ETHICAL GUIDELINES ON WITHHOLDING/WITHDRAWING THERAPY

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CONFLICT OF INTEREST

- None

INTRODUCTION

- End-of-life decision making in medicine has been very topical in recent years with a new openness among doctors and laypersons around the subject of death.
- The majority of ICU deaths now occur following a decision to limit life-sustaining therapy.
- This can occur in one of two ways: withholding or withdrawing therapy.
- **Withholding therapy** implies no therapeutic escalation – DNR order.
- **Withdrawing therapy** implies removal of therapy that was started in attempt to sustain life but is now deemed to be futile – mechanical ventilation, vasoactive agents.
- Much controversy still exists around these two concepts however with significant variation in practices from facility to facility.
- It is important that these often difficult ethical areas be discussed openly.

CASE STUDY

- 69-year-old female patient currently undergoing chemotherapy for metastatic small cell lung ca.
- Background medical history of hypertension and COPD (on home oxygen).
- Now presents with:
- ✓ Type 1 respiratory failure – suspected hospital acquired pneumonia
- ✓ Septic shock-with hypotension and increased lactate
- ✓ Pancytopenia – with a platelet count of 9 x 10^9/L , a WCC of 2 x 10^9/L, a neutrophil count of 0.6 and an Hb of 6.8 g/dl.

AN ETHICAL TREATMENT DILEMMA

ETHICAL PRINCIPLES

- AUTONOMY
- BENEFICIENCE
- NON-MALEFICIENCE
- DISTRIBUTIVE JUSTICE

AUTONOMY

- All persons have intrinsic and unconditional worth – Kant and John Stuart Mill.
- All entitled to exercise his/her own power of self-determination and decision making.
- Autonomy does not extend to those who don't have the capacity to make decisions (children, mentally or developmental disorders)
- Autonomy is not applicable if one persons autonomous decision impacts negatively on anothers'autonomy (e.g. criminal act).
- Informed consent and confidentiality.
- Advanced directive and living wills

BENEFICIENCE

- The obligation of the physician to act for the benefit of the patient/in the patients best interests.
- Supports a number of moral rules:
- ✓ Protect and defend the rights of others
- ✓ Prevent harm
- ✓ Remove conditions that will cause harm
- **Not merely avoiding harm, but to benefit patients and promote welfare.**
- CPD activities and in service training fall under this ethical obligation we have to our patients

NON-MALEFICIENCE

- **First do no harm.**
- Do not intentionally create a harm or injury to a patient – through acts of commission or omission.
- Onus on physicians to weigh the benefits against the burdens of all treatments and interventions.
- This principle affirms the need for medical competence.

DISTRIBUTIVE JUSTICE

- Fair, equitable and appropriate distribution of health care resources.
- All patients receive the medical care they are entitled to.
- Scarce resources place restrictions on this ethical principle.
- Decisions need to be made for the good of the patient, but also the good of other patients and society as a whole.
- Allocation of resources should not be based on effort, contribution, social standing or free-market exchanges.
- **ICU triage: patient that will benefit the most from the ICU bed**

THE 4 ETHICAL PRINCIPLES AND WITHDRAWAL/WITHHOLDING THERAPY

ETHICAL PRINCIPLES	RATIONALE
AUTONOMY	Futility of care , advanced directive
BENEFICIENCE	What is the benefit to the patient of continuing a therapy that carries no advantage?
NON-MALEFICIENCE	Even with optimal analgo-sedation, continuing futile therapies will cause distress and discomfort
DISTRIBUTIVE JUSTICE	Scarce resource – used optimally for the good of the individual but also of other patients and society as a whole

IS THERE A DIFFERENCE BETWEEN WITHHOLDING AND WITHDRAWING THERAPY?

- **Ethical perspective**
- There is no ethical difference between withholding and withdrawing therapy.
- Withdrawing has been seen as an action rather than the passive omission of withholding.
- While the acts are not the same in practical terms, the end result is the same.
- This viewpoint is supported by all major societies and professional bodies.
- The British Medical Association's guidelines state that: '**Although emotionally it may be easier to withhold treatment than to withdraw that which has been started, there are no legal, or necessary morally relevant, differences between the two actions '.**

IS THERE A DIFFERENCE BETWEEN WITHHOLDING AND WITHDRAWING THERAPY?

