**Title: Ethical and legal challenges associated with decisions to forgo life-sustaining treatment at end-of-life: an ethical case deliberation from Sri Lanka**

**Running title:** *Ethico-legal issues at end-of-life*

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**Author contributions**

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| Been involved in drafting the manuscript or revising it critically for important intellectual content. | **CF, SN** |
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| Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. | **CF. SN** |

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**Ethical and legal challenges of life-sustaining decision-making at end-of-life:** *a reflection from Sri Lanka*

**Running title:** *Ethico-legal issues at end-of-life*

**Abstract**

This case report focuses on a young male patient diagnosed with metastatic osteosarcoma, who explicitly verbalised his wishes to be managed conservatively without involvement invasive life-sustaining measures. However, the patient faced cardiopulmonary resuscitation before his demise against his previously stated wishes, which was also contradicting to the medical point of view. This report discusses the moral, ethical and legal dilemmas faced by the doctors while dealing with conflicts at the verge of a terminally-ill patient's death owing to deficiencies in the medical and legislative frameworks in Sri Lanka.

**Keywords:** clinical ethics, ethical issues, legal aspects, end of life care,medical decisions, advance directives, advance care planning, autonomy, decision-making, 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 conducted 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 family physician involved with patient care voluntarily.

**Case presentation**

This reflective ethical case deliberation focuses on an engineer, a male vicenarian diagnosed with osteosarcoma. Having separated from his wife three years earlier, he lived alone. He was initially managed by an oncology team and was well for nearly one 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 managing the patient in liaison with him, a nurse and the anaesthetist.

**Case assessment and management**

During his review visits, the patient expressed his satisfaction with the degree of symptomatic relief achieved. He found his solitary lifestyle blissful, aided by a few friends and suffered no significant psychological ailments besides the distress associated with the terminal diagnosis.

In approximately one month, the patient rang me from the hospital expressing his wish to see me urgently. Upon 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. In the discussion that followed, the benefits and harms of each therapeutic option that would potentially sustain life and the possible care pathways were explained. He affirmed his intense disliking for invasive procedures, including cardio-pulmonary resuscitation (CPR) and artificial ventilation. He requested to limit his management to maximisation of comfort.

In consultation with the oncologist in charge of the ward, his medications were optimised (including an infusion of opioids and benzodiazepines. [2, 3] Simple interventions like postural adjustments were adopted aiming symptomatic relief (mainly dyspnoea, headache and anxiety). The treating oncologist was also informed regarding the patient’s strong aversion towards invasive life-sustaining measures and the explicit request for comfort care.

**Case Outcome**

Two days later, it was learnt that the patient had suffered cardiac arrest, and the ward notified his wife. Despite the previous unfruitful attempts to summon her, she had eventually visited the patient and demanded that “his life must be salvaged at all costs" despite the ward doctor's strong disapproval. The doctor had had to resort on administering CPR to the subconscious patient for 45 minutes before announcing him “dead”.

**Discussion**

Severe ethical and legal concerns related to this scenario are reflexively appraised below.

The ethical and legal dilemmas faced by the clinicians with this scenario are discussed below with a specific focus on the four basic principles of clinical ethics (respect to autonomy, beneficence, non-maleficence and justice), [4] utilitarian and deontological viewpoints. [5].

The principle of 'autonomy' affirms the right of a mentally competent patient to advocate for the decisions on their further treatment and care. [6] This particular patient has not only been deprived of his free, well-informed choice against CPR but also his values have been overridden by a person who was not a proxy decision-maker appointed or implied by the patient. It had been agreed among the treating oncologist and the PCC team, that the patient would benefit from treatment of supportive nature. Hence, measures were taken to optimise the patient's symptom management, and it was decided to withdraw further palliative chemo-irradiation on him. By limiting the management to comfort care, the healthcare decisions aligned well with the sentiments of the patient. The decision arrived at in consensus not to attempt CPR was not documented by healthcare staff members, which is not unusual in this setting provided the potential legal implications prompting the doctor to administer CPR upon the patient's wife's forcible request. This violated the patient's decisional-autonomy and the rational decision made by the clinical team. Despite having cerebral metastasis with a potential to impair decisional capacity, the patient demonstrated to possess mental capacity in terms of all four criteria outlined in the Mental Capacity Act (2005): in comprehending the information relevant to the decision, weighing the options available, arriving at a decision and communicating his decision to the clinical team. [7]

