

Ethical and legal Issues at End of Life

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Outline

1. Introduction
2. Common Symptoms at End of Life
3. Ethical and Legal issues at EoL
4. South African legislative context
5. Case study

1. Introduction

We are all going to die one day. As health care professionals our duty is to ensure death with dignity. Everyone would like to have a good death, but do we know what that entails? Tookman describes it as; being at peace, dying in their place of choice, surrounded by their loved ones, knowing that they are dying and their symptoms are controlled.

“How people die remains in the memory of those who live on” - Dame Cicely Saunders. After caring for two husbands with cancer, changing 3 professions, Cecily Saunders mastered caring for the dying, and her experiences continue to inspire us. All patients at end of life would benefit from a palliative care approach. Palliative Care is defined by WHO as “An approach that improves the quality of life of patients (adults and children) and their families, who face life-threatening illness by preventing and alleviating unnecessary suffering”.

Being able to identify patients who are nearing death, identifying their need and addressing them is imperative.

Disease Trajectories

Understanding disease trajectories enables us to be able to discuss and engage the patient and the family on the goals of care, which have to be modified as the disease progresses. This enables clinicians to avoid ethical dilemmas, or deal with them in a sound manner.

Advanced Care Planning: A process that enables individuals to make plans about their future healthcare. Advance care plans provide direction to healthcare professionals when a person is not in a position to either make and/or communicate their own healthcare choices. Not legal in South Africa

2. Understanding common distressing symptoms at End of Life which have to be managed:
 - Pain

- Dyspnoea
- Vomiting
- Terminal restlessness

3. Principles of bioethics

Autonomy

Patients have the moral and legal right to rule themselves. They have a right to:

- Adequate information that is easy to understand, and that will enable them to make informed choices
- Receive necessary support throughout the decision-making and treatment process. This includes the opportunity to discuss and make decisions with family, significant others, knowledgeable personnel and other health professionals
- Determine what will be done for them
- Accept, refuse, or stop any treatment without undue influence, coercion, or fear of penalty
- Receive assistance to evaluate benefits, burdens, and available options in their treatment

Beneficence

All medical interventions has a benefit, but also carry a risk of harm. At end of life, some treatment is futile and carry no added benefit. All interventions at end of life have to be weighed, which usually necessitates shifting goals of care.

Wikipedia defines futile treatment as “continued medical care or treatment to a patient when there is no reasonable hope of cure or benefit”. Willmott et al gave three main reason cited by doctors as leading them to provide futile treatment; orientation to curative treatment, patient and family expectations, lack of patient’s wishes and availability of resources in hospitals. Decision to withdraw futile treatment is ethically sound, and must be done in a consultative manner.

Non-Maleficence

- “Do no harm”
- Requires the balance between benefit and the harm medical treatment or an intervention can have on the patient.
- The discussion on futile treatment comes into play again
- Do we withhold or withdraw treatment- need for food or hydration at end of life?
- Do we resuscitate or don’t we resuscitate?

- Robert Twycross puts it this way: “the doctor has neither the right nor the duty to prescribe a lingering death”
- Palliative sedation also raises questions on whether it is beneficial or harmful to the patient. The aim of palliative care sedation is to relieve distressing and refractory symptoms in dying patients. Properly titrated, palliative care sedation is of benefit to both the patient and the family.
- Assisted suicide
- Euthanasia

Justice

- Treating people equally in relation to criteria acknowledged to be morally relevant (needs, rights, benefit, autonomy).
- Distributive justice: Fair allocation of available resources
- Social justice- right to access to health care
- Rights based justice: respect of people’s right
- Managed health care challenges

4. Some of the South Africa legislative Context to cover

South Africa Constitution

Health Act

Patient Right Charter

Medical Scheme Act

5. Case Study:

Case 1:

Ms B: 20 years old, P2G2, Unmarried

- Diagnosis: End stage Renal Failure
- Failed to comply with Renal Clinic Requirements for renal dialysis and renal transplant
- Referred to Palliative Care for end of life care

6. Ethical Decision making at the end of life

- Identify the ethical dilemma
- Engage in discussion with the patient, family and care team
- Explore assumptions, present factual information
- Need to consider:
 - o Stage of the illness
 - o Patient’s preferences and family’s wishes

- The patient as an individual and a relevant care plan
- Shared Decision making – preparing a care plan
- Review

7. Conclusion:

Conversations we have to consider for our patients nearing end of life

1. Reality of the disease progression, understanding the disease trajectory.
2. Exploring and understanding the person's goals for care (including advance care planning).
3. Perceptions of their suffering and sense of burden to others.
4. Patient's desire for good quality end-of-life care, curative?
5. The care and support that is or can be offered by good health care and supportive significant others.
6. Support to family

References:

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