

Practical & Ethical Issues in Research with Older People

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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)

... do no harm (e.g. assuming incapacity - takes away patient's independence & control)

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). The ‘principle of therapeutic proportionality’ relates to *due proportion* between the means employed and the end pursued. Also benefit to burden ratio.
- Need to understand burden also in sense of ‘costs’, including financial, physical, psychological, or even spiritual burdens to patients, families or health care providers, and opportunity costs to other patients.

Informed Consent - Impact of Legislation

- *Rogers v. Whitaker* (1992) 175 CLR 479.
- Mrs Whitaker - elective eye surgery
- Dr Rogers - 1 in 14,000 chance of damage to “good eye”
- Mrs Whitaker not told - damage occurs
- Dr Rogers’ defense - the *Bolam Principle*
- Court rejects defense, awards \$800,000

Post Rogers v. Whitaker

- Practitioner has duty to warn patient of **material risk**.
- Risk is material if
 - a reasonable person in the patient's position, if warned of the risk, would attach significance to it; and
 - the medical practitioner is, or should reasonably be, aware that the particular patient, if warned of the risk, would be likely to attach significance to it.
- General & specific information, as required

Practical Implications of Moral Principles for Research

- Respect for autonomy
 - respect individual rights (NB: privacy)
 - informed consent
 - confidentiality (including for interviews)
 - use of data
 - protect those with ↓ autonomy (more vulnerable is study population, e.g. old, frail people - more care/responsibility accrues to researcher)

Practical Implications of Moral Principles for Research - 2

- Justice
 - duty to share knowledge, disseminate information, i.e. publish research findings
 - resource allocation – OK to discriminate – as long as its favour of the least advantaged
 - protection of the individual (above interests of researcher, profession, society)

Autonomy & Informed Consent

- What does “Informed Consent” (for health care) mean?
 - Patient has been given all relevant information, including risks/benefits/alternatives
 - patient has capacity to make decision
 - patient agrees to/authorises procedure (no pressure)
 - agreement is freely given (no coercion)
- Having someone sign a consent form does not, of itself, constitute “informed” consent.
- Informed consent is a process, not an event

Evaluating Capacity To Consent

- **Assume capacity** - UN Declaration of Human Rights
- Major depression, early dementia, - patient may still have capacity to consent
- Family/RACF staff may say “not competent” – but may be
- Beware the Mini-Mental State Test - better to provide information and check comprehension

When Does A Person Have Capacity To Make A Decision?

- Person must understand *the nature* and *the effect* of the decision to be made (example);
- 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
- (Case study)

Examples of Poor Ethical Practice

- Cases Reported (“60 & Better”)
 - 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”.
 - “Mum always said she wouldn’t want to be resuscitated if her heart stopped, but they wouldn’t listen”.

Carers' stories -2

- (Husband – who felt that the specialist just could not accept “defeat”). “Because of (X – specialist) they were still trying to cure her but it was not any point. They were doing everything. Everyone was making out that this was going to be the answer, when they knew damn well it wasn't”.
- (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”.

Other Ethical Issues Relating to End-of-Life Medical Treatment

- Respecting patient's right to refuse treatment
- Withdrawing/withholding futile treatment, incl. PEG tubes – strong evidence of futility for people with dementia
- Giving adequate pain relief which may also hasten death

(NB: none of these is euthanasia)

- Responding to requests from patients for physician-assisted suicide or euthanasia (Not the same thing)

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
 - a non-competent patient with an AD refusing life-sustaining medical treatment; or
 - (more extreme), a competent patient requesting assistance to die, may challenge a doctor's training or personal ethical values (and possibly religious beliefs)

Dealing with Competing Ethical Values

Euthanasia

- Assist patient – may “do harm” by breaking the law and possibly acting against own training & values;
- Do not assist patient – may “do harm” by not respecting patient autonomy and possibly not alleviating patient’s suffering, and perhaps acting contrary to their own sense of compassion

Dealing with Competing Ethical Values - 2

- Options:
 - Accept that some problems do not have perfect solutions and choose to stay within the law and within the AMA Code of Ethics (but this carries an ethical imperative to keep palliative care skills high). This option would not require the doctor to come to an ethical conclusion re: euthanasia.
 - Make a moral judgement, come to an ethical conclusion about euthanasia and then act according to his/her conscience.

(Note: even if a doctor decides that euthanasia is morally acceptable, it is ethically justifiable to take one's own well-being into account and consider the risk of criminal prosecution)

Ethical Issues Relating to Research with Older People

- **Autonomy/Justice** - treat all equally
 - competent person's right to consent to or refuse to participate, does not diminish with age
- **Beneficence** – do good /**Non-maleficence**- do no harm
 - can harm someone by not providing opportunity to participate in research – miss benefits of participation

Ethical Issues Relating to Research with Older People -2

- Beneficence – do good /Non-maleficence- do no harm
 - great care needed in talking about death & dying, e.g. with carers, may cause anguish if too soon after bereavement; may be poor recall of issues, emotions if too long after; often people want to talk about deceased person and no one “lets them”
 - Time taken to conduct interview – is older person becoming tired? Do they know they can take a break, or stop the interview? (May disappoint researcher – “push” boundaries)

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

Issues about Data Analysis & Interpretation

- Older people not generally included in RCT but results often applied to them – yet, they may not actually apply, e.g. drug trials: older people metabolise drugs at different rates to younger people
- Where older people are included, they should not be considered one homogenous group – often analysis by age group puts all 65+ together; may be 3 distinct groups (e.g., 65-74; 75-84; 85+), having very different perspectives and even clinical reactions
- For longitudinal studies, risk of loss to study by death of participants must be identified/controlled for in proposal

Why Older People Take Part in Research

- Most reasons same as anyone else:
 - interest in topic because of personal/family experience
 - My research: several respondents had witnessed bad deaths and felt that “the system” needed to change
 - altruism – want to help others in community
 - My research: “while I don’t think I would ever want euthanasia for myself, I think it should be available to those who do”; “if my experience helps one other person I’ll feel as if I made a contribution”
 - sense of obligation
 - My research: “The Blue Nurses did so much for my wife, if this research can help them, then I’m happy to do it”.
 - need to be heard/anger
 - My research: Very elderly man, extremely angry over poor treatment of his wife by GP – “I only agreed to this interview because it might save someone else going through what we did”

Why Older People Don't Take Part in Research

- Family objections
 - Family believe it would upset the person – despite the person themselves thinking it would not
 - Some family members “afraid” of what the person will say – guilt over level of support; sometimes family believe a person was assisted to die – not always so.
 - My research: appointment made, arrived at house, “my daughter said I’m not to be involved in this”
- Distress
 - “I can’t – it was all too hard and it will just bring it all back”
 - “My doctor said it would probably be good for me to do it but I just can’t, it’s too soon” (12+ months post husband’s death)

In summary....

- Issues are similar to doing research with any age group but more consideration should be given to issues of physical, mental and emotional capacity
- Most older people are happy to be involved in research and want to know that they are making a contribution to others
- Older people have a right to be included in research, particularly if it is likely to be applied to them