

Ethics: Shades of Grey in Everyday Medicine
Module - 6
Facilitator Guidelines

General Points

- The modules have been developed for presentation by facilitator(s) who are acute hospital-based clinicians, though not necessarily practicing specialist palliative care.
- The modules have been designed as a group (of six), though are independent of each other and can be delivered individually, or out of sequence.
- The target audience is junior medical staff, post graduate years 2-4 of all training streams.
- It is envisaged that each module will take about an hour in total (including discussion time).
- Technical requirements include a computer and data projector, able to run PowerPoint. It is suggested that pre-reading be distributed, electronically or by hard copy prior to the presentation.
- It is hoped that the presentation will stimulate discussion amongst the group and sharing of clinical experiences. Appropriate facilitation and management of these discussions is an essential role of the facilitator.
- The presentations aim to enable attainment of the objectives outlined below.
- There is an accompanying evaluation form, based on the stated objectives.
- It is recommended that facilitators familiarise themselves with the material prior to presenting it and contact the authors or local palliative care consult service with any questions.

Module Summary

Everyday medicine and the decision-making involved is far from 'black and white'. Indeed many would feel that these 'shades of grey' are what draws them to clinical medicine. There is no doubt however that the complexities involved, the impact of values of patients, families and the treating team, alongside the ever present uncertainties of medicine and life itself can present very real challenges. Many times there isn't a single right answer and legitimate differences of opinions exist. An ethical framework helps us approach and consider these everyday challenges, and will be presented in this module. Some selected ethical issues will be discussed in more detail, including truth telling, the role of food and fluids and the end of life and responding to the desire for hastened death.

Objectives

Knowledge:

- Build on their understanding of the principles of medical ethics and their application to everyday practice

Attitudes:

- Be prepared to strongly advocate for a patients right to comfort and good medical care at the end of their life
- Reflect on their own personal beliefs and stressors and how these may impact on the care they provide to patients and their families

Skills:

- Apply the ethical decision-making process to clinical problem solving, particularly in the framing of discussions about issues such as:
 - Truth telling
 - The role of parenteral food and nutrition at the end of life
 - The desire for hastened death

Pre-Reading

- Casarett JK and Caplan A **Appropriate use of artificial nutrition and hydration: fundamental principles and recommendations** *New England Journal of Medicine* 2005;353(24):2607-2612 (*see attached*)
- [No author listed] **“It’s over, Debbie”** *Journal of the American Medical Association* 1988;259(2):272 (*see attached*)

Handouts

- nil

PowerPoint Presentation - notes

SLIDE 1

SLIDE 2

- Rarely in medicine are decisions about a patients' care unambiguously 'right' or 'wrong'. Rather there are many shades of grey confronting our patients', their families and us.
- An ethical framework helps us approach complex decision making, and though it won't provide the elusive 'right answer', it can help clarify the relevant issues and tensions.
- This module will briefly review some of the key concepts of medical ethics and then consider a few selected examples.

SLIDE 3

- Ethical dilemmas are frequent in clinical medicine where, despite the evidence base, there are inherently uncertainties about what is the 'best' treatment for a particular patient in their unique context.
- Clearly our own personal values and beliefs are important determinant of our approach to these situations, as are those of our patients and their families. The different values we all as stakeholders place on particular actions and their consequences are the source of ethical dilemmas.

