



Online Ethics Course

Topic 7

Issues around the Beginning and End of Life, including DNR



Intended learning outcomes

After completing the topic, learners should be able to:

- Identify ethical dilemmas in the context of beginning and end-of-life care
- Explain primary ethical concepts associated with beginning and end-of-life care and their relationship with the law



Part one

Beginning of life care

- The concepts deal with onerous issues surrounding medical decision-making, including the medical care and treatment of premature babies and neonates
- Such decisions are prone to raising ethical and legal problems; effective communication between the health care team and the patient is essential to help mitigate these problems



Overview

Under beginning-of-life care, the following topics will be covered:

- *Before Birth: Issues Involving Embryos and Fetuses*
 - Personhood
 - Abortion
 - Mother-foetus conflict
- *Issues in Reproduction*
 - Assisted Reproduction, including prenatal screening and sex selection



Personhood

- The term ‘person’ usually refers to individual human beings and their characteristics
- Philosophically, it is hard to define a person (e.g., a being that possesses consciousness, has preferences, has conscious desires, is capable of rational thought, has a sense of time, can remember its own past actions and mental states, can envisage a future for itself, has non-momentary interests involving a unification of desires over time, is capable of rational deliberations, can take moral considerations into account in choosing between possible actions, has traits of character that undergo change in a reasonably non-chaotic fashion, can interact socially with others and can communicate with others etc.)



Cont.

- Personhood is sometimes attributed to fetuses; while in law they are not yet persons in their own right, they have many characteristics needed in order to become a person; one alternative is to describe a fetus as a *potential* person
- These issues are crucial to the wider debate about termination of pregnancy; e.g., if an embryo is considered a person, then by definition, its destruction is morally wrong
- This debate can lead to more questions than answers; nonetheless, the issues are important and need to be discussed



Abortion

- Abortion is about terminating a pregnancy before the due time of child delivery
- The world remains divided between jurisdictions in which abortion is legal and those where it is not



Cont.

*Ethical Arguments **for** Abortion*

- Abortion is morally right for,
 - a) it protects women's independent rights, including the right to health care
 - b) it offers a way for women to control their own fertility
 - c) it can avoid harmful consequences in the lives of both mother and child



Cont.

*Ethical Arguments **against** Abortion*

- Abortion is morally wrong for,
 - (a) human fetuses, from conception, are human beings, and thus have the same moral right to life as other human beings
 - (b) fetuses have the right to life by virtue of their potential to become human beings
 - (c) It offends basic principles of sanctity of life



Mother-Foetus Conflict

- Conflict can occur when the woman is pregnant and the unborn baby is still a fetus; efforts to protect a fetus have to be made through the body of the pregnant women, raising issues of privacy and bodily autonomy
- Just as parents have obligations to avoid exposing children to risk of serious harm, so pregnant women have obligations to protect the baby ‘in utero’



Cont.

- Therefore, women have moral obligations to avoid inflicting prenatal harm
- The avoidance of prenatal harm can involve the mother making sacrifices and taking risks in terms of her own health
- This involves balancing obligations and interests; i.e., welfare of the fetus and survival of the child vs. a woman's right to privacy, bodily integrity and personal autonomy



Assisted Reproduction

- A specific approach to reproduction that involves a third party in the normally two-person enterprise of making a baby
 - Techniques include AID (artificial insemination by donor), egg donor, IVF (in vitro fertilization), and the related technologies of GIFT (gamete intrafallopian transfer) and ZIFT (zygote intrafallopian transfer), plus various forms of surrogacy



Cont.

*Arguments **for** assisted reproduction*

- Benefiting the infertile
- AID or egg donation can prevent the birth of children at risk from congenital disease
- Approaches such as surrogacy can protect women at special risk of harm from pregnancy



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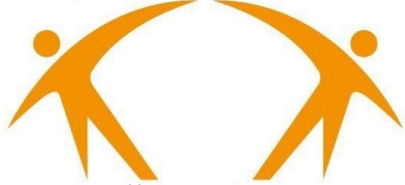
*Arguments **against** assisted reproduction*

- a) Assisted reproduction tends to separate sexual intercourse from human reproduction; this kind of objection is either based on *natural law* or religious principles stating that non-procreative sex is immoral
- b) Assisted reproductive technology usually involves the creation (and potential destruction) of spare fetuses
- c) Assisted reproduction alters traditional assumptions about family and relationships



Cont.

