

# **Indian Journal of Palliative Care**



Palliative Medicine Commentary

# Caught between Scylla and Charybdis

Akshat Malik<sup>1</sup>, Siddhant Singh<sup>1</sup>, Rohit Nayyar<sup>1</sup>

<sup>1</sup>Department of Surgical Oncology, Max Institute of Cancer Care, New Delhi, India.

Decision-making while dealing with advanced head-andneck cancer patients is often perplexing. One such area where we often find ourselves at a corner is when there is a question of palliative tracheostomy. We are sure many people would have faced a similar conundrum.

A patient on palliative therapy may be referred for tracheostomy for breathing difficulty or stridor, where a growth filling up the upper aerodigestive tract may force the patient to be in a propped-up position and unable to move or exert. Sometimes, patients may present with severe bleed and a tracheostomy may be needed to protect the airway or for ventilation purposes.[1]

In such cases, we normally inform the patient about why the tracheostomy is needed. Along with that, we explain about associated changes in speech and swallowing. [2] The patient is explained about how the tracheostomy won't help in treating the main disease and it is just to help with the breathing.

However, whatever is said and done, it is not possible to truly explain how things will be with a tracheostomy tube in place for the individual patient. The quality of life of these patients definitely goes down.[3] We stress this point to the patients because we have noted that a few patients with advanced disease feel more miserable after the tracheostomy. Hence, our discussion with the patient and the caregivers does mention that they need to decide bearing in mind not only the 'quantity' but also the 'quality' of life. There is a concept of shared decision-making, where we give all the facts to patient and allow him or her to decide about the further course of treatment in an 'informed' manner. In Indian subcontinent, many patients are illiterate and are not able to understand the implications of the treatment involved. Even if educated, there is a cultural trend where they would let the treating doctor decide for them and only take involvement in decision-making if there is a financial burden involved. Many times it is the caregiver who decides what needs to be done for the patient. Although, the scenario is changing and doctors are making more efforts to let the patient has the autonomy but more often than not they themselves are forced to decide for the patient.[4]

Many people at such an instance may jump in and perform a tracheostomy right away. The pillars of medical ethics include - beneficence, non-maleficence, autonomy and justice.<sup>[5]</sup> It can be argued that performing such a procedure may not be beneficial to the patient always. They may already be having a short lifespan and giving them the added 'stress' of tracheostomy or prolonging their 'miserable' life may not be counted as a service to the patient. I am aware that this can be argued either way, and patient should be allowed to decide what's good for them. But that is what the point is, in our setup, the patient and the caregiver may refuse to choose and the onus may completely fall on the treating doctor.

Recently, we had a patient with recurrent carcinoma of the tongue having unresectable disease. He had presented to the emergency department with bleeding off and on from the oral cavity. He was cachectic and very frail. Due to recurrent disease, previous surgeries and radiotherapy, he was unable to speak and had severe trismus with barely one finger mouth opening and negligible neck extension. He was a retired anaesthetist and was extremely alert. He carried a note pad with him and used to scribble his queries into it.

As there was no active bleed, he was admitted for observation. In the ward, he had a sudden bleed and was rushed to a high dependency unit (HDU) as his blood pressure had started dropping. The bleed had stopped on its own in the interim. We spoke to him and reassured him. We gave him the option of undergoing an angioembolisation or an external carotid artery ligation. We explained that it would be difficult to intubate him and we may have to resort to doing a tracheostomy if he bled again. As he himself was a doctor, he did not require any further explaining, and he immediately wrote that he would not prefer a tracheostomy. We were about to include his brother waiting outside the HDU in

\*Corresponding author: Akshat Malik, Department of Surgical Oncology, Max Institute of Cancer Care, New Delhi, India. akshatmalik@gmail.com Received: 27 July 2021 Accepted: 22 August 2021 EPub Ahead of Print: 09 September 2021 Published: 29 July 2022 DOI: 10.25259/IJPC\_30\_2021

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this discussion when he started bleeding profusely form his mouth and within seconds collapsed.

We packed his oral cavity as best as we could, meanwhile, the intensivist while taking control asked us to proceed with a tracheostomy. We conveyed the patients wishes and refused. A blind nasal intubation was attempted and was luckily successful in the first attempt. As his resuscitation was going on, we discussed with his brother and wife. They felt that he was a 'fighter' and everything possible should be tried. As soon as he was stabilised, he was taken for angioembolisation where the lingual artery was embolised and bleeding was controlled. He was subsequently stepped down to the ward and survived for 5 more days eventually passing away due to cardiac arrest. This case of patient autonomy and being a shared decision maker is an exception rather than being a norm in out setup.

In contrast, a few months back, there was a patient of carcinoma of base of tongue with progressive metastatic disease in spite of chemoradiation. He was wheel chair bound and had a very poor performance status, he had presented with aspiration and occasional dyspnoea on lying down. A feeding tube was inserted and a discussion about the tracheostomy tube was held, overall a poor prognosis was also explained. We explained about the care of the tube and potential deterioration of quality of life in view of his pre-existing poor performance status. The patient himself refused to take any decision and relatives wanted that 'something' must be done and refused to entertain any other possibility. He underwent tracheostomy but had a hard time afterwards. He and his relatives were not able to maintain the tube that well and he came with a blocked tube and excessive coughing several times in the following week. He died after 3 weeks, but in a state of misery.

Some of the readers may not really see a point of this discussion as they may feel that not doing tracheostomy is not merited, but our point is to highlight those cases where it may not be of much advantage and may depreciate the remaining quality of life. Another aim of writing this is to highlight the importance of shared decision-making and give the push it merits. A multidisciplinary team discussion with all parties involved is a must. The patients and the caregivers should be given all the options and should be assisted in deciding the best treatment course for the patient.

## Declaration of patient consent

Patient's consent not required as there are no patients in this

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#### Conflicts of interest

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