

Ethical issues in palliative care: introduction

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Introduction

- Challenges facing us
- Ethics and ethical principles in health care
- Cultural/spiritual considerations
- Importance of excellent communication
- Hydration at the end of life
- Withdrawing/withholding treatment
- Advance Care Planning

- Quality of life
- Value of life
- Meaning of life

It's not death itself that people fear – rather the manner of their dying

“Its not that I’m afraid to die I just don’t want to be there when it happens.” Woody Allen



Medical advances made in the recent decades are so astonishing that this now makes end of life decision making that much more difficult

Death is nothing new

- The fact we die is nothing new
- Illness and death have always been part of human experience
- However how we get sick today and how our society responds to sickness has changed radically
- As the nature of illness has changed ... so too has dying
- Palliative care is trying to respond to these changes and uses the tools developed by modern medicine to meet the needs of the dying to relieve suffering and enhance quality of life
- Dying is an important phase of life, one in which people have the right to expect quality of life to ensure a death with dignity occurs

Ethical issues in aged care

“An ethical problem is a situation involving conflict about the right thing to do. Any health care decision that involves competing values is an ethical problem” Cameron, 2002, p 637

The older person, and those caring for them at the end-of-life face many complex issues surrounding physical, psychological and spiritual needs. Challenging issues such as:

- Ensuring informed consent
 - Determining capacity
 - Ensuring confidentiality
 - Withdrawing/withholding life sustaining treatments
 - Continuing futile treatments
- Utilising ethical guidelines means we can help the patient and family make decisions about the care they would like

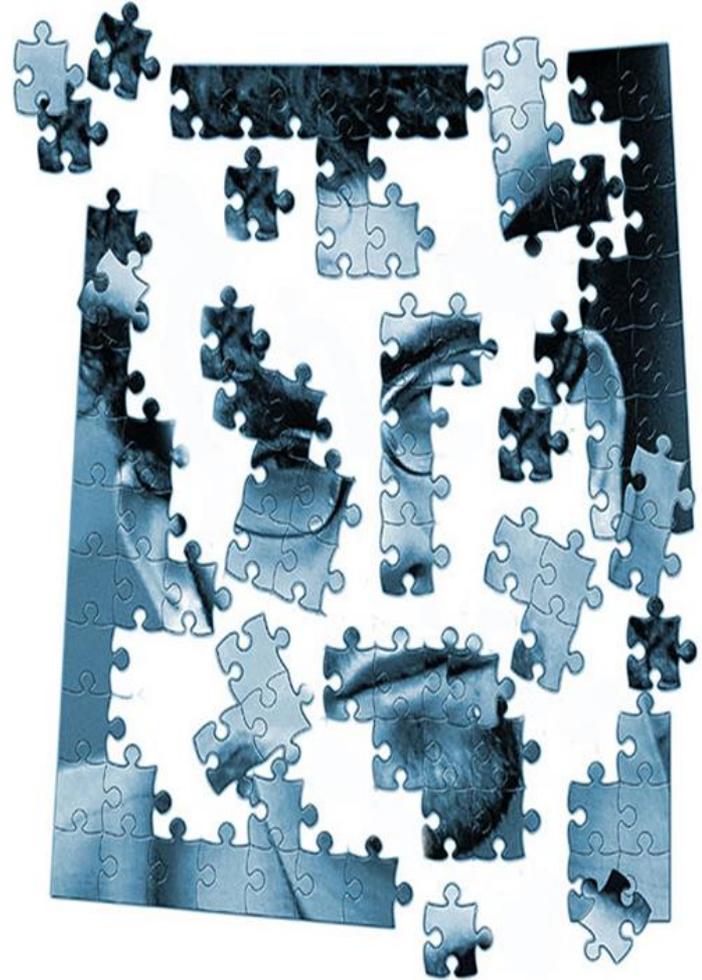
Ethical issues in context

- Ethical issues are raised by virtually all clinical decisions we make – we make them on a daily basis and most of the time don't realise it
- Clinical decisions are often made not knowing in advance whether the decision will prove to be right or wrong
- Knowledge of abstract principles that follow is helpful but difficult ethical issues cannot be resolved simply by applying principles
- Patients, families and health workers often hold different values and they may come into conflict requiring creative resolution

Our responsibility

Naming and clarifying ethical issues is an important part of all our roles.