The principles of 'beneficence' and 'non-maleficence' are concerned with making decisions in 'best interests' of the patient balancing benefits over adversities, ultimately aiming a net favourable outcome. [6] Nevertheless, the doctrine of "double effect" describes the possible unintended accompaniment of adverse consequences of an intervention, otherwise aiming patient welfare. [8] Among outcome measures of palliative care, the enhancement of *quality* of life gains more prominence over the *quantity* in terms of longevity. On this note, the added hours or days into the patient’s life in the unlikely event of successful yet traumatic CPR, have negligible value over the last few minutes of his life which could have been spent peacefully with optimum relief of the accompanying symptoms. From the medical perspective, although the patient was young, the scope for a cure was negligible owing to the extensive metastasis. The overall "survival to discharge" rate of CPR in metastatic cancer is 5.6%. [9] The procedure ensues a painful and unpleasant terminal experience to the minimally conscious patient according to the literature. [10] There were also no significant life events shortly that the patient looked eagerly forward to, in which case attempts to extend life could have been justified. [11, 12]. The ‘best interests’ based medical decision not to administer invasive life-sustaining measures aligned well with the patient’s ‘subjective’ expectations. The events that led to his death in an undesired manner reflects the deficiencies in the local legislative structure and the medical ordinance complicated by the lack of institutional protocols. This traumatic death amounts to me a gross ethical crime where the maleficence well surpassed beneficence.

The principle of 'justice' encompasses the fair allocation of scarce resources and respect for human rights and morally acceptable laws. [13] The patient's relationship with his wife cannot be gauged by the number of years they have spent together or apart. Albeit the possible argument for the contrary, the wife would have sincerely wished her husband to survive by all means. The doctor not attempting CPR on the dying patient would have intrigued her and aroused her emotions to demand it forcibly. The fact that she never visited her husband earlier despite repeated requests from the hospital would also have led to her poor understanding of her husband's preferences under the current circumstances complicated by the terminal diagnosis [14] However, eventually, her wishes were brought to justice at the expense of the patient's rights and autonomy. Time, human resources and the resources misutilized in resuscitating this patient means distributive injustice. This case is further prejudiced by the fact that the dying patient was not receiving the optimum symptomatic relief and comfort care, which was all that he expected in the terminal phase, despite the availability of necessary medicines in this hospital.

‘Utilitarianism’ examines the ‘right’ or ‘wrong’ of the act based on the consequences. In this scenario, the futility of life-sustaining measures was already established. Therefore, CPR and ventilatory support would have only proven to be a burden to the patient. From a ‘deontological’ standpoint, the care of duty transcends the calculations of net benefit. In this case, the wife was estranged and did not know the patient’s last wish, and therefore was not the justifiable surrogate to make a decision. She probably was shocked to realise that her husband is dying and might have been guilty that she did not visit the hospital when summoned by the treating team. Even though the wife was separated, she was legally still his wife and hence can make decisions on the patient’s behalf. Unfortunately, the decision the wife made was diametrically opposite to what the patient made. If the patient’s decision was converted to an Advance Care Directive or a living will, the trauma that the patient went though could have been avoided, and the patient’s autonomy respected.