SLIDE 4

- These are some of the ethical principles you will have learned about as undergraduates. Perhaps now, given your experience with complex decision-making they seem much less simple and straightforward.
- For instance, beneficence implies that we should always do our best and act in the best interest of our patients. While this may seem straightforward, it is not hard to think of examples where the shades of grey creep in, for instance mechanical ventilation in end-stage COPD. Whether an intervention will contribute to a particular patient's well-being can only be determined after considering the specific intervention in the context of a particular patient (*an approach will be discussed in more detail on slide 21*).
- Non-maleficence is to do no harm, which can be surprisingly difficult to define. For example the patient with slowly progressive localised NSCLC who is bed bound and dependent from chemotherapy induced peripheral neuropathy. Other examples specific to the end of life include, failing to stop burdensome treatments, unnecessary sedation and failure to provide adequate symptom relief. Many of these violations may actually stem from lack of knowledge or clinical confidence – another reason for attending education sessions and knowing when and how to enlist help.
- Autonomy, the individual's right to make decisions, is perhaps the most obvious source of conflict and contention. It is also frequently misused and blamed for our own violation of the principles of beneficence and non-maleficence. There is no doubt that people (both ourselves and our patients) make bad decisions all the time. The issue is however whether they are competent to make those bad decisions and whether we have appropriately informed them. Of note, a patient may use their autonomy to refuse treatments (using the medical treatment act) assuming they are informed and competent, but this principle does not extend to a right to demand any treatment, regardless of its likely benefit or cost. Autonomy does not outweigh the other principles, and we are not required to provide treatments that will not contribute to a patients well being or may be harmful (ethically or legally).

- The principle of justice talks about the fair allocation of resources, and is a reality of many of the everyday medical decisions we make. Obviously our duty to the patient is our first obligation, but distributive justice may appropriately limit personal autonomy when the needs of others impinge on a patient's desires. Some examples may be provision of biventricular pace makers, intensive care beds, or even more simply triage systems for surgery or the emergency department.
- As you can see, conflicts emerge readily just in this brief discussion.

SLIDE 5

- These principles are often insufficient to unravel the complexity and variability of clinical situations. A number of other approaches have been suggested, such as the concept of 'clinical pragmatism'; which integrates clinical and ethical decision making. Clinical pragmatism focuses on the interpersonal processes of assessment and consensus formation as well as the ethical analysis of relevant moral considerations (Fins et al 1997).
- As you will see, the process has many similarities to the communication skills discussed in the earlier modules and focuses firmly on the patient and their unique clinical context. Essentially it is a commonsense and practical approach.

SLIDE 6

SLIDE 7

- Pragmatic ethical decision making accepts there is no 'right' or 'wrong' in a given clinical situation, and employs good communication skills, an ethical framework and awareness of the complexity to reach a reasonable plan, that will be reviewed and modified if necessary.
- We probably employ this approach subconsciously in the microethics of our everyday practice, but a more conscious awareness and clear framework is needed for more complex clinical situations.

SLIDE 8

- Truth-telling and honesty are admirable qualities in all human relationships, however they can also be troublesome. This very much holds true for doctor-patient relationships.
- In the past, doctors did not see truth-telling or the provision of information as particularly valuable, and would avoid distressing patients with bad news and instead focus on alleviating their suffering.
- However in current Australian practice, this approach is no longer acceptable and patients look for trust, truth and transparency. But it is not always that easy.
- A critical question is how much truth should be told. Here are two options.
 - The first, 'all they can comprehend', can lead to large amounts of 'bad news', which can be overwhelming and confronting. Indeed some may not be particularly relevant and will certainly be traumatic, no matter how good the communication (and is most unlikely to be taken in and processed).
 - The second, 'all they want', while preferable can also be challenging particularly in striking a balance between what they need to know and what they want to hear. Obviously this is subjective and requires judgement and experience; excellent communication skills are

necessary to ensure the patient has every opportunity to gather information without feeling forced.

- If time allows, consider the example of a patient in the terminal stages of their illness that, though acknowledging they are dying, asks if they will see Christmas (more than 6 months away).
 - In this situation giving ‘pieces of truth’ may actually be less harmful than a bland ‘no’ (though this may be the truth). For instance, begin by asking what they think, pause, suggest it is unlikely, pause again for comments or questions from the patient, talk about their current situation, etc...
- Lying is rarely appropriate, though ‘never’ is probably too absolute in medicine
 - Take for example a patient with profound memory impairment due to a malignant brain tumour who asks daily why she is in hospital, and every day relives the horror of her diagnosis and prognosis, only to ask again the next day. It is hard to argue that daily disclosure was of benefit to her and little doubt that it was profoundly distressing.
- Telling the truth in a clinical context is an ethical obligation but determining just what constitutes the truth remains a clinical judgment.
- *Any comments / experiences to share?*