- *Feminist Objections:* (a) Assisted reproduction could help men to subjugate women and even lead to eugenics
- *Other Objections:* IVF techniques can lead to abuse and violation of various rights and consents, leading to unjust killing; surrogacy arrangements can bring into question the welfare of a child that is conceived



Prenatal Screening and Sex Selection

- *Prenatal screening* is about the pursuit to investigate health and other characteristics of a cluster of human cells that pass through the early process of development (including pre-embryonic, embryonic, and fetal)
- It aims to reduce the incidence of congenital abnormalities for which no treatment is available, and produce information that is of use in pre- and post-natal treatment or management of various disorders



Cont.

- Prenatal screening is identified with the removal and/or examination of different types of tissue and bodily fluid
- If used for gender screening, it can lead to demographic imbalance, and could be used to enhance physical and even psychological aptitudes of a child yet-to-be born



Cont.

- It can result in terminating a pregnancy before the due time, thereby denying ‘the intrinsic properties of a fetus’ such as sentience, personhood or potential personhood
- Some believe the technique could be used to affect population growth and/or promote paternalistic culture



Cont.

- Prenatal screening may be desirable if it respects the autonomy of pregnant mothers; however, decisions can potentially be manipulated for the sake of family members, especially in developing countries, where the rights of the individual are less well defined
- The cost of these procedures is high and not all families can afford the treatment; furthermore, procedures can raise levels of maternal anxiety affecting the health of both mother and the child that is conceived



Reading suggestions

- <http://plato.stanford.edu/entries/identity-ethics/>
- <https://cbhd.org/content/abortion-bioethics-and-personhood-philosophical-reflection>
- <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2702.2008.02616.x/epdf>
- <http://www.nhs.uk/conditions/Abortion/Pages/Introduction.aspx>
- <https://depts.washington.edu/bioethx/topics/matern.html>
- <http://www.thehastingscenter.org/Publications/BriefingBook/Detail.aspx?id=2210>
- <http://www.mayoclinic.org/healthy-lifestyle/pregnancy-week-by-week/in-depth/prenatal-testing/art-20045177>



Part two

- *End-of-life care*: the ethical concept centres around quality of care, and quality of decision-making at or near the end-of-life
- The subject usually includes death and dying, although that tends to raises slightly different questions



Ethics in End-of-life care

Topics include:

- Definitions and human rights
- Quality in end-of-life care
- Difficult decisions in the provision of end-of-life care
- Voluntary euthanasia and physician assisted suicide
- Advance care planning and proxy decision-making



Cont.

- The basic premise in end-of-life [EOL] care is to respect patient wishes and try to make the patient as comfortable as possible
- Issues therefore include:
 - Pain management
 - Comfort and physical surroundings
 - Diet and medication
 - Pastoral care



Principles of EOL care

1. Maximising patient autonomy
2. Respect for patient dignity, especially as a patient nears death
3. Truth-telling, honesty and the exchange of information (including dealing with the unknown)
4. Knowing when to continue treatment (and when not)
5. Knowing if and when to initiate palliative care

NB Not all topics are covered in this introductory course



Cont.

- Bad EOL care infringes someone's basic human right; however, it is important to distinguish between the right to life and so-called right to die
- One does not infer the other; the first is classed as a human right but not the second



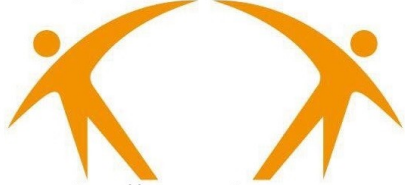
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- If the patient has capacity, s/he should be involved in open discussion about the condition, prognosis and interventions available, plus risks, burdens and benefits associated with the alternatives (including no active treatment)
- If patients lack capacity and there is no advance directive in place, discussion should then be initiated with close family members and/or caregivers, keeping an accurate record of all discussion and decisions made [see topic 6]



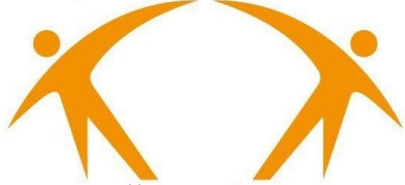
Pain management

- Pain management is a major recurring theme in EOL care
- Too much sedation and the patient feels dizzy and can slip in and out of consciousness
- Too little sedation and the patient is in constant pain leading to significant loss in terms of quality of life
- Inappropriate sedation can lead to doctors being questioned about their intent (e.g., to hasten death or simply ease pain)



