Palliative Care for Motor Neurone Disease (MND) – A Case Study

Introduction

Motor Neurone Disease (MND) is a progressive neurodegenerative disorder characterized by muscle atrophy leading to their weakness and wasting (Knight, 2020). Its most important symptoms are immobility, and difficulty in swallowing and breathing (Foster and Salajegheh, 2018). As per the National Institute for Health and Care Excellence (NICE) guidelines, people diagnosed with this disorder should be immediately assigned to a multidisciplinary care team and a palliative care team for improved quality of life and prognosis. Patients who are provided with this type of care at an early stage can have improved chances of survival and a better quality of life (Veigh et al., 2019).

In this case study, the patient was diagnosed with MND at an early age of 40 and died within 18 months of his diagnosis. The objective of this paper is to analyze the clinical care and palliative care provided to the patient in light of the End of Life Care Clinical Practice Guidelines (CPG), the National Safety and Quality Health Service (NSQHS) Standards and the Nursing and Midwifery Board of Australia (NMBA) Standards. It focuses on whether the patient's wishes were followed based on the Advanced Care Directive (ACD) filled out by the patient early in his diagnosis, whether his wishes verbalized towards the end were followed, and whether the clinical care administered to him was competent, appropriate, and in accordance with his ACD.

Description of the case

Tyler Morton is a 40-year old patient suffering from Amyotrophic Lateral Sclerosis (ALS). This diagnosis was made 18 months ago after he developed weakness in his left hand that progressed to his right hand, foot drop in his left ankle, and shortness of breath without exertion. Initially, these symptoms seemed unusual because he was otherwise fit and healthy, and so he decided to get them checked leading to his diagnosis. About 12 months ago, his condition deteriorated and he gradually developed headaches, fatigue, dyspnea, dysphagia, and required help in mobility. As his condition kept deteriorating, he underwent gastrostomy and suffered from several infections at the site of insertion of the tube. He began requiring non-invasive ventilation (NIV) at night and started developing limitations with his mobility. He required help in movement and fed through a peg tube. He also had recurrent infections at the site of insertion of the peg tube, which led to fever and confusion in the patient. Gradually, his breathing began to worsen and he was given NIV to assist with breathing. Finally, his ALS and infections progressed to the terminal phase and he died in his family home with his wife at his bedside.

Discussion

ALS or Motor Neurone Disease (MND) is a progressive neurological disease which manifests as paralysis of the extremities, problems with breathing, speaking, and swallowing, and progressive muscle weakness. Death usually occurs due to respiratory failure secondary to weakness of muscles in the chest wall and diaphragm (Oliver, 2019). The prognosis of this condition is very poor, and palliative care is recommended from the time of diagnosis (Oliver et al., 2016). It is also recommended that a multidisciplinary team be available to identify triggers for worsening symptoms and counsel the patient and family members regarding the prognosis of the condition (Flemming et al., 2020). Studies have shown that early palliative care can improve the quality of life of patients as well as increase their survival rate (NICE, 2016).

In this case study, the diagnosis of ALS was made 18 months before the death of the patient. The prognosis of ALS is usually 2 to 3 years; however, the patient's condition worsened and became terminal within just one and a half years (Masrori and Van Damme, 2020). In light of the End of Life Care Practice Guidelines, when a patient is diagnosed with a terminal illness, all measures should be taken to improve the quality of life of the patient, respect his wishes for end of life care, follow directions in the Advanced Care Directive (ACD), and have open discussions with the patient and family members regarding the prognosis of the patient's condition (Ahluwalia et al., 2018). Despite the recommendation for early palliative care for ALS, a palliative care team was appointed quite late in the patient's prognosis and they were not able to completely honour the wishes of the patient, either outlined in the ACD or stated verbally.

An important requirement of the ACD is to ensure that patient's wishes are followed towards the end of life where the patient is unable to take and/or communicate his decisions regarding his health (Goswami, 2021). As per the patient's wishes in the ACD, he did not wish to die in the family home and he had clearly requested to be moved to a hospice when the time came. As his condition deteriorated, he also verbalized this request to the palliative care team. Although the team member arranged for his admission to a hospice, it was too late and the patient died in his family home. Until the end, the patient was oriented to person, time, and place and was aware of his surroundings as well as the people around him. Despite verbalizing his request, the palliative care team failed to recognize the triggers that pointed towards his deteriorating condition and admit him to a hospice on time. One of the standards of the National Safety and Quality Health Service (NSQHS) is the 'Recognizing and Responding to Acute Deterioration Standard'. The members of the palliative care team showed lack of adherence to this standard in failing to recognize acute deterioration in the patient and taking action on time.

