Controversies in terminal cancer care

Abstract In the long term, about 75% of all cancer patients will need palliative care, but the curricula in courses of study leading to qualifications in the caring professions take no account of this, being concerned exclusively with curative strategies. Precise definition of palliative care as a medical discipline is needed, followed by insistence on proper funding and instruction. In addition, palliation should be integrated into the early stages of patient contact, e.g., prevention, diagnosis, treatment planning, and not only implemented when attempts at curative therapy have failed. Public and political awareness must be promoted; in particular it should be recognized that the caregivers themselves need support. There is a growing need for well-run hospices with purpose-trained staff. While “mercy killing” might be considered out of charity and humanity, the death of a terminally ill patient should be neither hastened nor postponed.

Key words Hospice care
Terminal cancer · Palliation
Education

Increasing numbers of incurable cancer patients – lack of resources

In the European Community about $1.2 \times 10^6$ cancers are detected every year. Only 50% of patients with malignant tumors will survive more than 5 years. About 25% will progress during or relapse following primary anticancer treatment. This means, that about 75% of all cancer patients sooner or later will need palliative treatment or care [6]. In absolute terms, about 730,000 cancer deaths occur in Europe every year.

During the last 40 years cancer research has made a major contribution to our understanding of how tumor cells develop from normal cells and how established tumors can be eliminated by antiproliferative radiation or drugs. Despite the fact that 95% of all existing knowledge in scientific oncology has accumulated in the last 50 years, we still do not have a cure for the majority of patients with solid tumors.

For more than 30 years it was a prerequisite for an academic career that a young doctor, before starting clinical education, experienced solid scientific research in a theoretical institute. His or her task was primarily to study or induce tumors in experimental animals before being exposed to a living human being, diseased with a malignant process. When faced with a patient, the young scientist suddenly realized that, for the patient, his tumor did not mean merely a biological host/tumor interaction but an existential catastrophe with unforeseeable consequences not only for himself but also for his family.

Most of us as young doctors and nurses have felt hopelessly isolated and sometimes paralysed by the abundance of problems encountered in our first contacts with a terminally ill cancer patient, who wanted a caring human being much more than a sophisticated, scientifically skilled, insecure and possibly sometimes even slightly arrogant mouse doctor.

Intensive training in basic research and a focus on prospective, controlled, well-documented clinical trials created a generation of oncologists aiming for maximum success in cancer cure rates, measured in complete...
remission and tumor-free survival percentages over the years. There was more emphasis on years to life than on life to years.

More money was spent on work on single cancer cells, viruses and the study of the role of oncogenes in tumorigenesis than on pain control, supportive care measures and better strategies to help the patient through the final stages of death and dying. This was partly due to ignorance and the unwillingness of the scientific community to realize and accept the need to concentrate more on care than on cure, especially in the face of increasing numbers of incurable cancer patients. In addition, it was partly due to the lack of acceptable and compatible research programs or applications for funds fulfilling the requirements applied to scientific grant applications. The third reason for the continuing imbalance in the allocation of financial resources for research into cancer pain relief and palliative care is the unwillingness of the experts advising funding societies to accept palliative care research applications, possibly because of a lack of understanding of the inherent problems and an overestimation of the value of so-called hard facts, such as the Western blots and test-tube results of fundamental science.

Twycross summarizes this dilemma: “... all too often palliative care and possibly also research in palliative care is seen as the “waste paper basket” alternative among treatment and (-research-) options” [10].

**Is palliative care a medical discipline?**

From what I said earlier, it is obvious that this particular area of medicine, which concentrates on the care of terminally ill patients, is still underestimated in the medical world.

There is an intense debate, even among care givers attending terminally ill patients, about whether palliative care is a medical discipline or just a multidisciplinary appendix of several specialties like medical oncology, surgery, radiotherapy and psychosocial and religious institutions.

People involved in the care of terminally ill cancer patients often suffer from a lack of self confidence because of a poorly defined understanding of their status. The idea and operational institution of palliative care units and hospices have been propagated more by public opinion and the families of suffering and dying patients than by well-designed planning in medical faculties or by physicians.

Nurses, doctors, psychologists and priests giving care to terminally ill cancer patients often feel that the “conventional” medical community and even hospital administrations demonstrate an uninformed, distanced, sometimes even hostile attitude toward palliative care institutions. They feel the need for a more defined formal status, improvement of financial, organizational and human resources and a better integration in the continuum of medical care for all patients from the diagnosis to death.

Toscani [9] names several parameters underlying the fact that palliative care is not an integral part of the medical tradition:

1. Resistance to the recognition of palliative medicine as a discipline
2. Priority of financing medical projects and research concerning relatively rare pathologies
3. Lack of space allocated to palliation at conferences and in textbooks.

Furthermore, individual attitudes and prejudices hamper the recognition of palliative care as part of a comprehensive strategy of cancer control. For example, it is widely believed that therapies and techniques for symptom control are of secondary importance, specific training is unnecessary, any nurse or physician knows exactly how to proceed in pain relief, psychosocial comfort-giving and helping patients to die [9].

These attitudes result from our current concept of medicine as a discipline based on natural science, emphasis being placed on quantification more than qualification. Medical ethics is based on deontological principles or ethics of obligation, which imply *sanare infirmos*, heal the sick by fighting the cause and the aggressor: a virus, bacterium or a transformed cell, and cure the illness. The second principle: *sedare dolorem* means relieve the pain and care for the incurable, suffering human being; this defines the ethics of mercy, the ethics of humanity, which do not aim at maximal health or the ultimate biological perfection of the human body, but at the wellbeing and consolation of an incurable patient.

The cardinal ethical principles governing medical practice are defined by several authors [1] and the WHO in 1990 [11]:

- Respect the patient as a person
- Do good
- Minimize harm
- Respect life
- Accept the ultimate inevitability of death
- Use available resources adequately.

To resolve this controversy between the “ethics of obligation” in traditional cure-orientated medicine and medical practice under the auspices of the “ethics of mercy” means to liberate palliative care from the odium of voluntary charity and missionary self-fulfillment and promote it to an integrated discipline of palliative medicine.