Developing an ethical response to end-of-life choices legislation: An overview of end of life issues

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Outline

- Legal and ethical context (Joy)
- End-of-life ethics and issues (Martin)
- Articulating your ethical position (Participants)

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NZ law, research, advocacy

- 1961 Crimes Act Section 167 a)
- 1978 Voluntary Euthanasia Society
- 1990 Bill of Rights Act Section 11
- 1996 Code of HDS Consumers Rights
- Death with Dignity Bill (1) 1996 Vote 29 Yes/61 No
- Death with Dignity Bill (2) 2003 Vote 58 Yes/60 No
- 1990 - 2013 court convictions or not including Lesley Martin
- End-of-Life Choice draft Bill 2013

- *2004, Bickley Asher; 2005, Lewis; 2012, Maher; Havill & Nicholls.* Nursing calls to be engaged.
- *2002, NZ research on GP (n=1255) practice Mitchell & Owens;* Hastening death actions taken by 693 NZ GPs with or without consulting patients; 5.6% supplying or administering drugs to cause death.
- *2012, Malpas & Mitchell, NZMJ;* 'I wouldn't want to become a nuisance under any circumstances'.
- *2012, Donnelly, NZMJ;* People yearn to receive care unconditionally.

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International law, research, advocacy

- *1996,1997*; voluntary euthanasia legal in Northern Territory, Australia.
- *2002, Magnusson*; Angels of death.
- *2012, Kouwenhoven et al, Netherlands;* Ample support for the law after eight years of legislation.
- *2012, Carter v Canada;* Charter of Rights and Freedoms takes precedence over Canadian Criminal Law.
- *1996 RCN, Australia position statement*; Nurses' conscientious beliefs ought to be respected and supported.
- *2009, Smith;* "If I terminated your mother's life, I would be changed by the experience in ways that would not be loving."
- *2011, Storch;* Nurses must help develop guidelines and legislation with appropriate safeguards for those who may need a planned supported death (planned assisted suicide).

The draft End-of-Life Choice Bill 2013

Drafted ready for ballot by Labour MP Maryan Street; withdrawn October 2013.

Purposes:

To provide consenting individuals with a choice to end their lives and, should they become incompetent, through an End of Life (EOL) Directive.

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In the draft Bill

The person

- Makes a verbal request to doctor
- Not required to discuss with friends and family
- Reflects for minimum 7 days
- Completes a written, signed or marked request
- May nominate a person other than the medical practitioner to carry out or assist in the act
- Must state absence of coercion
- May choose the procedure
- May choose who to be present at the procedure
- May choose where the procedure will take place
- May delay or cancel the procedure
- Medical practitioner not required to be present
- If the person unable to self-administer medical practitioner must administer.

The certifying medical practitioner

- Receives a request
- Encourages the person to discuss with others
- Observes wait of minimum 7 days
- Completes a certificate
- Arranges for a second doctor to also complete a certificate
- Carries out procedure or provides means for the person
- Is protected from civil or criminal liability
- Registers the death

Note: Refusing a request must result in referring to another doctor who will agree.

The art of delegation

- The certifying doctor may delegate to another nominated by the person
- The assistance or task can be delegated only with the agreement of the dying person who has made the request
- The delegated person may be a health professional or a lay person who may refuse the request.

- How likely is it that the delegated person might be a nurse?
- What might that mean for her or his relationship with his or her:
  - conscience and professional ethics
  - patient and their loved ones
  - peers?

A bioethical decision-making framework

- *Ethical practice is simply doing the right thing*
- What are the rights of the relevant people?
- What are their duties?
- How has autonomy been addressed?
- Where does safety and freedom from harm fit?
- Who benefits and how?
- Whose values take precedence over others'?
- Which value prevails? (Rogers & Niven, 2003).

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Indigenous ethics decision-making framework (Durie, 2008)

'Honouring the collective decision for the protection of the community'

- Balancing between people and the environment
- Respecting with aroha, humility, integrity and honesty
- Creating a safe space for discussion and decision-making
- Remembering the past, the present and the future
- Demonstrating guardianship and responsibility.

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A relational ethics decision-making framework

'*More important than the stance of the individual is the engagement and dialogue that occurs between them*'

- What are the feelings of those involved?
- What ethical knowledge and language are they using?
- How do they engage and communicate with one another?
- How do they determine the right thing to do?
- What decision best expresses aroha/caring about and for the patient and their whanau/family?

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Death with Dignity/End of life choice

The concept of “death with dignity” or allowing a person to retain dignity as they die is a popular argument among those who support active euthanasia.

The idea stems from the notion that prolonged death in a medical setting is unnatural and undignified.

