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Palliative sedation in an adolescent with intractable respiratory distress: Ethical issues and doctrine of double effect

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Palliative sedation in an adolescent with intractable respiratory distress: Ethical issues and doctrine of double effect

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Introduction

Intractable respiratory distress is the second most common indication for palliative sedation in a palliative care setting; the most common indication is uncontrolled and unrelieved refractory pain. Metastatic soft tissue sarcomas have aggressive course and pretreated and advanced sarcomas are poorly responsive to disease modifying treatments (Quill & Byock, 2000). This case is presented to highlight the complexities of managing respiratory distress in a terminal phase of illness and its associated ethical issues.

Case study

A 13-year-old boy, who was suffering from metastatic Primitive Neuro-Ectodermal Tumor (PNET) has been referred to the department of palliative medicine for pain and symptom management. Premorbidly, he was a high school going boy, who fared well in academics and sports. He was the eldest son and had a younger sister aged around ten years. His father worked overseas and mother was the primary caretaker for her son. Initial site of diagnosis was left femur and he received two lines of chemotherapy and external beam radiation (28 fractions) and his disease had progressed on treatment. Follow up scan showed disease progression in the form of extensive pulmonary and hepatic metastasis and increase in the size of the primary tumor.

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He followed up regularly on an outpatient basis and later, at home for symptom control measures and support. His pain was well controlled with oral Morphine and adjuvants. He was on regular home Oxygen and Dexamethasone to improve shortness of breath. The family received adequate psychosocial support from the hospital medical social worker. The family members were regularly appraised about ongoing disease progression, changing clinical condition, and goals of care, and with their complete understanding of the severity and irreversibility of illness, opted only for pain and symptom control measures.

Again, he was admitted to the hospital with severe respiratory distress [Grade V on MRC (Medical Research Council) scale] (Paternostro-Sluga, et al., 2008) and was unable to speak full sentences, desaturating, having tachycardia and tachypnea, hemodynamic collapse with significant pain and fear persisted. He was out on high flow O_2 by mask, Intra-Venous (IV) Steroids, IV Frusemide, IV bronchodilators, IV fluids, and IV antibiotics were administered. Over the next few hours' respiratory distress worsened and there was no improvement with his parameters. Palliative care team discussed with the patient's parents about the current clinical status and parents did not want their son to be intubated (Salins, Pai, Vidyasagar, & M, 2010), or ventilated or shifted to ICU. They wanted to be by the side of their son and requested his distress to be managed. He started on a very low dose of Morphine and Midazolam given IV as 1 mg incremental each, every 5 minutes, until his distress of breathing was reduced. He needed 8 mg of IV Morphine and 5 mg of IV Midazolam to relieve his acute respiratory distress. Then, he was commenced on

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a syringe driver with 10 mg of Morphine and 10 mg of Midazolam infused as a continuous IV infusion over 24 hours with breakthroughs of 1 mg Morphine and 1 mg Midazolam each. He was comfortable with this regime and he died. His parents and grandparents were with him during death. In the bereavement phase, the family thanked the palliative care team for the adequate symptom relief achieved and appropriate end of life care provided.

Discussion

In the above case discussed, the boy had an advanced life limiting illness with complications associated with disease progression. The primary treating team (Pediatric oncology) had opined that the disease had progressed and no further disease modifying treatment is possible or relevant at this point. The family had a good understanding about the nature and extent of illness and opted for symptom control measures and good supportive care. The ethical issues came under consideration, when this patient had presented with acute respiratory distress. As the patient was a minor and unable to make decisions for himself, his parents were the surrogate decision makers, who were acting in the best interest of the patient. Wishes of patient's family were respected and considered and hence, principle of Autonomy was preserved. Beneficence is to relieve this patient's respiratory distress hence; appropriate medical treatment was instituted followed by prompt symptom control measures. Maleficence would be intubating and ventilating this patient, fully understanding the cause of respiratory distress as extensive pulmonary metastasis causing respiratory failure, which is a potentially irreversible condition. Hence, the principle of Non Maleficence was adhered to. All the above process had led to fair and appropriate resource allocation hence, ethical principle justice was achieved (Mohanti, 2009).

Doctrine of double effect

The doctrine of double effect states that (A). *The nature of the act must be either morally good or indifferent.* Here, the act was morally permissible; to relieve the respiratory distress by all means. (B). *The bad effect must not be the means by which one achieves the good effect*. Here, the aim was not to cause respiratory depression and death, but only objective was relief of distress. (C). *The intention must be the achieving of only the good effect, with the bad effect being only an unintended side effect*. Though, there was a possibility of shortening of life with intended treatment, the intention was only to relieve distress. (D). *The good effect must be at least equivalent in importance to the bad effect.* This patient had a life limiting illness and was in terminal phase of illness with severe respiratory distress and was dying. Relief of distress with Morphine and Midazolam contributed to relief of suffering of a dying patient and distressed family. Hence, this can be considered much superior, when compared to any unintended bad effect.

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