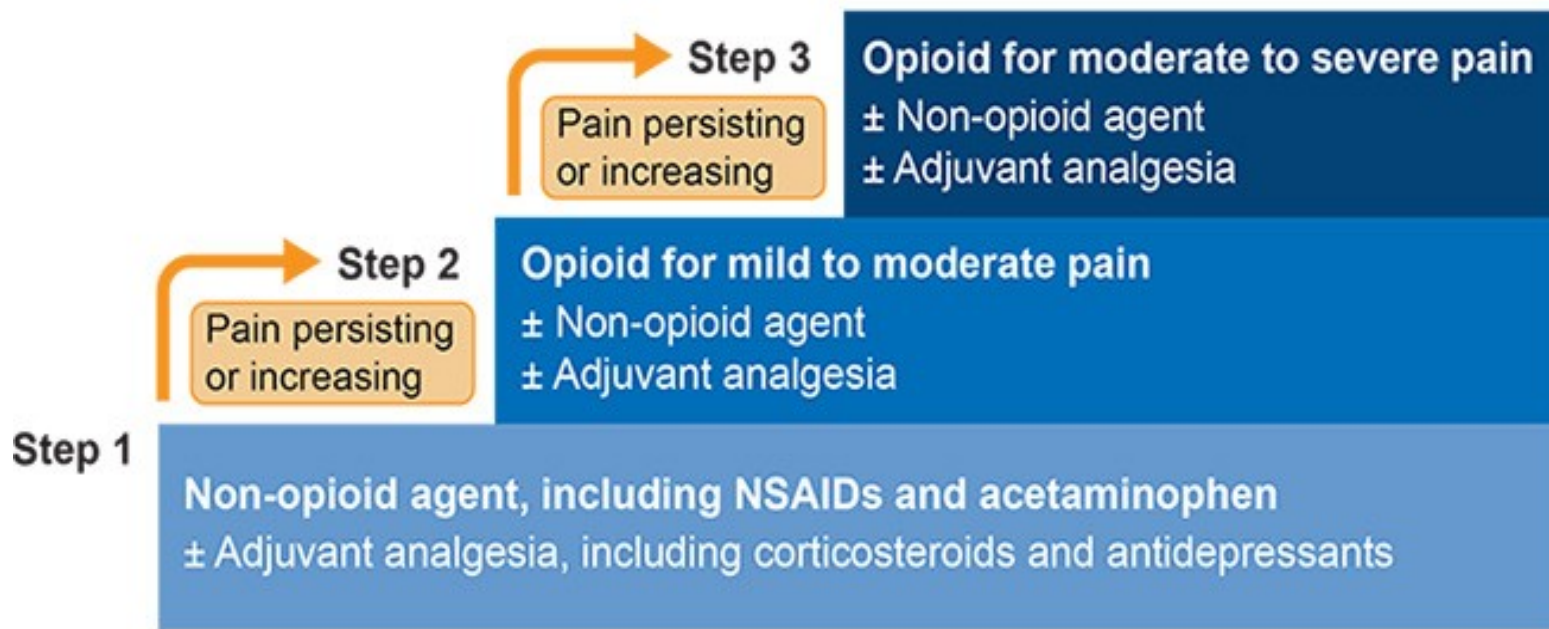
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- Pain, as reported by the patient, should be adequately controlled
- Oral medications provide better compliance and are usually easy to administer; opiate analgesics are widely used in end-of-life care, especially for conditions such as cancer
- Pain is often controlled using a combination of drugs (e.g., to reduce physical as well as emotional discomfort, including anxiety and/or depression)



WHO pain ladder

WHO's Pain Relief Ladder





Euthanasia and physician assisted suicide

- Euthanasia is the act of deliberately ending a person's life (e.g., in order to relieve suffering)
- Assisted suicide is the act of deliberately assisting or encouraging another person to kill themselves
- There are a number of different classifications