- **Legal perspective**
- No legal distinction between these two entities.
- The law recognizes that when treatment is futile, is refused or has no benefit, it should not be given just because the treatment is available.
- The disease process that causes death, not the doctor or the treatment that is withheld or withdrawn.

HPCSA GUIDELINES

- **BOOKLET 7**
- **Ethical framework for withholding/withdrawing treatment**
- Health care professionals have a responsibility to make the care of their patients their first concern.
- Allows for the ethical and legal practice of withholding/withdrawing life sustaining treatments.
- Prohibits killing, active euthanasia and assisted suicide.
- The health professional may withdraw/withhold treatment after consultation with another health care professional that is an expert in the field as well as the patient and closest relatives.
- HPCSA expects health care practioners to observe the provisions of the World Medical Association Declaration on Terminal Illness.

HPCSA GUIDELINES

- **BOOKLET 7**
- **Ethical framework for withholding/withdrawing treatment**
- Patients are encouraged to draw up a "living will" and nominate a surrogate decision maker in the case that they are not able to make decisions for themselves.
- Patients and their families must be kept up to date regarding treatment, treatment alternatives and outcome probabilities.
- If the patient or family request continued treatment against health advice that considers the treatment to be futile, the patient must be given a choice of transferring to an alternate facility where this treatment may be offered. If this option is refused and the futility of care is confirmed by an independent medical specialist, treatment may be withheld/withdrawn.
- All decisions must be fully and clearly documented in the notes, including the reasoning and the procedure followed to reach the decision. Where significant disagreement exists regarding the patients' best interests , physicians should seek additional clinical and ethical opinions. If this fails a legal opinion with the option of a court interdict may be the only recourse.

WMA DECLARATION ON TERMINAL ILLNESS

- **REVISED BY THE WMA GENERAL ASSEMBLY, PILANESBURG, SOUTH AFRICA IN 2006**
- The WMA condemns as unethical both euthanasia and physician-assisted suicide.
- It is the duty of physicians to heal, to relieve suffering and to protect the best interests of their patients-even in incurable disease.
- In end-of-life care the primary responsibility of the physician is to assist the patient in maintaining an optimal quality of life through controlling symptoms and addressing psychosocial needs – patient should die in dignity and comfort.
- The patients right to autonomy must be respected with regard to decisions in the terminal phase of life – to refuse treatment and to request palliative measures to relieve suffering.
- Physicians are ethically prohibited to actively assist in patient suicide.
- The physician must not employ any means that would provide no benefit for the patient.
- The clinical management of pain is of utmost importance- physicians should have access to best practice guidelines and the most current treatments and methods available-without legal repercussions.

WHO MAKES THE DECISION TO WITHHOLD/WITHDRAW THERAPY?

- HPCSA guidelines: The decision should be made only by the senior clinician in charge of the patients care, taking into account the views of the patient or those close to the patient.
- Multidisciplinary team decision
- Mandatory from an ethical and legal point of view to involve the patient.
- While its critical to involve the family in a situation where the patient is incapacitated never make them feel that you are putting the onus of the decision to withdraw therapy on them – they will always feel guilty and responsible for causing the death of a loved one.

DECISION MAKING IN END-OF-LIFE CARE

- **PATIENTS WITH CAPACITY TO DECIDE**
- The HCP must discuss the diagnosis, prognosis and options for treatment with the patient in detail.
- Respect patient autonomy.
- If the decision of withholding/withdrawing therapy is made, terminal care options must be discussed with the patient in order to identify the patients concerns and needs in order to allow them to die with dignity.
- Identify a surrogate decision maker.
- These discussions are often very difficult but are essential and should not be avoided – allow psychosocial/religious support for the patient and family.
- If a linguistic or cultural barrier exists an interpreter fluent in the language of the patient must be used.