Another one of the patient's request as written in the ACD was that all infections should be treated. However, the patient seemed to suffer from multiple infections at the site of insertion of the feeding tube. It is apparent from the case study that risk of infections was not appropriately understood, prevented and managed for the patient. In case of patients suffering from MND, it has been shown that occurrence of infections can lead to rapid deterioration in the patient (Hussain et al., 2018). Here, the patient suffered from multiple infections following gastrostomy; however, appropriate action was not taken to treat this infection and prevent its occurrence in the future, despite the patient specifying in the ACD that he would like all infections to be fully treated (Carter, 2020). Therefore, neither was the patient's wishes in the ACD respected nor did the clinical team follow the Nursing and Midwifery Board (NMBA) Standards that require healthcare professionals to maintain the capability for practice, comprehensively conduct assessments, and provide safe, appropriate, and responsive healthcare services.

From the ACD, it is apparent that family meant a lot to the patient. He has indicated that if he wouldn't be able to recognize and/or communicate with his family members, he would consider life to be unbearable. In such a case, as stated by the patient, he would have liked treatment to be stopped and to allow him to die a natural death. When the patient was approaching his end, he clearly stated that he wanted his mother and brother with him when he died. However, due to tension between his wife and mother, his wife did not take the initiative to call his family at an early time so that they could spend his last moments with him. In such a scenario, it was the duty of the palliative care team to honour his wishes, recognize his impending death, and call his family (Hall et al., 2019). They should have known that his family lived in another city and it would take several hours for them to reach the patient. According to the End of Life Care CPG, once the palliative care team establishes that the patient is dying, the team members should take immediate action to communicate this clearly to the patient's family so that they are mentally prepared for the situation (Pearse et al., 2019). However, in this case, the patient's wife also was not clear about the prognosis and/or was in denial and the palliative care team did not talk to the patient's mother on time about her son's prognosis, therefore depriving them of being next to their family member when he died. This kind of sudden death of a family member can be devastating for people, especially when they had no prior knowledge of what was about to happen (Carr and Luth, 2017). Therefore, neither did the palliative care team respect the patient's wishes nor did they recognize the signs of dying and inform his family members in a timely manner. The patient had also requested in the ACD that he would like a priest or minister to visit him towards the end; however, this was not followed by the caring team either (Fleuren et al., 2020).

An important requirement of the End of Life Care CPG which is also an NMBA Standard is that the palliative care team members should be able to conduct comprehensive assessments, identify the signs that indicate that the patient is approaching the end, and do the needful as per the patient's wishes. In order to accomplish this, the team members need to be aware of the prognosis of the specific life-limiting condition that the patient is diagnosed with, and the ACD filled out by the patient (Jimenez et al., 2018). In this case, the medical instructions of the ACD were followed with respect to feeding him through a tube and not trying to keep him alive using a ventilator. However, his values-based instructions were not followed which included having his family near him at the time of death and being transferred to a hospice towards the end. As per the CPG, reversible causes of deterioration in the patient should be considered, one of which is infection (Sudore et al., 2017). In this case, the patient suffered multiple infections throughout the course of his illness and also developed an infection towards the end. It is possible that this infection could have worsened the patient's condition in a short timeframe, and sufficient steps were not taken by the palliative care team to address this. The CPG also outlines the need for communication between the clinical team and the palliative care team; however, this is also not apparent in the case study.

Conclusion

In conclusion, the patient's palliative care was not complete to a large extent. Despite the fact that he had complete decision-making capacity until the end, his wishes were not followed in a timely manner. The palliative care team members were not competent enough to recognize his approaching end, and so they could not refer to his ACD for reference. Furthermore, the patient made some specific requests which were also not followed by the care team in a timely manner. Therefore, this case study reflects poor judgement of the palliative care team members, lack of coordination between the clinical team and the palliative care team, lack of effective communication, and not taking timely action based on the patient's deteriorating condition.

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