Building trust between ourselves, the patient, their family and all other members of the care team is vital to resolving ethical issues.



A question of respect

Respect for individuals is one of the most basic principles in ethics. Treating them as the unique person they are and creating (if possible with them) a care plan that reflects that uniqueness incorporating their beliefs, values and goals.

Framework for discussion

- Developing a trusting relationship with the patient and their family is essential for ethical discussions
- Studies show that framing this process will help patients and families make informed choices
- Steps include:
 - Assessing the patient's knowledge if possible
 - Teaching the patient about care alternatives
 - Examining the patient's values and beliefs about dying
 - Discussing the patient's beliefs and choices with their significant others who will be affected by their decisions
 - Recording the patient's care choices

Doing what's best

“The experience of decision making can be a tremendous emotional burden for family members, likened to an arduous, unwelcome journey over unfamiliar territory filled with unrecognisable landmarks”

Forbes et al, 2000, p.251

- Family members feel a great deal of uncertainty about the decisions they make
- They fear that limiting treatment will mean less care for their loved one so they give priority to life sustaining treatments
- We can help by discussing the wishes of patients and their families before a health crisis occurs

The I's



- The **'I'** of the client: look at me and hear what I am really saying
- The **'I'** of the family: remember I am often the eye and ears for my family member
- The **'I'** of the health worker: I have a responsibility to keep an eye on the ball at all times

Kathy Peri, Lecturer/Researcher in Gerontology

Autonomy

- Recognises the individual's right and ability to decide for him - or - herself according to their beliefs, values and life plan
- Decisions are unique and may be different from the course that is deemed "right" or "wise"
- **Gentle truth-telling** and exchange of accurate information about their health status, options, planned care and future expectations is essential
- Informed consent

Beneficence

“Doing good”

Standard health care activities including:

- effective pain and symptom management
- sensitive interpersonal support
- acknowledgement of the person as a unique human being to be respected and valued

Non-maleficance

“Doing no harm”

- unnecessary physical pain
- unnecessary psychological distress
- insensitive truth-telling
- denigration of the individual
- continued aggressive life-prolonging or cure-orientated treatment not suited to the patient’s need or wishes
- unnecessary or unwanted over sedation
- premature, unrequested or uninformed withdrawal of treatment

Justice

- Concept of fairness or what is deserved
- Describes what individuals are legitimately entitled to and what they can claim
- Sometimes justice may serve to limit autonomy; what the individual wishes, chooses, or feels entitled to may not be possible or allowable in the context of the society

Cultural considerations

- Culture is the prism through which we see the world
- Cultural perspectives will have a major influence on our attitudes, values and beliefs around end of life care
- Within any cultural group there is a wide range of similarities and differences in the rituals and meanings associated with illness, dying and death
- It is easy for health workers to ignore ethnic and cultural differences when they are part of the dominant culture
- Asking the patient and their family about their beliefs and values is a way to establish their personal preferences and gives the patient a sense of control

Spiritual considerations

- Spirituality involves the search for meaning, a connectedness with a greater power that may be much more than purely religious beliefs
- Spiritual beliefs vary widely within ethnicities
- The time approaching death may be one of contemplation or of personal completion or preparation
- The patient's beliefs will affect what treatments or care they may wish to have
- Establishing the patient's beliefs and values will be important in planning their care

Specific issues

- Hydration and nutritional supplementation
- Palliative sedation
- Limitation of treatments
- Advance Care Planning / Cardiopulmonary resuscitation
- Informed consent

Hydration at the end of life

- Symbolism of food and fluid
- Fears of starvation
- Organs slow down in preparation for death
- Burden of hydration outweighs the benefits
- Little link between hydration and hunger and dry mouth
- Address cultural/spiritual issues
- Mouth care with familiar tastes

The ethical dilemma

Main argument is that it is unethical to let a person starve or thirst to death

REALITY

- The person is dying from a chronic incurable illness **not** dehydration

The person will suffer intolerable dry mouth and thirst

REALITY

- All dying people have a dry mouth
- There is no correlation between the complaint of dry mouth and the biochemical changes caused by dehydration
- A dry mouth is NOT relieved by parenteral fluids but is by good and frequent mouth care

The ethical dilemma

Fluids will not cause harm

REALITY

- In the course of the dying process the person's organs slow and stop working therefore fluids accumulate
- Fluids can lead to or worsen pulmonary oedema, lung secretions, ascites, lymphoedema