LIVING WILL/ADVANCED DIRECTIVE

- The South African National Health Act of 2003 provides that the patient has the right to refuse treatment.
- A living will has not been recognized in South African statutory law as yet.
- The 2018 National Health Amendment Bill proposes the following:
- ✓ Recognition of a 'Living Will' and a 'durable power of attorney'.
- ✓ Prescription of the purpose, scope and format of these documents
- ✓ Confirmation that a proxy decision makers decision may not override the contents of the living will
- ✓ Medical practitioners acting on the contents of a living will, will be immune from any criminal or civil prosecution.
- This bill while gazetted has not yet been passed or signed off as law.

DECISION MAKING IN END-OF-LIFE CARE

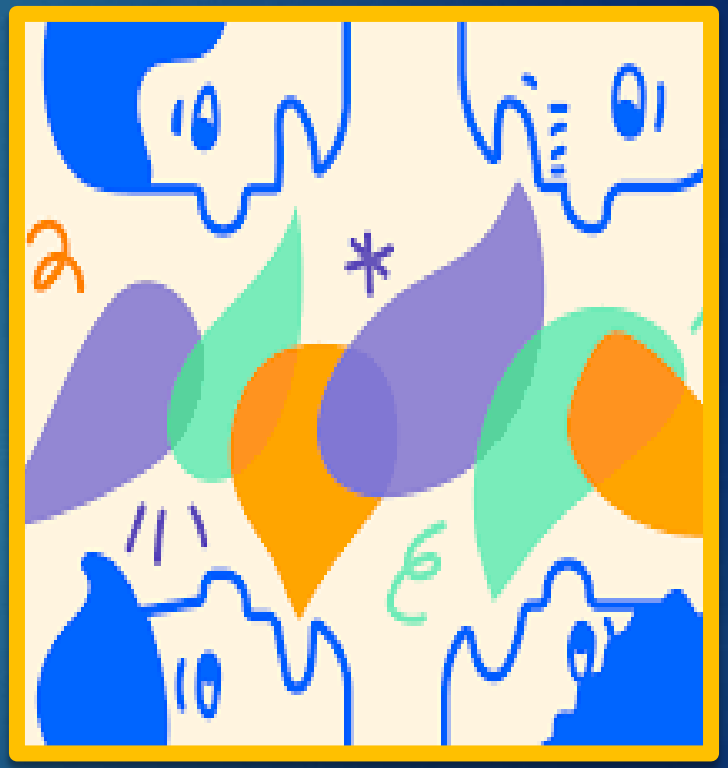
- **PATIENTS INCAPABLE OF DECIDING FOR THEMSELVES – SURROGATE DECISION MAKER**
- Where a patient lacks the capacity to decide, health care practioners must respect any valid advance refusal of treatment.
- Where there is no advanced refusal of treatment the senior clinician responsible for the patients' care must make the decision about what course of action would be in the patients' best interest.
- This should then be discussed with the patients next of kin/surrogate decision maker.
- Family meeting
- Psychosocial support for the patients' family.

COMMUNICATION

- **COMMUNICATION WITH PATIENTS AND FAMILIES**
- Studies have shown that the aspect of care that patients and their families were most often unhappy about was communication from medical staff.
- Poor communication is also a major contributor to litigation.
- Patients and families feel more satisfied when health care professionals spend more time listening rather than talking.
- Satisfaction increases if physicians express empathy and understanding.
- Make a point of reassuring them that care is not being withdrawn and analgesia and comfort is a priority – we are all worried about pain and suffering.

STRATEGIES FOR GOOD COMMUNICATION

- Always identify yourself and introduce others present.
- Allow enough time and allot a specific place for discussion
- Be honest and explain the situation in simple terms
- Act as a team and get junior members and nursing staff involved.
- Be willing to admit you don't have all the answers
- Be a good listener
- Explain the process of withdrawing or withholding therapy
- **Stress that withholding/withdrawing therapy does not mean withdrawing care.**



COMMUNICATION

- **COMMUNICATION WITH THE INTER-DISCIPLINARY TEAM**
- Essential to discuss all major decisions such as withdrawing therapy with all team members involved in the patients care and that a consensus is reached.
- Good communication lessens conflict and leads to better patient care, greater job satisfaction and decreased rates of burnout.
- Don't forget to include nursing staff and allied health care professionals in these discussions.