***Practical issues experienced in Sri Lanka***

Significant “loopholes” are noted in the current Sri Lankan medical ordinance. [15] and legislative structure in terms of the ability of patients to form legally binding advanced directives, legally appoint suitable surrogate decision-makers and for the physicians to forgo clinically inappropriate life-sustaining treatment. [16] The legal status of withholding or withdrawing life-sustaining treatment is unknown, [17] and doctors are not necessarily immune from legal conviction for not resuscitating the patients. This could be causing the perceived lack of ACP discussions in Sri Lankan clinical practice. Furthermore, cultural factors in the country are known to place patient autonomy in a subordinate position to the familial preferences. [18]

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. [19]

***Tips from the United Kingdom (UK)***

In the UK, an adult patient secures the right to make informed decisions regarding the refusal of life-sustaining treatment including CPR, unless he is deemed to have lost mental capacity in terms of the particular decision. [20] Such a decision must be honoured even though it is considered to be detrimental from the medical viewpoint or may also shorten their lifespan. [4]

As part of Advance Care Planning (ACP), the legislation in the UK facilitates palliative patients to plan future care and treatment modes in anticipation of the likely mental capacity loss along disease trajectories. Having considered the pros and cons of the care options suggested by the healthcare professionals alongside the patients’ own opinions and wishes, a legally binding document (Advance Care Directive [21]) could be formulated delineating the future care pathways to be executed. [22] Patients could also document a “statement of wishes and preferences” in a non-legally binding manner to facilitate the decision-making process by the healthcare providers in the future. There are provisions for patients to legally appoint a proxy decision-maker to decide on the patient’s behalf following mental capacity impairment through a Lasting Power of Attorney (LPA) for health and welfare. [23]

Ideally, the patients must be at the liberty of changing the care preferences along the course of periodic discussions with the health care providers. [24] Most importantly, the legal and health systems of the UK have proper channels to communicate these decisions to the healthcare providers in order to ensure that the unnecessary invasive interventions do no ensue as the patient’s condition deteriorate unexpectedly.

In the UK, in the event of a medical emergency in a mentally incapacitated patient without an ACD, the treating doctor could decide in the best interests of the patient. Neither the relatives could demand, nor the physician is obliged to administer treatments deemed inappropriate or does more harm than any benefit from the medical perspective. [25]

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

There remains a dire need for collaborative work between the clinicians, policy-makers and the legislative bodies with regards to eliminating the deficiencies and enacting necessary regulations. Moving beyond provisions to formulate advance directives and to appoint proxies, the establishment of a system to appoint Independent Mental Capacity Advocates, [26] for unbefriended patients (without next-of-kin) is also immaterial. Should a protocol and legal provisions be in place in keeping with a clear decision-making hierarchy (1. Subjective standard, 2. Substituted Judgement Standard and 3. Best interests Standard), each stakeholder responsible for patient’s care will feel empowered to act prudently in the event of an unprecedented deterioration in the patient’s condition. [27] 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.

Clinicians in Sri Lanka, who are not sufficiently familiar with the unique principles of palliative care (a clinical discipline thriving in infancy in the country), [28] should avail themselves adequately to educational resources on this discipline. This would lead to a realisation among the clinicians the robust emphasis palliative approach to care places on clinical ethics. Furthermore, education of the general public about the negligible success rates of procedures such as CPR in the terminal illnesses can minimise not only unrealistic expectations among them but also irrational accusations.

Owing to the arbitrary role I assumed as a voluntary physician, my authority to make clinical decisions about the resident patients of this institution reasonably intrigued specific individuals. Establishment of hospital-based palliative care teams and hospital ethics committees authorised to address these sensitive issues will assist in alleviating the authority related scepticisms.

Finally, clinicians must be encouraged to summon the patients’ significant others upon patients explicit consent and discuss the prognosis while setting realistic care and support goals aiming holistic care provision.

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**Table 1: Ethical, legal and moral conflicts faced while deciding on life-sustaining care**

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| --- | --- |
| **The aspect of clinical ethics** | **Ethical and legal dilemmas** |
| *Respect to autonomy* |  |
| *Beneficence and non-maleficence* |  |
| *Justice* |  |
| ***The above four principles were inadequate to determine the ethical justice of this case scenario. Hence, two additional principles of ethics were also brought in here to help with decisions.*** | |
| *Utilitarian approach (consequentialism)* |  |
| *Deontological approach (duty of care)* |  |