Types of euthanasia

1. **active euthanasia** – when a person deliberately intervenes to end someone's life (e.g., by injecting them with a large dose of sedatives)
2. **passive euthanasia** – when a person causes death by withholding or withdrawing treatment (e.g., because it no longer benefits the patient)
3. **voluntary euthanasia** – when a person makes a conscious decision to die and needs someone else to help (e.g., a healthcare professional, or close relative)
4. **non-voluntary euthanasia** – when a decision is made to withhold or withdraw treatment on behalf of a patient who lacks capacity (e.g., where a patient has previously made his/her wishes known)
5. **involuntary euthanasia** – when a person is killed against his/her express wishes (which amounts to murder)



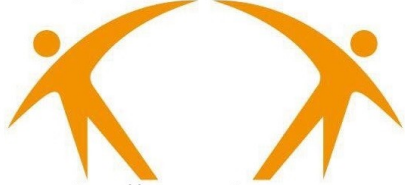
Law and ethics

- Euthanasia and physician assisted suicide [PAS] are generally against the law; however, much depends on the particular category (see previous slide), and the particular jurisdiction (see next slide)
- Doctors are not required to provide unnecessary treatment (i.e., that which provides no benefit to the patient and deemed futile); therefore, withholding or withdrawing treatment may be entirely lawful



Cont.

- Euthanasia is currently only legal in the Netherlands, Belgium, Colombia and Luxembourg
- Assisted suicide is currently legal in Switzerland, Germany, Japan, Albania and in the United States of Washington, Oregon, Vermont, New Mexico, Montana and California; the following guideline is applicable to the UK (2015)



Definitions of death

- Classically, death is defined as the cessation of all vital functions of the body including heartbeat, brain activity (including brain stem), and breathing
- However, with advances in medical science, it is possible to continue circulation and respiration artificially, even after the brain and brain stem have ceased to function, creating a distinction between brain and circulatory death



Cont.

- Presently, brain death is widely considered as the medical and legal point of death
- *Brain death* is defined as the irreversible loss of all functions of the brain, including the brain stem
<http://plato.stanford.edu/entries/death-definition/>
- Essential findings in brain death are
 - Coma
 - absence of brainstem reflexes
 - apnoea



The ethics of brain death

- Circulatory and respiratory function can be artificially maintained with ventilatory and circulatory support, even after brain stem activity has ceased, with no possible hope of patient recovery
- This is important in the context of organ transplantation (which falls outside the scope of this course) and raises various ethical problems; similarly, persistent (or permanent) vegetative state



Advanced directives

- Advance directives are documents that allow people to outline their decisions about end-of-life care ahead of time
- A living will sets out the treatments that a patient does or does not want in particular situations (e.g., regarding the use of renal dialysis, artificial respiration; cardio-pulmonary resuscitation; clinically assisted feeding and hydration, and organ or tissue donation [see topic 6])



Cont.

- There is no legal framework for advance directives in most developing countries, including India; however, if diagnosed with a terminal disease, a patient can decide on the limit of intervention that s/he wishes to undergo
- This may depend on the quality of consent and the willingness / ability of clinicians to honour these wishes when the time comes
- *Do Not Resuscitate* orders are type of advanced directive; they can be made by the patient and/or clinical team; they are not permanent and should be reviewed at regular intervals [see topic 6]



Proxy decision making

- In most developed countries, there is an option to appoint someone to act under durable or lasting power of attorney
- In India, there is no such provision in law and the onus of decision-making rests with next of kin
- Proxy decision-making is when a patient appoints a trusted person to represent the wishes of the patient in the event that s/he loses capacity [see topic 6]
- Substituted decision-making is a slightly different principle, and will not be discussed here



Reading suggestions

- <http://www.nhs.uk/Conditions/Brain-death/Pages/Introduction.aspx>
- <https://www.nlm.nih.gov/medlineplus/advancedirectives.html>
- <http://www.nhs.uk/Conditions/euthanasiaandassistedsuicide/Pages/introduction.aspx>
- <http://supremecourtfindia.nic.in/outtoday/wc2152005.pdf>
- <http://www.tandfonline.com/doi/pdf/10.1080/15265161003599691>
- Mohanti BK. *Ethics in Palliative care*. Indian J. Palliat Care (2009) 10.4103/0973-1075.58450



Acknowledgement

Dr Roger Worthington gratefully acknowledges generous support in the preparation of these slides from Dr Rhyddhi Chakraborty and Dr Suparna K Pal