

# Ethical Decision-Making: End-of-Life Issues and Advance Care Planning

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# What is Ethics?

- Basically, Ethics is the study of what *should* be done
- Includes - morals, moral questions, critical study of right/wrong, good/bad
- Framework for making moral judgements - decisions about difficult moral problems
- Requires: discussion, argument, reasoning, thinking - to understand **your** beliefs/values and the **authority** for those

# Main Ethical Principles in Western Thinking

- **Autonomy** - Respect for Individual Rights
- **Nonmaleficence** - Do No Harm
- **Beneficence** - Do Good
- **Justice** - Treat all Equally (but may sometimes need to treat unequally to “level the playing field”).
  - May be divided into 3 areas:
    - distributive justice -fair distribution of scarce resources
    - rights-based justice - respect for the rights of all
    - legal justice - respect for morally acceptable laws

# What Does Autonomy Mean?

- It does not mean “doing whatever you want”.
- At the very least, it means “reflected decisions” - assumes capacity
- Socrates: “The unreflected life is not worth living”
  - We all have values, beliefs, attitudes that we have “inherited” from family, or “learned” from society
  - they may be entirely valid for you - but you can’t know that if you never question them
  - someone else may hold exactly the opposite belief or value and it may be entirely valid for them
  - tolerance/respect for beliefs/values of others –e.g. J.Ws

## Beneficence/Nonmaleficence

... do good: incl. maximising benefits to patients; working with patients and their families to find the best outcomes for patients in different settings; conducting scientifically sound, rigorous research that may provide benefit to your participants and/or others

... do no harm: e.g. assuming incapacity - takes away patient's independence & control; conducting research of such poor quality that it is unlikely to produce "useful" results – if government funded, waste of public money but in any case, waste of participants' time. (Note: some qualitative research may not produce "generalisable" results but may still be worthwhile.

# Justice in Public Health

- All allocation decisions are based on some moral assessment of how competing claims can be adjudicated fairly... ie. *they are all explicitly or implicitly based on some theory of justice*
  - includes micro-allocation and macro-allocation choices

There is no obvious way to give consistent moral priority to any criterion for allocating scarce health resources (e.g. age, gender, merit)

# Proportionality

- Conceptual distinction between ‘proportionate’ and ‘disproportionate’ interventions (also known as ‘ordinary’ and ‘extraordinary’ means). Relates to *due proportion* between the means employed and the end pursued.
- Also includes benefit to burden ratio. Need to understand burden in sense of ‘costs’ - financial, physical, psychological, or even spiritual - burden to patients, families, health care providers, community; and opportunity costs to other patients.

# End-of-Life Issues: Context

- Better living conditions/health care have led to increased longevity.
- In 2008, the Australian Bureau of Statistics estimated that there were 3,400 people in Australia aged 100 or older.
- Increased longevity is a success story, and it is right to celebrate this.

# Use of Medical Technology

- In addition, rapid technological development has allowed people who would have previously died to be kept alive for long periods of time, often through the use of such things as ventilators and feeding tubes.
- These successes have led to practical, legal & ethical issues, in particular around end-of-life care and extending the dying process

# Fears and Concerns in the Community

- Cases Reported

- Loved one “left hooked up to machines until the very end. We couldn’t even get close enough to give him a hug and say goodbye”.
- “My mother always said she wouldn’t want to be resuscitated if her heart stopped, but they wouldn’t listen”.
- “I want to make sure that doesn’t happen to me”

# Carers' Stories

- (Husband) Close to the end of his wife's life, "because the cancer was attacking the bone and she had bad pain in her hip, they put a pin in. And ...it was a terrible mess...It just added to her pain. And they gave her more chemo as well...and they took numerous X-rays, 3 or 4 a day".
- (Wife) "First of all he was stubborn when he was in hospital; he wouldn't eat - he was just starving himself. They couldn't get him to eat ... so they had to force-feed him. They put a tube down his nose and then they had to tie him in the bed, because he kept pulling it out. He just didn't want it".

(It is an assault to continue to treat a competent patient who has refused treatment, even to save that person's life; it is also an infringement of the ethical principal of respect for autonomy – ref JS Mill).

