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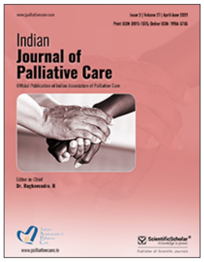

*Case Report*

# A Typical Perplexing Life-sustaining Therapy Decision at the End of life: A Case Report from Sri Lanka with Attributes Potentially worth Adopting from the UK Legislature

Gunasekara Vidana Mestrige Chamath Fernando[1,2], Shoba Narayanan Nair[3]

[1]Department of Family Medicine, Faculty of Medical Sciences, University of Sri Jayewardenepura, Colombo, Sri Lanka, [2]National Centre for Primary Care and Allergy Research, University of Sri Jayewardenepura, Sri Lanka, [3]Department of Pain and Palliative Medicine, Amrita Institute of Medical Sciences, Kochi, Kerala, India.

***Corresponding author:**
Gunasekara Vidana Mestrige Chamath Fernando,
Department of Family Medicine, Faculty of Medical Sciences, University of Sri Jayewardenepura, Colombo, Sri Lanka.

chemetf@sjp.ac.lk

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## ABSTRACT

In many developing parts of the world, evidence on advance care planning (ACP) is either lacking or fragmented. Lack of streamlined means for ACP is known to lead to inconveniences for the clinicians as well as the patients and their families. This case report focuses on a young male diagnosed with metastatic osteosarcoma, who explicitly verbalised his wishes to be managed conservatively without involving invasive life-sustaining measures. However, the patient faced cardiopulmonary resuscitation before his demise against his wishes, which also contradicted with the medical point of view. Sri Lankan doctors face moral, ethical and legal dilemmas as they deal with terminally ill patients at the verge of their death due to the deficiencies in the medical and legislative frameworks in the country.

**Keywords:** Advance care planning, Clinical ethics, Decision-making, End-of-life care, Legal aspects, Palliative care

## INTRODUCTION

A leading cancer hospital in Sri Lanka conducts a 'Palliative Care Clinic' (PCC) one afternoon a week. In the absence of clinicians primarily qualified in palliative care in the island, the clinic is operationalised by an anaesthetist, an oncologist, a few middle-grade doctors, a nutritionist and nursing officers currently employed in the hospital. My role in PCC is in the capacity of a visiting physician involved with patient care on voluntary basis.

## CASE REPORT

This reflective account focuses on a vicenarian male engineer diagnosed with osteosarcoma. Having separated from his wife 3 years earlier, he lived alone. He was initially managed by an oncology team and was well for nearly 1 year until the subsequent detection of pulmonary and cerebral metastases: the latter a rarer manifestation in osteosarcoma.[1] The patient was then referred to the PCC from the oncology ward. There, I embarked on his management in liaison with a nurse and the anaesthetist.

During his review visits, the patient expressed his satisfaction with the degree of symptomatic relief achieved in terms of the dyspnoea, headache and anxiety. He found his solitary lifestyle blissful, aided by a few friends and suffered no significant psychological ailments besides the distress stemming from the terminal diagnosis. In approximately 1 month, the patient rang me from the hospital expressing his wish to see me urgently. On visiting him in the same evening, it was apparent that the patient was dyspnoeic and was on supplemental oxygen. He attributed his recent deterioration in breathing and intermittent clouding of consciousness to impending death. The role of life-sustaining therapy options and their pros and cons were discussed in comparison to the conservative management option that places more emphasis on symptom alleviation.

On explaining through a detailed discussion of the potential detrimental effects that life-sustaining therapies may have on his quality of life, the patient affirmed his intense disliking for invasive procedures, including cardiopulmonary resuscitation (CPR) and artificial ventilation. In liaison with the doctor on call, his medications, especially the infusions of opioids and benzodiazepines, were optimised to ensure maximisation of comfort and optimal relief of dyspnoea and anxiety. The titration of these sedating medications was done with caution to maintain 'adequate wakefulness' as per the patient's wishes.[2,3] Simple interventions like postural adjustments with frequent feedback from the patient also enabled to ease his dyspnoea significantly. On meeting in a ward round, the treating oncologist was verbally informed regarding the patient's strong aversion toward invasive life-sustaining therapies and his preference for comfort care. However, the discussion that took place and his preference were not documented in the clinical records.

