Points of View

The Little Wound

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s a 6th year Medical student, I was presented with a unique opportunity to carry out an analysis of the provision of Palliative Care in Portugal. In fact, my daily experience, although undeniably limited, with patients of various services, and the successive adjustments to the *modus operandi* of the respective medical teams, essentially enabled me to carry out an in-depth experiential and ethical reflection on the path taken by these patients and their families, and the way in which the medical community tends to act under these circumstances.

Firstly, I believe it is important to reaffirm, clearly and unequivocally, the concept of Palliative Care as assistance provided to patients with advanced, progressive and incurable diseases. The common practice of reserving this type of care only for moribund patients in the final stages of life means to deprive all the others, who are not necessarily in a terminal stage, of a range of specialized care, guided by and based on their real physical, psychic, social and spiritual needs, and not simply on their diagnosis or prognosis.

This type of follow-up includes the approach of death in a totally humanized perspective, recognizing the dignity of the Human Being in a context of profound suffering, with which the end of life is often associated, its main objective being to preserve the patient's quality of life as far as possible. Thus, rather than being repeatedly postponed, based on the hope of a recovery that may be unrealistic, it should be provided as early as possible, in order to guarantee

individualized care for the patient.

However, I understand that this practice can sometimes be worrying, since a failure to invest in the curative act can be mistakenly seen as a lack of technical knowledge, lack of professional effort, and personal defeat, as though the inevitability of death were not the natural end of life, but rather, the personification of our fears, uncertainties and failures.

It is necessary to uphold ethical principles of welfare and nonmaleficence, to which we are committed, on behalf of each and every patient. Thus, we are responsible not for offering cure in all circumstances, preserving life at any cost, but with providing appropriate treatment for each situation, as the search for cure is not always in the best interests of the patient, and because our medical duty, according to the *Hippocratic Oath*, includes the obligation to act "for the patient's good", therefore our investment should not be in the disease, but rather in the patient.

One component which I believe is of vital importance in this area is communication, which reminds me of some fairly common scenarios in the hospital context. I remember the hushed voices at the patient's bedside, as though the very sound of the words would make them become real, the piously told lies, as though the truth would somehow speed up the course of the disease, and the visits by the medical team, almost instinctively in a hurry, as a form of protection against having to answer awkward questions.

I clearly remember one particular patient, with whom I had contact two years ago in a ward, who told me, in a calm, convinced voice, "I'm having surgery for a small wound in the intestine, but it's nothing more than that. The Doctor told me it wasn't a tumor".

I later learned that "the small wound", as they had decided to call it, was, in fact, an adenocarcinoma of the rectum.

I confess that over the years, I have often caught myself wondering how that patient would have reacted, on waking up from the anesthetic and noticing that he had, after all, undergone mutilating surgery

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and for which he had not been prepared, or how he would react, years later, if the Dr. told him that the "small wound" had in fact spread to the entire body.

I also remember episodes witnessed in other wards, where we were informed in advance that certain words, like "tumor" or "cancer", should not be uttered in front of the patients, and where the students were strategically asked to observe certain patients, to avoid embarrassing situations, since "you are not involved in the case, so they don't ask you questions".

In all areas of medicine, but especially in the context of Palliative Care, a lack of communication can give the patient the feeling that he has been abandoned, and that the doctor is not investing in him, which can increase the anxiety faced with a lack of knowledge. This may be accompanied by feelings of self-recrimination and loneliness.

Thus, the doctor should attempt to establish a relationship of empathy with the patient and pay close attention to the type of information he/she is providing, and that the patient is capable of receiving.

Even though at times, most of the information is given to the family, whether due to the patient's inability to perceive, or at the patient's own request, the family members often expect the doctor to collude with their decision not to tell the patient the whole truth. In these cases, it is important to attempt to perceive what are the family's true motives, always bearing in mind that our duty, first and foremost, is towards the patient.

False hopes should never be raised, as these serve only to escape the reality in the short term; as the truth comes to light, the patient's lack of confidence in the relationship with the doctor will increase.

On the other hand, the patient's expectations should always be upheld, as this, as a positive expectation of reaching a determined objective, is always valid. It is therefore essential that these be based on realistic premises, and that new routes and perspectives be discovered over time.

However, I have observed that this is sometimes a thankless task for the doctor who, in practice, sees his or her practice as constantly conditioned by a set of limitations, multiple etiologies which are difficult to resolve, and which tend to be exponentially combined.

When the moment of imparting bad news is constantly interrupted, or when a moment of privacy takes

place behind a curtain in a room with eavesdroppers, or in a corner of a corridor where others can listen in, it is understandable that discouragement will grow and deeds move away from convictions.

An additional effort is therefore needed, to provide quality healthcare for patients who are facing death, just like that offered in life.

Death, being an uncomfortable issue, is usually addressed only in an implicit way by health professionals, and discussion of it is generally restricted to the technical aspects.

Therefore, it is important to stress the transversal nature of themes associated with the area of Palliative Care, as dignity and respect for others should be two common premises for any doctor; as Philippe Ariès, a French historian of the last century affirmed, "to forget death and the dead is to provide a poor service to life and the living".