SLIDE 9

- It is helpful to stake a step back and consider what may be informing the desire for truth-telling and information disclosure.
 - The imperative for telling the diagnosis (ie. your beliefs / culture / values)
 - The imperative for not telling the diagnosis (ie. For some situations, the patient and families beliefs / values / culture)
- Our individual beliefs and values play a large part in determining our ethical viewpoint. While medical training has some impact, there is a lot of evidence that physicians attitudes, beliefs and ethical values vary markedly across regions, cultures, and religions, irrespective of medical specialty. For instance, this study by Bruera and colleagues compared attitudes and beliefs of palliative care specialists regarding communication with the terminally ill in Europe, South America, and Canada. Given these physicians all specialised in palliative care some cohesiveness in their responses may have been expected. Instead very different attitudes to decision making, and weighting of ethical principles were found across regions, the genders and with physician age (Bruera et al. 2000).
- Similarly there is evidence that many patients, particularly of certain cultures, would much rather have decisions made on their behalf by family and do not wish to know information, even about their diagnosis (Searight and Gafford, 2005). In some countries (eg. Spain) this is the more common position.

SLIDE 10

- To return to our basic principles, autonomy cannot be the only principle involved. Truth telling is inextricably linked with the principles of beneficence and non-maleficence. The interpretation of these principles is clearly not straightforward, and is influenced by our culture, values and beliefs. As discussed, autonomy does not necessarily correspond to a universal desire for

full disclosure or total patient control over treatment decisions. Equally benefits and harms may not be immediately apparent, and determining the best balance requires thorough exploration, good communication and sound judgment.

- Autonomy should not be just about the concept of choice. Perhaps it is better understood as living in keeping with one's life plan, according to personal values and beliefs (Young 1986).

SLIDE 11

- While there are many examples of the complexities of truth telling, this (true) case arises frequently and having a considered approach is very helpful.
- Consider the case using the ethical principles and framework we have discussed and formulate an approach.
- *Encourage discussion.*

SLIDE 12

- These are some of the principles to consider, assuming the patient is competent.
- Many will have experienced these situations and be aware of the intense feelings and emotions they can inspire. Often the relatives can be angry and these encounters are challenging, even with good communication skills. These are often situations where reinforcements, from within your clinical team, or considering referral to the palliative care team or clinical ethics team may be appropriate.
- Being respectful of the family, their wishes and particularly their judgements about the patients' wishes is essential.
- Acknowledging the burden of 'the secret' can often be a helpful means of supporting the often stressed and distressed family and a way to convert angry interactions with medical staff into more empathic ones.
- It is also essential to emphasise your duty to your patient and it is often helpful to state explicitly that you will not lie and will answer direct questions from the patient. However it is appropriate to reassure them that you won't provide information they do not wish to know. On occasion this reassurance alone may suffice to defuse the situation.
- An independent interpreter should be sought, to facilitate clinical assessment, but also to clarify information needs. A compromise may be to have a family representative present, but they should not be relied on for communication (an important trap to avoid).
- As we have discussed, some patients will readily consent to their family members being their decision makers and controllers of information. Ethically, it is important for this to be established and not assumed. For example: "*Some patients want to know a lot of information about their disease so they can make decisions about their treatment, others would prefer that we talked about these things with a family member instead. Can you tell me what you would prefer?*"

SLIDE 13

- In this particular case, we followed these principles.
- The family agreed to an independent interpreter and despite reassurances about information provision insisted on 'sitting in'. The interview went well, focussing on the history, examination and symptoms. The patient interacted well and the family member was visibly relieved when the patient said she did

not have any questions and directed us back to the family for all information and decisions.

- This served the purpose of confirming the patients' wishes, our primary duty, but also gaining trust from the family – which was essential to establishing a strong therapeutic relationship.
- Eventually we were able to use the interpreter without the family present and it was on one such occasion that the patient disclosed that 'of course' she knew she had cancer and was dying. This was a watershed moment. When she shared this information with her family the relief was immense and they were able to communicate openly and share quality time together prior to her death. A good outcome on all accounts.