Two days later, the patient had suffered cardiac arrest, and his wife had been notified. Despite the previous unfruitful attempts to summon her, she had eventually visited the patient and demanded that his life to be salvaged 'at all costs' despite the on-call-doctor's strong disapproval. The doctor had had to resort on administering CPR to the subconscious patient for 45 min before announcing him 'dead.'

## DISCUSSION

The ethical and legal dilemmas faced by the clinicians with this scenario are reflexively appraised below. The principles of 'beneficence' and 'non-maleficence' aim for net favourable outcome to the patient. Furthermore, from a utilitarianism viewpoint that examines an act based on the consequences,[4] CPR proves maleficence to the patient, while comfort care may prove beneficence. As agreed between the oncology and the PCC team that the patient would benefit exclusively from therapies of supportive nature, measures were taken to optimise the patient's symptom management. There, the provider perspectives aligned well with the sentiments of the patient. However, the 'do not attempt cardiopulmonary resuscitation' decision may contradict with the 'deontological' perspective of ethics that views the act of not attempting CPR to oppose the physician's duty to salvage the patient's life.[4] The decision was also not documented possibly due to the Sri Lankan legislature that prohibits forgoing of life-sustaining therapy.[5] This prompted the duty doctor to administer CPR that deprived the patient of his free, well-informed choice against CPR. Further, the decision was overridden by a person who was not a surrogate decision-maker appointed or implied by the patient. Patient's wishes playing a subordinate role to those of the colluding family members is a frequent obstacle to patient autonomy within the Sri Lankan cultural context.[6]

The doctrine of 'double effect' legitimises acts aiming net benefit to the patient regardless of their unintended harms.[7] From a medical perspective, the overall 'survival to discharge rate' of CPR in metastatic cancer is 5.6%,[8] and the procedure entails a painful, unpleasant and possibly undignified terminal experience to the patient.[9,10] On this note, the improved longevity in the unlikely event of successful yet traumatic CPR has negligible value over a peaceful dying phase pacified with optimum symptomatic relief. The absence of imminent life events that the patient looked eagerly forward to, further prejudice these attempts to extend life (Taubert, 2016).[11] His traumatic demise amounts to me an ethical crime that could not be attributed to the 'double effect.' This could have been prevented with proper advance care planning (ACP) that is lacking in Sri Lanka alongside many other South Asian contexts.[12] It portrays the typical deficiencies in the local legislative structure complicated by the lack of institutional protocols on forgoing life-sustaining therapy.

The bioethical principle of 'justice' encompasses the fair allocation of scarce resources and respect for human rights and morally acceptable laws. The patient's wife did not honour the previous requests from the hospital to visit him that could have led to her poor understanding of her husband's preferences under the current circumstances complicated by the terminal diagnosis. Nevertheless, she arguably claims the right of a default surrogate.[13] The doctor not attempting CPR on the dying patient would have intrigued her and aroused her emotions to demand it forcibly. However, eventually, her wishes were brought to justice at the expense of the patient's rights and autonomy. Time, human and healthcare resources were thus misutilised in resuscitating this dying patient vigorously, leading to distributive injustice. To add to the misery, the dying patient did not receive the optimum comfort care, despite the availability of necessary medicines. Integral to the establishment of a framework to build the ethics-based laws would be the input from countries currently practising effective laws such as the UK.[14]

### Tips from the United Kingdom (UK)

A significant portion of the legislature established during the British Empire in Sri Lanka (1815–1948) remains unchanged to date including certain elements of healthcare decision-making.[15,16] In the meantime, the corresponding legal frameworks in the UK have evolved overtime and provide clearer directions for the decision-making process at present. Therefore, the prohibitive legal elements in the Sri Lankan framework are compared with the prevailing legal system in the UK, thus recognising directions for necessary reforms.

