependent human individual who does not lose his/her dignity despite all infirmity and frailness (Oduncu 2003a).

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