Therefore, encouraging death with dignity supports people who wish to cease non-beneficial or unwanted treatment for themselves or a loved one.

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Defining the end of life stage

For the purposes of this guidance, patients are ‘approaching the end of life’ when they are likely to die within the next 12 months.

This includes patients whose death is imminent (expected within a few hours or days) and those with:

(a) advanced, progressive, incurable conditions

(b) general frailty and co-existing conditions that mean they are expected to die within 12 months

(c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition

(d) life-threatening acute conditions caused by sudden catastrophic events

(General Medical Council, 2010, p. 8).

End of life: Ethical issues

Frequency of moral distress: Top five situations

1. Less than optimal care due to management issues	39.1%
2. Watch patient care suffer due to lack of provider continuity	37.9%
3. Work with nurses/others who are not as competent	36.4%
4. Carry out physician orders for unnecessary tests	33.5%
5. Initiate extensive actions when only prolonging dying	31.6%

(Woods et al., 2012).

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Major ethical perspectives

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SANCTITY OF LIFE	QUALITY OF LIFE
• Theological concept	Philosophical concept
• Associated with duty	Associated with values
• Generally understood	Difficult to define
• May be objective	Largely subjective
• Singular or common meaning	Multiple meanings
• Dependent on traditional expectations	Dependent on self-concept: body, interpersonal, achievement self-identification
• Principle based	Concept based
• Descriptive (morally neutral)	Evaluative (value laden)
• Generally clear, unambiguous	Generally unclear, very ambiguous
• Easier to follow as a rule	Difficult to follow as a rule

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Euthanasia

Euthanasia is an act where a third party, usually implied to be a physician, terminates the life of a person—either passively or actively.

The use of modern medical technologies can also keep patients alive who are:

a) living in a situation that they consider to be worse than death,

b) are in a coma

or

c) are in a persistent vegetative state (PVS).

(Center for Bioethics University of Minnesota, 2005, p.39).

Active & passive euthanasia

- Passive euthanasia allows a patient to die by stopping or refraining from beginning some type of medical intervention, e.g. withholding ventilator support or discontinuing dialysis.
- Passive euthanasia is often thought of as a “allowing a person to die” because while the action of the physician removes the supportive treatment, the life-threatening illness or medical situation actually ends the patient’s life.
- Active euthanasia requires performing some action that terminates the life of a person. E.g. a situation where a physician would inject a patient with a lethal dose of a drug.
- In cases of voluntary, active euthanasia, a competent patient who wishes to avoid suffering and a slow dying process asks a physician to terminate his or her life.

Active or passive?

- “If a doctor lets a patient die for humane reasons, he is in the same moral position as if he had given the patient a lethal injection."
- In fact, Rachaels argues that since the latter action spares the patient from prolonged suffering, it is "actually preferable to passive euthanasia."

[James Rachaels, "Active and Passive Euthanasia' *New England Journal of Medicine 292* (1975), 78-80].

Physician Assisted Suicide

With physician assisted suicide, a doctor provides a patient with a prescription for drugs that a patient could use to end his or her life.

The main distinction between physician assisted suicide and active euthanasia is that the doctor is not the person physically administering the drugs.

Physician assisted suicide is only contemplated by—and would only be considered as an option for—patients who are conscious and capable of making their own decisions.

Legal alternatives to active euthanasia/PAS

- **Refusal of interventions**

Patients have the legal right to consent to, decline, or withdraw any intervention (e.g., surgery, chemotherapy, pacemakers, ventilators, medications including antibiotics, IV fluids) or settings of care.

- **Refusal of food or oral fluid**

Patients with advanced disease often lose appetite and/or thirst. This is based on the principle of bodily integrity, i.e. force-feeding is not acceptable.

- **Palliative sedation**

For those with unbearable and unmanageable pain or other intractable symptoms who is approaching the last hours or days of his or her life, the induction and maintenance of a state of sedation may be a legally acceptable.

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Ending life: The main issues

- Not every nurse necessarily has an opinion about end of life choice issues.
- Some nurses are clearly pro-choice, and support the individuals right to decide when and how he/she is to die.
- Some nurses are clearly against any act that involves one individual killing another, whether it is acceptable to both or not.
- Some nurses would most likely take part in active euthanasia; others would not.
- *All* nurses need to be part of any nationwide debate about end of life/euthanasia issues.

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ARTICULATING YOUR ETHICAL POSITION

A few pertinent questions:

- Are you prepared to offer a considered opinion about end of life issues?
- Do you accept the proposition that doctors tend to ‘initiate extensive actions when only prolonging dying?’
- Would you ever support active euthanasia?
- What is your opinion about physician assisted suicide?
- Should Palliative Care Nurses have a collective response to end of life issues?

END

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