In the UK, all adult patients are deemed to possess mental capacity unless proven otherwise and secure the right to arrive at informed decisions regarding the refusal of life-sustaining treatment.[17] Regardless of the possibly contradicting medical viewpoint, such decisions are legally bound to be honoured by the clinicians.[18] As part of ACP, the legislation in the UK facilitates patients with terminal illnesses to plan future care and treatment modes in anticipation of the likely mental capacity loss along disease trajectories. Having considered the advantages and disadvantages of the care pathway options in the face of likely clinical deteriorations in liaison with the healthcare professionals, the patient could formulate a legally binding document (Advance Care Directive[19]). Patients may alternatively document a 'statement of wishes and preferences' in a non-legally binding manner to facilitate the decision-making process by the healthcare providers and family in the future. There are also provisions for patients to legally appoint a surrogate decision-maker to decide on the patient's behalf following mental capacity impairment through a lasting power of attorney for health and welfare.[20]

Ideally, the patients must be at the liberty of modifying the care preferences along the trajectory of their illnesses supported by periodic discussions with the healthcare providers.[21] Most importantly, the legal and health systems of the UK have proper channels to communicate these decisions to all providers caring for the patient to ensure that the unnecessary invasive interventions do not ensue as the patient's condition deteriorate unexpectedly. In the event of a medical emergency occurring in a mentally incapacitated patient without an ACD, the treating doctor is legally empowered to decide avoiding therapeutically futile measures that are disliked by the patient. Neither the relatives could demand nor the physician is obliged to administer treatments deemed to do more harm than any benefit from a medical perspective.[22] Moreover, measures such as the legal appointment of Independent Mental Capacity Advocates (IMCD) are in place to safeguard the best interests of unbefriended patients (without next of kin).[23]

### Potential means to remedy the situation in Sri Lanka

There remains a dire need for collaborative efforts between the clinicians, policy-makers and the legislative bodies with regard to eliminating the deficiencies and enacting necessary regulations. Moving beyond provisions to engage in formal ACP discussions early in the course of the terminal illnesses, the establishment of a system to appoint IMCDs is also immaterial. A legally enforced clinical decision-making protocol must be in place. Physicians responsible must feel empowered to act prudently in the event of an unprecedented deterioration in the patient's condition following the internationally prescribed hierarchy for clinical decision-making that is, (1) 'Subjective standard,' (2) 'Substituted Judgement Standard' and (3) 'Best interests Standard.'[24] It is also mandatory to devise a system to communicate the patient's decisions and preferences to all the healthcare staff members involved in their care.

Sri Lankan doctors are not sufficiently familiar with the unique principles of palliative care, a clinical discipline thriving in infancy in the country.[25] The sense of importance the Sri Lankan clinicians from oncology settings place on symptom alleviation as opposed to aggressive treatment of the disease is also shown to be low.[26] The palliative approach to care and the emphasis it places on ethics must form integral parts of the clinician's education and training. Furthermore, increasing public awareness about the negligible success rates of many life-sustaining therapies in terminal illnesses may minimise unrealistic expectations and accusations directed at the clinicians. Finally, due to the arbitrary role I assumed as a voluntary physician, my authority in caring for patients of this institution quite reasonably intrigued specific staff members. Establishment of hospital-based palliative care teams, ethics committees authorised to address these sensitive issues may assist in alleviating these authority-related scepticisms.

## CONCLUSION

This case report suggests that Sri Lankan clinicians are perplexed with life-sustaining therapy decisions concerning patients with life-limiting illnesses. In addition to training of the clinicians to arrive at clinically, ethically and legally justifiable decisions, the constraints they experience in such decision-making needs to be found and addressed. This warrants in-depth approaches to explore into the context-specific barriers the clinicians face in their routine clinical practice in view of finding solutions for the same.

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### Declaration of patient consent

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### Conflicts of interest

There are no conflicts of interest.

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