# Community Concerns in Terminal Illness: Rank Order for 3 Studies

<b>FACTORS</b>	<b>Study 1</b>	<b>Study 2</b>	<b>Study 3</b>
<b>Loss of Mental Faculties</b>	<b>1</b>	<b>1</b>	<b>1</b>
<b>Loss of Control</b>	<b>2</b>	<b>2</b>	<b>2</b>
<b>Loss of Independence</b>	<b>*</b>	<b>3</b>	<b>3</b>
<b>Burden on Family</b>	<b>*</b>	<b>4</b>	<b>4</b>
<b>Loss of Dignity</b>	<b>4</b>	<b>5</b>	<b>5</b>
<b>Leaving Loved Ones</b>	<b>5</b>	<b>*</b>	<b>6</b>
<b>Protracted Dying</b>	<b>*</b>	<b>*</b>	<b>7</b>
<b>Extreme<sup>1</sup> /Physical Pain<sup>2,3</sup></b>	<b>3</b>	<b>6</b>	<b>8</b>
<b>Death Itself</b>	<b>9</b>	<b>9</b>	<b>10/10</b>

# Confusion About what is/is not Euthanasia

- Many problems stem from confusion over what is, or is not, euthanasia. This leads to:
  - Inadequate pain management
  - Inappropriate use of medical technology
  - Fear among health professionals of legal consequences of care provision
  - Poor doctor-patient communication
  - Disillusioned patients/families/carers

# Common Beliefs

- Some commonly held beliefs are that euthanasia includes:
  - (a) giving increasing amounts of needed pain relief which may also have the effect of shortening the person's life; or
  - (b) respecting a patient's right to refuse further treatment; or
  - (c) withholding or withdrawing life support systems that have ceased to be effective or that will provide no real benefit to the patient

None of these is euthanasia

# Definitions of Euthanasia

- The World Medical Association defines euthanasia as "the deliberate ending of a person's life at his or her request, using drugs to accelerate death".
- Definition used in studies by Steinberg et al, 1996, 1997; Cartwright et al, 1998, 2000
  - Euthanasia is a deliberate act intended to cause the death of the patient, at that patient's request, for what he or she sees as being in his/her best interests (i.e. Active Voluntary Euthanasia – AVE).

# Giving Pain Relief Which May Also Shorten the Patient's Life

- This is often referred to as "the doctrine of double effect" – the primary intention is to relieve pain; a secondary, unintentional effect may be the hastening of the person's death by a few hours or days.
- In Australia, the UK and many other countries "double effect" is accepted by most religious and medical groups, including those who strongly oppose euthanasia.
- (Note: **not giving adequate pain treatment** when it is needed may actually shorten life: the patient may suffer complications such as life-threatening cramps or severe respiratory problems if severe pain is left untreated. Infringes the ethical principal of non-maleficence or *primum non nocere* – first, do no harm!).

# Respecting a Patient's Right to Refuse Treatment

- In Australia, every competent person has a legal and moral right to refuse medical treatment – any treatment, even life-saving treatment.
- It is also the right of a non-competent patient who wrote down their wishes in an Advance Directive or legally appointed someone to make those decisions for them at such a time.
- However, this right is not always respected. (Again, infringes the ethical principal of respect for autonomy)

# Withholding/Withdrawing Futile Life-Supports Systems

- Used to be called "passive euthanasia"; now generally agreed that that term is unhelpful - it can lead to the inappropriate continued use of invasive technology.
- Often it is not prolonging life, it is merely prolonging the dying process!
- Removal of futile treatment is good medical practice. Futility is generally considered to be when burden outweighs benefits – but “burden” and “benefit” should be from patient’s viewpoint.

# Terminal Sedation

- Recent, controversial addition to the debate - terminal sedation and its relationship to euthanasia.
- Refers to use of sedative drugs to induce unconsciousness in terminally ill patients in order to relieve suffering (therefore supports ethical principal of beneficence), including anxiety, when other attempts at relief have failed. Includes withholding or withdrawing artificial nutrition/ hydration.
- Some doctors have described Terminal Sedation as "slow euthanasia" and claim that it is ethically inferior to EU because it takes patients longer to die, with the potential for further suffering (i.e. "do harm").

