



PACES Free Ride - Saloon

The economics of dying

« The care that a people give to dying patients, within available resources, is an indication of their degree of civilisation. » World Medical Association Declaration on End-of-Life Medical Care, adopted by the 62nd WMA General Assembly, Montevideo, Uruguay, October 2011.

Death, from a medical perspective, is often seen as the enemy to defeat. Health professionals strive to prevent death. Thus, massive amounts of resources are invested to pursue the universal goal of life expectancy, to postpone the inevitable. Past decades have shown the great effectiveness of medical care in curing bacterial infections, and in identifying and addressing cardiovascular risk factors, among other major breakthroughs.

But when death is recalled inevitable and seems quite near, the goals of care need to change for those defined as “dying patients”. Cure becomes care. Quality of life replaces quantity of life. Personalization skyrockets. Palliative care comes into play.

The World Health Organisation defines palliative care as *“an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient 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 patients illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”*



This broad definition covers aspects that go way beyond public opinion of palliative care, often reduced to end-of-life care.

The care given to dying patients follows the same four principles of biomedical ethics as for all patients. Tom L. Beauchamp and James F. Childress enunciated these four principles: respect for autonomy, nonmaleficence, beneficence, and justice. Among these four, justice particularly echoes the WMA Montevideo Declaration in its phrase “within available resources”. Available resources imply the need to make choices. The principle of justice promotes the choice of a fair distribution of resources. Choices can be considered either from an individual perspective, or from a societal perspective. In the former, micro-economics guides the decisions. In the latter, macro-economics guides the decisions. This all leads to hypothetical “economics of dying”.

Micro-economics informs individual decisions, either from a patient’s point of view or from a health professional’s point of view. For example, swelling wounds need frequent dressings changes, which take a long time for specialised nurses, physicians and nurse-aids. The frequency of this care can be determined by the long-lasting comfort it brings to the patient, the discomfort it brings during the care, and/or the total cost of changing the dressing. Micro-economics will help define the right pace according to complementary points of view.

Macro-economics informs public health decisions through evaluations such as health politics evaluations. Three aspects are evaluated: effectiveness, equity, and efficiency.

Effectiveness can be seen as the pragmatic efficacy of interventions in “real life”. Using the example of contraception, male condoms have a 98% efficacy in preventing unintended pregnancies, but only an 82% effectiveness because of mistakes in their use and/or non-systematic use. In palliative care, effectiveness is measured by patients and their caregivers. The outcomes of palliative care in terms of comfort and symptom management have to be balanced with the required burden on caregivers and their care-related satisfaction. Unmet needs can also be an evaluation criterion for the effectiveness of palliative care politics, which emphasizes on the importance of patient-centred care.

Equity is strongly linked with accessibility. Financial accessibility is the main key to equity, matching needs and means. Geographical accessibility is the second main key to equity, matching healthcare



needs and healthcare settings distribution. Cultural accessibility is more difficult to achieve as it relies on all actors' open-mindedness. For example, dignity is a value with many diverse cultural applications. Therefore, protecting one's dignity until death can mean opposite options depending on their cultural background. Equity is also linked with setting priority among priorities. Which plan should get the most resources between a rare disease plan (diseases affecting mostly children, but very few patients), and a palliative care plan (condition affecting mostly aged patients, but most of them at some point)?

Efficiency is the ratio between investments and health outcomes. Several methods help explore efficiency, among which cost-utility studies. Cost-utility studies are more adapted to palliative situations, relating invested costs and "soft criteria" such as quality of life. How much is an intervention worth it? One criterion mixes quality of life and quantity of life, and is called QALY, for Quality-Adjusted Life Years. Patients rate the utility of their condition, from 0 (dead) to 1 (perfectly healthy). For example, an intervention after which the median survival is 5 years with an estimated utility of 0.3 leads to 1.5 QALY. It can be compared with the absence of intervention, after which the median survival is 2 years with an estimated utility of 0.9, leading to 1.8 QALY. In this situation, the absence of intervention should be preferred. Unless the total costs are higher in the abstention option, which opens a whole new field of discussion!

To conclude, health economics in palliative care estimates, to some extent, our degree of civilisation. The political act of choosing the distribution of resources reflects the respective importance of priorities. Concerning dying patients, distribution of resources is not only a matter of economics and health, but also a matter of ethics and humanity.

