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LECTURE

The role of palliative care

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Abstract

Introduction: Stroke patients and families go through significant distress in their illness trajectory related with symptoms, function loss and psychosocial factors. Often there is a significant uncertainty of prognosis and recovery potential. According to WHO, Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness.

Case description: We present a clinical case of a 27-year old male with catastrophic stroke after replacement of aortic valve due to endocarditis/aortic stenosis, the challenges in his care and reflect about the role of the different teams involved in his care. After the surgery he did not recover consciousness and needed ventilator support with tracheostomy. The magnetic resonance showed diffuse ischaemia of cerebral hemispheres with generalized cerebral atrophy and microhaemorrhages of the basal ganglia and thalamus. The electroencephalogram reported global dysfunction without epilepsy. The patient was reported as a being at a minimally conscious state at the time of the first evaluation by the palliative care consulting team (PCT). The PCT was requested because of restlessness, perception of discomfort and family suffering. At our first evaluation, the patient scored 8 on the Glasgow coma scale, was breathing with BPAP by tracheostomy, fed by gastrostomy, with dyskinesia of upper limbs and paraplegia and generalized spasticity. Most of the time, there were several non-verbal pain signs such as flexion withdrawal, grimacing and crying facial expression that prompted opioid analgesics administration without relief. His parents were very anxious and in conflict with the surgical team. In the following months, before discharge to a long-term care facility, the PCT worked together with cardiac surgery, neurology and rehabilitation specialists to relief patient suffering by means of identification and treatment of pain and other problems. The opioids were mostly discontinued except for incidental pain and antidepressants were successful at pathological crying/pseudo bulbar affect. He responded to muscle anti-spasticity drugs. There were several challenges at the level of family relation with the clinical team with disagreement of medical limitation of the intervention level that posed ethical dilemmas, in addiction to blaming the team for the late recognition of endocarditis. In the following 2 years after hospital discharge, the patient was submitted to rehabilitation at the long-term care facility and recovered from the minimally conscious state, was successfully decannulated, recovered upper limb motor function and verbal response. He was discharged home with the support of both rehabilitation home team and palliative care team with successful family adaptation. Currently, he he has been discharged from palliative care team and is being followed at a local rehabilitation clinic.

Discussion: Patients with catastrophic stroke pose several challenges at the level of prognosis, rehabilitation capacity, and definition of levels/limitations of intervention. The palliative care team work was an added layer of support to the patient, family and clinical specialities involved with care. Sometimes patients recover significantly; others do not, but both patients and families need support to adjust to the new realities and that imposes that all the teams involved in care have training in communication, symptom management, ethics and psychosocial intervention that constitute the basic of palliative care intervention.

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