

## Editorial

# A Nurse's Glance Towards Palliative Care in the Neurological Patient

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Palliative care is recognized as a right, and therefore should be applicable to all patients who need it regardless of the etiology of the disease they suffer. But the truth is that for different reasons, palliative care for the non-cancer patient is unequal.

Palliative care is necessary and effective in the care of patients with neurological involvement, especially if it is degenerative. With the same aim, we need to consider certain differences regarding palliative care in the oncological patient. Families spend long periods of time with the patient feeling powerless and witnessing a progressive loss of the patient's abilities. Besides, we must consider the high prevalence of communication difficulties, cognitive impairment and the behavioral disorders that these patients suffer. This causes families to go through an increasing overload that makes them especially vulnerable. Therefore, an adequate emotional support is necessary during both the disease process, and after death. To a large extent, this can prevent the appearance of complicated mourning. Despite this, in general, the family that takes care of a patient with a neurological disease usually resorts less frequently to external help. Together with the patient they establish a meticulous routine that sometimes clashes with the rigidity, for example, of the hospitalization units. They are less inclined to establish bonds of trust with the therapeutic team, which means that they are not able to completely disconnect, limiting the reduction of overload.

The integration of palliative care from the moment of diagnosis in addition to other therapies aimed at delaying the progression of the disease, contributes to improving symptomatic control and, to a large extent, improving satisfaction in the perception of care received in patients as in relatives. The application of palliative measures within neurological care helps to improve the quality of life of patients and relatives.

From the point of view of nursing, the palliative care model allows for complete professional development. Based on the essence of our profession, care allows us to meet the needs of the patient and family in an integral way, considering all the spheres of the person. It facilitates the support to the patient and family throughout the entire process,

using tools such as emotional support, communication or symptomatic control. All this is done from the perspective of interdisciplinary work with the other professionals that make up the therapeutic team. The nurse is the person who spends the most time with patients and families. Having as object of care the binomial that both form and, assuming the privilege of our position within the therapeutic team, we must be able to provide integral care from the individuality; understanding that each patient and family are unique. They bring with them a history of their own that should be considered. We need to be consistent, not only among the different nursing shifts in a hospitalization unit, but also between the different levels of care or among the different members of the team. Without contradictions. All under the same objective. We need to be flexible, being aware that patient and family are subject to changes to which we must adapt. They are the ones who impose their rhythm and set the standard to follow, while nursing must be facilitating the numerous adaptation processes they face due to progressive losses. We need to be accessible, and support the continuous and changing needs, so they are

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aware that they can count on our support at any time. And finally, we need to be versatile, since working as a team means knowing the work of other colleagues and often complementing it.

Palliative care, in this case focused on the neurological patient, is flooded with behaviors, many times invisible to the eyes of others, but which characterize nursing. The concern, the commitment or the affection, configure the essence of accompaniment.

Patients and families expect from us, perhaps unconsciously, an attitude of welcome from where to create that space of trust that is so necessary for an honest communication to flow properly. Let us leave aside our fears and concerns, and make them see that we understand their suffering and that we will not leave them alone on their last journey. This task is not easy, but it can be achieved with maturity and personal balance, the ability to adapt or listen, patience or self-care.

In short, our aim is to support our patients so that the time that remains for them does not become an inexorable waiting for death, but rather a time of life.