# Competing Ethical Principles

- Sometimes principles compete with each other, e.g.
  - screening - test lots of healthy people, possibly create anxiety/stress, to potentially benefit a few
  - researcher has given assurance of confidentiality but realises there is possible elder abuse occurring
  - a competent patient refusing treatment, may challenge a doctor's/nurse's training or personal ethical values (and possibly religious beliefs)

# Hastings Centre Standards

- 1. No one should, in the modern world, have to live longer in the advanced stages of dementia than he (sic) would have in the pre-technological era.
- 2. The more advanced the damage of dementia, the more legitimate it is to overturn the usual bias in favour of treatment.
- 3. Whoever is making the decision has as strong an obligation to prevent a painful and degrading death as to promote health and life.

# Advance Care Planning Helps to Address Fears & Concerns

- Health/Personal Care Mechanisms:
  - Person can appoint own substitute decision-maker for future time of loss of capacity (usually a trusted relative or friend): (Note: In NSW, NOT EPoA)
  - Write wishes in Advance Directive
  - Most states/territories in Australia have legislation for who can make health care decisions, **if no-one has been appointed by the patient** (Note: Usually NOT Next-of-Kin)
  - At the very least there should be a discussion with the doctor or other health care provider/Noted in patient's file

# Advance Directives

- An Advance Directive
  - is a written legally-binding document, which allows a person to make their wishes for future health care known
  - extends the current legal right of a competent person to refuse treatment to a future time when they may not be competent
  - is NOT a form of euthanasia, as it only allows actions which a person could legally consent to for themselves if they were competent to speak
  - only comes into effect when the person making it loses decision-making capacity.

# Benefits/Ethical Basis of Advance Directives

- Supports ethical principal of patient autonomy
  - Gives control back to patient
  - Ensures patient's wishes are known - patient's own words
- Supports ethical principal of beneficence (do good)
  - Assists health care provider with decision-making
  - Relieves family stress at time of trauma
  - Gives security in relation to future events (allows person to live well now by taking away fear of end stage of life)

# Paternalism – “Older People don’t want to think about/talk about end-of-life issues”

- E-O-L study with Qld community – 8 groups
  - Men 60-69; 70-79; 80+
  - Women 60-69; 70-79; 80+
  - General community members – 18-29, 30-59
- 38-page questionnaire covering range of end-of-life issues, including causes of distress, advance care planning, pain management, palliative care, euthanasia
- Highest response rates – men 70-79, 60-69, 80+; then women 60-69; 70-79, 80+; then 30-59, 18-29

# When Does a Person Have Capacity to Make A Decision?

- Legislation is based on support for autonomy
  - Person is competent unless proved otherwise
- Person must understand *the nature* and *the effect* of the decision to be made – (case study)
- Person must be able to communicate their decision in some way - not necessarily by speaking or writing - body language may be adequate, e.g. nodding/shaking head

# Incapacity is Not:

- Ignorance (because of being given insufficient information)
- Having different cultural or ethical views
- Communication failure (some health-care providers are not very good communicators)
- Making what someone else thinks is a bad decision.
- Disagreeing with the doctor or other health care provider
- (Again, all above support ethical principal of autonomy)

# Tools for Evaluating Capacity

- **Beware the Mini-Mental State Test** – this was NOT designed to test Capacity – it is a screening tool.
- There is good evidence that it should not be used for older people, people with low education or people from ATSI or CALD background. (Cases – clear infringement of autonomy, non- maleficience).
- Better to provide information, check comprehension
- New Capacity Toolkit is a big step forward
- Darzins 6-step Capacity Assessment Instrument is also very good (available from Alzheimer's South Australia)

# Issues in Hospitals & RACFs - 1

- In many Hospitals and RACFs, still no provision on admission forms for recording existence of:
  - Advance Directive; or
  - Patient-appointed substitute decision-maker; or where none
  - Person with legal authority to make substitute decisions
- Forms do not comply with legislation in most States/Territories – still ask for Next-of-Kin.
  - Next-of-Kin has no legal status in relation to making medical decisions in NSW, Qld
- Not following Advance Directive or determining correct decision-maker puts staff – and the facility -at legal risk

# Healthy Ageing: Healthy Dying

- An ageing world population brings many challenges – including the imperative to protect our most vulnerable older people
- When older people not only live well but also die well, we can claim success!

Thank You