SLIDE 14

- *Any comments / questions?*

SLIDE 15

- We have all been asked about food and fluids in patients who are dying, imminently or otherwise.
- These are often difficult and emotive situations that make international headlines and the courts (eg BVW and Terry Schiavo).
- Often, it is that the patient has no appetite, but is still tolerating food and fluids. This situation can usually be managed by:
 - talking about anorexia and cachexia as a natural part of advanced illness and the dying process (McDonald et al. 1995)
 - reassuring patient and family that they should eat and drink only what they want, for the purpose of comfort (rather than sustaining life or putting on weight).
- The more difficult situation is when the patient cannot manage food or fluids orally, and the request is for artificial means of hydration and nutrition. Hopefully you have read the NEJM article, which provides good evidence and background to the discussion.

SLIDE 16

- We will begin with a case.
- *Consider and discuss how you might approach this?*

SLIDE 17

- There certainly is evidence of benefit for artificial nutrition and hydration in specific clinical situations. Though a documented survival benefit does not necessarily indicate that ANH is appropriate in all such situations.

SLIDE 18

- The evidence is conflicting about patients having intensive chemotherapy or cancer surgery. However, time limited trials are often appropriate and employed in practice.
- Despite what is practised, there is good evidence and clear inter-speciality consensus opinion that there is no benefit to ANH in patients with advanced dementia.
- The evidence for cancer patients and those with terminal illness is understandably fraught because of differing disease burdens, reasons for anorexia and cachexia, stage of illness and prognosis. For most with active and progressive disease there is little evidence of meaningful clinical benefit; and the evidence is lacking in terms of benefits in QOL, functional or psychological status. It should be recognised that benefits need to be assessed

for the individual, for instance a very small survival benefit may be very meaningful for a particular patient, if it facilitates a particular event or milestone.

SLIDE 19

- The burdens of ANH are not insignificant and often relate to the means of delivery. For instance NGT's can be difficult and traumatic to place, particularly in patients with swallowing problems or obstructing lesions. If incorrectly placed they can cause aspiration. They can dislodge, are uncomfortable, can cause local irritation and bleeding, can erode the nostrils, and can be a source of embarrassment leading to social isolation. Equally central access can be complicated by bleeding, infection, and require expertise for insertion and ongoing care. The risks of late infection are not insignificant and can be life-threatening. This list is really just a start...
- The final point, regarding natural history, is often overlooked. Take for example a case reported in the literature of a young woman with inoperable malignant bowel obstruction complicating gynaecological cancer. ANH was used and felt to be of benefit in terms of improved energy, QOL and survival. However, the patient then went on to develop progressive localised disease with large painful tumour masses and fistulae. These were complicated by difficult to manage symptoms, particularly pain and vomiting; and ultimately a symptomatic death (Philip 1997). The complications of ANH, but also of progressive cancer after the natural disease history has been altered, require careful consideration in decision-making.

SLIDE 20

- The ethical dilemmas in terms of our key principles should now be evident.
- There does however remain some conflict between these principles.

SLIDE 21

- When evaluating the benefits and costs of a proposed treatment, such as ANH, in the setting of advanced disease, these are some questions to consider.
- You will note that the notion of natural history is raised again. Often it is helpful to consider this in very simple terms, such as: what will they die of instead because of a given intervention?
 - Another example is to consider the role of nephrostomy in a patient with end stage pelvic malignancy complicated by bilateral ureteric obstruction. With a functioning nephrostomy they will not die of renal failure (often a 'good death'), but instead may live to die of other disease related complications. Importantly ureteric obstruction indicates disease adjacent to the pelvic side walls which is where the lumbosacral plexus lies. People with significant pelvic side wall disease frequently develop difficult to manage neuropathic pain problems. Or perhaps live but require institutional care because of the requirements to care for the nephrostomy to die later of other cancer complications or of renal failure when the nephrostomy ceases functioning. Such considerations may significantly alter decision-making, and should be taken into the decision-making processes. The resulting decision may remain the same but it will be a better informed outcome.