Fluids will not bother the person

REALITY

- Having needles sited is painful
- They may be incontinent or require catheterisation

The relatives expect it

REALITY

- They need education to understand
- They want compromise
- They need to know of other ways to care

To feed or not to feed

- There is no evidence that artificial nutrition prolongs survival in advanced disease
- Studies showed that people in hospice care who refuse food and fluids usually die a 'good death' within two weeks
Ganzani et al 2003
- Further studies have shown that starvation and dehydration might also have analgesic benefits produced by the generation of endorphins and the action of ketones
- **There is no right or wrong answer**
 - each person and their significant others are unique and need education and understanding. Compromise is important

Withholding or withdrawing treatment

- No-one is obliged to live by technological means – a competent person may refuse any treatment
- A treatment that is no longer effective in achieving its goal should be stopped - this may serve to remove resistance to the natural dying process
- It is assumed that once a treatment is started it cannot be stopped - this has **NO** ethical, medical or legal basis - if a treatment becomes futile with time, or too burdensome without clear benefits, the ceasing of that treatment **must** be considered
- A doctor is not ethically obliged to provide a treatment that is unlikely to benefit the patient

Symptom management at the end of life

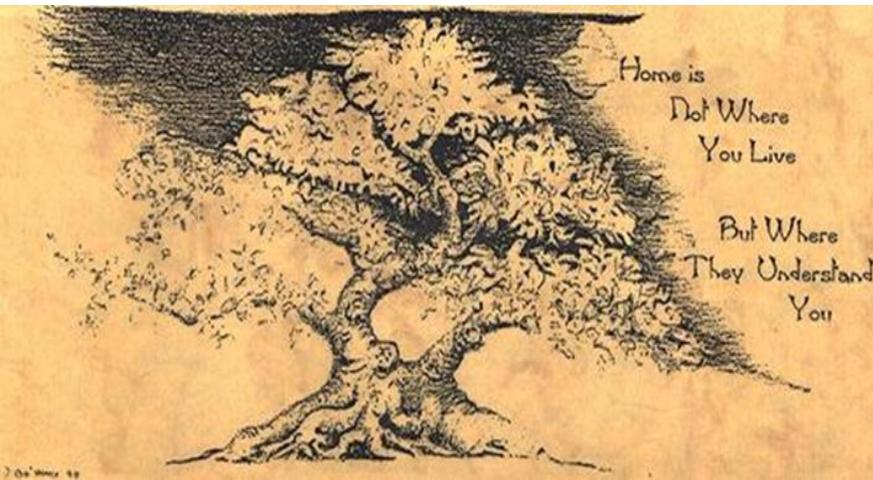
- Health workers are sometimes reluctant to administer medication to a dying patient for fear of “killing them” but it is imperative good symptom management is maintained
- Medications for symptom management that cannot be taken orally need to be continued subcutaneously and extra medication charted for breakthrough symptoms
- Anticipatory prescribing when patients are deteriorating allows staff to respond to patient distress without delay
- Bereavement can be complicated if relatives have to see their loved ones in distress
- **In ethical terms, the patient has the right to be freed from suffering and the clinician has a responsibility to see that happens**

Palliative sedation – the principle of “double effect”

- Some people who are dying experience suffering as a result of symptoms that are difficult or impossible to control
- They can be offered palliative sedation in order to relieve or palliate unusually difficult symptoms such as pain or breathlessness
- There is controversy over whether this hastens death
- The clinician must intend only the good effect, although some untoward effects might be foreseen
- The good result (e.g. relief of suffering) must outweigh the untoward outcome (e.g. hastening death)

You are important too

- Ethical dilemmas may challenge our own values and beliefs
- Work as a team – need to trust and support each other
- Good communication – share in decision making, confront difficult issues in non-judgemental way
- Share your feelings and concerns with other staff
- Conflicts may be inevitable but should not be seen as negative but rather an opportunity for growth and improvement
- Have strategies to preserve emotional and physical health



Conclusions

The patient is the central figure in end of life decision making

Life is a process with death as an integral part of the continuum

Ethics or principles of moral conduct are not fixed and static but subject to change and interpretation

Social, historical, cultural, racial, political, professional and spiritual influences all shape the ethical beliefs that affect the actions of health care providers and patients and their families