RECORDING DECISIONS

- The HPCSA mandates that health care practioners must ensure that decisions are properly documented as follows:
- ✓ Relevant clinical findings
- ✓ Details of discussions with the patient or surrogate decision maker and other health care professionals.
- ✓ Details of treatment
- ✓ Other factors which may affect future care.
- **Family meeting form**
- The record should be legible, clear, accurate and unambiguous.
- Health care practioners should ensure that the records are appropriately accessible to all team members and others involved in providing care to the patient – after hours this is of critical importance.

FAMILY MEETING FORM

- Persons present at the meeting – identified by name and role/relation to the patient.
- Patients current condition and prognosis.
- Management plan going forward
- Patients wishes
- Families concerns and wishes
- MDT input.
- Decisions and goals of therapy decided
- Family to summarize
- Ask if there are any other questions

- Signatures of all persons present at the meeting.

WITHHOLDING TREATMENT DUE TO SCARCITY OF RESOURCES

- There are circumstances when withholding treatment, even if it is not in the best interest of the patient is permissible-scarce resources such as intensive care and chronic dialysis units.
- A health care institution has the right to limit life-sustaining interventions without consent of a patient or surrogate by restricting admission to these units – based on national admission criteria agreed upon by expert professional bodies and the HPCSA.
- **Soobramoney vs Minister of Health 1998**
- A health care institution is however obliged to provide appropriate palliative care when specialized care is withheld.
- If the patient does meet all the criteria for admission, but cannot be admitted because of limited resources at an institution, the health care practitioner must transfer the patient to another institution where such resources exist – following emergency treatment.
- **Consider however that the majority of ICU beds are in the private sector for the minority of the population.**

PRACTICAL ASPECTS

- Once the decision has been made to transition care from cure to comfort all therapies should be critically evaluated in terms of whether they make a net positive contribution to the comfort of the patient.
- All antibiotics, vasopressors , renal replacement therapy should be stopped.
- Stop all laboratory investigations, blood gasses and radiology.
- Intravenous fluids and nutrition don't provide comfort so should be stopped – however this is often controversial.
- Intubated patients – differing schools of thought and institutionally dependent – extubation vs T-piece vs minimal ventilator settings with an Fi02 of 21%.
- Allow the family unrestricted access , if possible, in a private room and prepare them for the process of dying.
- Family should be assured at all times that patient care and comfort is the priority and therefore analgesia and if necessary, sedation will be given.
- Members of the clergy should also be allowed if requested.

SYMPTOM MANAGEMENT IN END-OF-LIFE CARE

- **PAIN**
- ✓ More than 50 % of seriously ill patients report some level of pain.
- ✓ Use of different pain scales.
- ✓ Multimodal pain relief – opiods still remain the mainstay, however ketamine, dexmedetomidine and cannabis are also used.
- ✓ All have some sort of sedative effect as well
- **DYSPNEA AND RESPIRATORY DISTRESS**
- ✓ Supplemental oxygen , bronchodilators, corticosteroids
- ✓ Opiods
- ✓ Individualize according to patient and circumstances
- **DELIRIUM**
- ✓ Optimize analgesia first
- ✓ Sedation – benzodiazepines or haloperidol

DOCTRINE OF DOUBLE EFFECT

- **“A harmful of effect of treatment, even resulting in death, is permissible if it is not intended and occurs as a side effect of a beneficial action”**
- The intended effect must be a good one.

BEREAVEMENT AND SUPPORT

- End-of-life care requires support systems and resources for health care workers that address moral distress, burnout and PTSD.
- This may include regular debriefings after patient deaths, access to spiritual and psychosocial resources.
- Mutual support, communication and resolution of ethical conflicts are essential.

CONCLUSION

- The majority of deaths in ICU are now preceded by a decision to withdraw or withhold life sustaining therapy.
- There is still a considerable difference in views regarding end-of-life decision making in health care.
- Ethically and legally there is no difference between withholding and withdrawing therapy.
- Concerned, compassionate, and considerate care at the end of life with good communication with the patient, family, and other staff members can make this difficult time easier for all.
- **The right to die with dignity is a fundamental universal right of all living creatures, and as health care professionals we are in the unique and privileged position to ensure that this happens.**

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