SLIDE 22

- Back to our case example, many of the principles listed here may already have been raised.

- Feeding has a lot of symbolism in our culture, it is often the only way a family feel they can express their care and love. It is essential to acknowledge this, upfront.
- The clinical context is clearly vitally important as it informs the goals of care, which guide our decision-making
- ANH should be evaluated as the medical intervention that it is, with clear discussion of risks and benefits, as with any other procedure.
- As with any other intervention the goals should be clear. ANH is an intervention and the goal is to provide nutrition and hydration, not comfort. Comfort can be provided with good palliative care, and there is good evidence to support mouth care in alleviating common symptoms in those who forgo ANH, such as thirst, dry mouth, delirium and diminished alertness (note the later are also part of dying).
- It is often helpful to suggest alternative ways for families to be involved in their loved ones care, such as: hand feeding small amounts of favourite foods (being aware of the consequences of aspiration and if the patient is alert enough), or swabs in favourite drinks, or involvement in mouth care.

SLIDE 23

- In the case, following careful communication around the state of his illness, the burden and benefits of treatments, an agreed upon outcome was that the family fed him small amounts of home made food as tolerated and participated in his mouth care. This was a satisfactory result for everyone, and the patient died peacefully and comfortably surrounded by his loving family a few weeks later.

SLIDE 24

- *Comments / questions?*

SLIDE 25

- *Discuss the pre-reading, any responses? Fairly chilling, and seemingly at odds with our ethical decision making principles. Understandably it resulted in considerable commentary in the medical and lay press.*
- Euthanasia and physician assisted suicide (PAS) are enormous topics with very apparent ethical dilemmas, well beyond the scope of this module. There is no intention now to debate the appropriateness of legalisation, as in Netherlands, Belgium (euthanasia) or Oregon (PAS); or the moral and ethical dilemmas, anymore than we have already. However clear and unambiguous definitions are helpful as these are topics frequently raised in the context of caring for the dying. We have talked about withholding and ceasing treatments and symptom relief. None of these should be confused with euthanasia or assisted suicide, where the intent is clearly and unequivocally the death of the patient.
- Requests for euthanasia or assisted suicide do arise in clinical practice when caring for patients with advanced disease. It can be very confronting and avoiding or ignoring it may well be your first response. As we will see this is potentially a lost opportunity for a very significant and meaningful therapeutic intervention. Indeed we have evidence that appropriate intervention can reduce the desire for euthanasia in terminally ill patients (Ganzini et al. 2000).

SLIDE 26

SLIDE 27

- Consider this case

- Has anyone had a patient or family member make a similar request, implied or explicit, they wish to share?
- How might you approach this, with the patient and the daughter?

SLIDE 28

- A good place to start is to consider what the patients' request for a hastened death or euthanasia might mean.
- Obviously there is a very broad spectrum of meanings, from passive wishes, to specific thoughts and even suicidal plans.

SLIDE 29

- Hudson and colleagues performed a literature review and despite the anticipated limits in the available evidence, were able to categorise desire to die statements into the 4 categories listed.
- The first is common. Expressing the desire to die may be a means of communicating their fear of death or perhaps the loss of autonomy and control that accompanies terminal illness. It is often not actually a request for hastened death at all – which is why clarifying the meaning and considering it instead an important cue is so important. By establishing the reason, appropriate interventions and supports can be enlisted.
- The second is also frequent in clinical practice, and describes the desire to die statement as a means of conveying the degree of suffering or distress; whether it is physical, psychosocial, or existential. It may also be a way of gaining more information about potential therapeutic options or resources. Again this is distinct from an explicit desire for hastened death.
- Reason 3 may represent a patient seeking information about the options of euthanasia or suicide, in response to elements from the first 2 points. Again, delving for the deeper reason is worthwhile.
- Reason 4 is uncommon in clinical practice, and represents a patient very specifically and knowingly seeking professional assistance with a hastened death or acknowledging suicidal intent. This is perhaps the most confronting and a considered approach is particularly important. (It is also the context that receives the greatest media attention.)

