A good death for cancer patients: still a dream?

For some time now more attention has been given to the patient–doctor relationship in patients with grave illnesses, and in particular terminal or pre-terminal cancer patients, in the hope that a more personal relationship can contribute to improving the difficult existential situation in which these patients find themselves [1–3].

In the Old Testament, Ecclesiaste, who has had his Hebrew name of Qoelet restored, said that of all the moments in human existence, life and death should be united: ‘there is a time to be born and a time to die’, what has happened in the past will happen again and what has taken place in the past will take place in the future.

These words, which probably precede Christ by several centuries, acknowledge the undeniable end of our earthly existence but their wisdom constitutes the premise for the acceptance of a binominal (birth and death) as the result of a process of transformation which is absolutely biologically natural.

Death, even though usually experienced with pain and inevitability as in the Book of Qoelet, could possibly find a connection in the antique rural civilization which was based on the large patriarchal family where the old died surrounded by the affection of family and relatives. It was the moment when the young family members began to understand life and death. The social transformations which have taken place and have led to the total disappearance of that civilization and with it the patriarchal family, have made it too much of a problem, too difficult to take care of the advanced cancer patient within the small family unit.

For at least 20 years our modern civilization, particularly Western society, has been trying to distance itself from, to cancel with every means at its disposal, the very idea of death since it is in profound contrast with our presumed omnipotence. It is therefore undeniable that in our culture the acceptance of a natural end to life is not even contemplated.

In her historic essay on Death and Dying, psychiatrist Elisabeth Kubler-Ross differentiating between the concepts of death and dying, defined the various phases which often accompany the sick person while, with varying degrees of awareness, they come closer to death [4].

The doctor who attends these patients must be aware of how the loneliness which they often experience in the last stages of illness becomes one of the most important components of the pain in which these patients find the last days of their lives immersed.

If a lot has changed in recent years in the field of controlling physical pain, thanks to new medicines and new therapeutic approaches, it is also important to remember that the cancer patient’s pain at this stage is global, not only physical but made up of numerous other components which are not always recognised by others such as anger, anxiety, rejection, depression, abandon and exhaustion, which are frequently experienced not only by the patient but also by the people who share this dramatic experience with the patient.

These feelings become more and more negative as time slowly passes and patients become more and more aware that there is no future; that their days are ending. They re-live the whole experience of the illness seeing some events as insignificant such as time in remission or symptoms, while magnifying others such as late diagnosis, bureaucratic difficulties and useless suffering (given the outcome) due to therapy. Therefore every action taken or decision made is seen as a mistake since they have not been definitively cured. In this situation, apart from the anger with those who have suggested or imposed a diagnosis or a course of treatment, a patient can also start to blame him or herself for not having accepted advice or on the contrary for having insisted on a certain course of treatment. To all this we can add other feelings of fear of being in hospital far from home, from family, of physical pain or worrying about how the family will cope ‘after’.

The knowledge that you are in the last days of your life, a time which is not seen as a residual moment before death but more as a moment to prepare for death, is often terrifying because it continues for a period of time, it is a process. This is why people wish death to be quick and not to have this experience of being aware that they are dying.

So, what is the role of the doctor, the nurse, the psychologist, and the family in these circumstances? Is it possible to share the last moments of a person’s life, taking into account all the limits imposed by the situation, in order to achieve a ‘good death’ [5]? Is it possible to accompany a patient along this last path making these last moments less tragic?

However difficult, it is the mission of these people to help patients improve their quality of life as long as possible, not by insisting on treating the illness but by taking care of the patient. The illness may be incurable but the patient can always be treated in the most honest way possible while respecting just to what extent the patient is willing to share this experience.

Will the promise of a ‘good death’ remain just that, a promise, or will we see at least a partial, gradual improvement?
Maybe even today a ‘good death’ in many cases is still only an illusion, but maybe, even if only in a very limited way, we are moving closer to death in patients with degenerative illnesses which is no longer dominated by physical pain or by those components which make dying and leaving loved ones such a terrifying experience. Research in recent years has found new energy after being neglected by the medical profession for many years. This research is focusing on some fundamentals such as an accurate psychological evaluation of the patient using methods created specifically to quantify the emotional impact of the various feelings mentioned above, adequate training for all those people who share this last stage of life with patients, the creation of a network which consents a coordinated response on the part of the hospice, assistance at home and the hospital, and financial help for those families who find themselves in economic difficulties with the death of a family member. This economic assistance, which is already available in some countries, could begin before the patient dies, for example with the loss of work or when it becomes necessary to prescribe expensive medicines which are not free or refundable.

The implementation of these practices would improve the quality of death by reducing, in part, the weight of some of the components of that global pain which oppresses patients and families especially if these interventions which contribute to a ‘good death’ are the result of harmonization between the technical and ethical aspects of the matter but never forgetting how the relationship between all the people involved in these experiences must maintain a profound anthropological dimension.

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references