SLIDE 30

- Hudson and colleagues suggest that the approach should proceed along the lines of these categories; and to that end developed a two phase approach through the four broad categories.
- They stipulate that these conversations:
 - Take time and should not be attempted in a single interview
 - Require excellent communication skills (and many of the skills developed in the communication modules).
- The categories are in black and the phrases are suggestions, and should not be used in a formulaic approach, but are rather a guide.
- Obviously, with the first category, an exploration of current fears and concerns is important. Screening for depression should be routine, with questions about mood, anhedonia and the persistence of these feelings.
- With the second category eliciting sources of distress or suffering, can be done directly (as in the sample phrase), or indirectly with the help of 'the 3rd person', for example: "some people give a lot of thought to their death and how it might be for them, have you ever had any thoughts about like that?"

- With the 3rd category, it is important to clarify what they are saying and look for suicidal ideation, intent and plan.
- Finally with those seeking health professional assistance the authors advise against a 'yes' or 'no' answer. Saying 'yes' is obviously illegal, and without exploring the context is also inappropriate. Answering 'no' however may close off communication and add to the patients' feelings of hopelessness. Instead, acknowledging their statement and attempt to explore it more thoroughly.

SLIDE 31

- The second phase is about consider broader information and instituting preliminary strategies.
- In the first category, assessing whether the patient is adequately informed about their disease, but also the resources at their disposal. Reassuring them about the goals of the care and the team can be very helpful in allaying concerns.
- In the second category, assessing for reversible symptoms is paramount. Often providing reassurance that the focus of care is comfort and the relief of suffering is very helpful. In this context, it is helpful to emphasise that all that can be done will be done, and that we are usually very successful in relieving suffering and distress. Often a lack of control is reflected in the DTDS; and assuring the patient that no life prolonging measures will be undertaken can be helpful and assist the patient in maintaining some influence over the course of their illness. Particularly in cases of non-physical distress or suffering, enlisting appropriate support from within the team is very helpful eg. Chaplain, pastoral care, psychologist, psychiatrist, etc...

SLIDE 32

- In those who are considering euthanasia or suicide it is helpful to review their end of life choices and particularly look for any problems, which if identified and addressed would perhaps change their feelings about ending their life. Again, ensure that they are not misinformed about the goals, or even the definition of palliative care. If they remain persistent it is essential to keep the lines of communication open and consider enlisting specialist help, for example from palliative care or psychiatry (depending on the circumstance).
- In the final category, assuming the patient is competent, it is appropriate to state clearly what can and cannot be done. Eg. "Although by law we cannot legally assist you, we will not abandon you. I will do my best to address your concerns and we can give you medications to relieve you pain and suffering". Again reinforcing that life prolonging measures will not be undertaken can be very reassuring. If however the patient remains adamant, and there are features or risk factors of psychiatric comorbidity, psychiatry referral should be considered.

SLIDE 33

- Returning to our clinical case, we did not ignore our patients DTDS, but instead returned to have more detailed exploratory discussions with both her and her family, together and separately.
- The patients main concern was of becoming a burden to her family because of her physical decline. This was managed by exploring her understanding of her illness, the likely course and likely timeframes. In this way, she was reassured that we would not send her home, that she needed to remain in hospital (where staff provided the care) and that her prognosis was sufficiently short that it

was acceptable to her. At the end of this discussion, with a clearer understanding of her situation and the goals of our care, she no longer wanted a medically hastened death and indeed derived some meaning from the last few days she was able to interact with her family.

- The daughters' concern was that her mother would suffer and that the dying process would not only be long, but unbearably painful and symptomatic. She had not seen anyone die before and was not aware of the usual dying process. After discussion about the usual process, and also our clear goals to ensure comfort and alleviate suffering (rather than prolong life), she too was reassured and became an active participant in ensuring her mother's comfort, engaging with staff about symptom issues as they arose. After her mother's death she was very grateful for the extra time and reflected on the peacefulness of the 'natural' dying process.

SLIDE 34

- *This may require adjustment to fit your institution.*

SLIDE 35

References

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