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1. Module 1 Key Points

1.1 Ethics, or moral philosophy: considers theories about what human beings are capable of doing, alongside accounts of what they ought to do if they are to live an ethically good life. Ethics may share common ground with the law, religious belief, popular opinion, professional codes, hospital policies and the dictates of authority figures, but it is also broader than all of these and offers a set of tools and values against which their appropriateness can be evaluated.

1.2 Healthcare ethics: is a domain of inquiry which focuses on the moral, or ethical, problems and challenges that arise in healthcare settings. While healthcare professionals may differ in relation to these issues because of their different roles and responsibilities, they nevertheless share much common ground. For example, in end-of-life situations, different professionals have different functions: consultants and doctors are, generally, the lead decision-makers in relation to treatment or non-treatment decisions, while nurses and allied professionals have much of the responsibility for caring for patients and their families through the dying process. However, these functions may also overlap in both directions; nurses and other professionals contribute to decision-making, consultants and doctors contribute to care.

1.3 A Good Death and Dying: The diversity of individual values and cultural differences tells us that an agreed consensus on what makes for a ‘good death’ may not be within our easy reach. But, although there may be no universal agreement about what a ‘good death’ consists of, there is some consensus as to the core features of the care that needs to be provided to those who are dying and their families and loved ones. For example, drawing on long-established ethical principles, the UK General Medical Council (GMC) describes good end-of-life care as that which ‘helps patients with life-limiting conditions to live as well as possible until they die, and to die with dignity’ (GMC, 2009, p.3).
2. Module 1 Definitions

2.1 Values: things that matter to us; that we care about; goals or ideals we aspire to, e.g., health and happiness. Ethical or moral values express ideals of conduct and character that we expect of ourselves and each other, e.g., honesty, loyalty and justice.

2.2 Family: may include the immediate biological family and/or other relatives, spouses, partners (including same sex and de facto partners) or friends. They may have a close, ongoing, personal relationship with the patient, be chosen by the patient to be involved in treatment decisions, and have themselves indicated that they are ready to be involved in such decisions.

2.3 Harm Principle: stipulates that individual freedom can only be limited on the basis of harm to others, i.e., when an individual, in exercising their autonomy, limits the autonomy or threatens the welfare and safety of others.

2.4 Objective perspective: a view that is independent of any particular person’s or group’s perspective.

2.5 Subjective perspective: a personal point of view.
3. Module 1 Background

3.1 What Ethics Is

Ethics is a branch of philosophy that attempts to understand people’s moral beliefs and actions (these modules use the terms, ‘ethics’ and ‘morality’; ‘ethical’ and ‘moral’ interchangeably, although traditionally ‘ethics’ described the process of thinking about people’s morality). Ethics, or moral philosophy, considers theories about what human beings are capable of doing, alongside accounts of what they ought to do if they are to live an ethically good life. Ethics also explores the meaning and the ranking of different ethical values, such as honesty, autonomy, equality and justice, and it considers ethical quandaries that human beings face in the course of living their own independent but, also, socially interdependent lives.

One of the key tasks of ethical reasoning, generally, is to analyse and critically consider the values we hold and the claims we make in relation to the perceived obligations that we might have towards one another. Applied to the processes of death and dying and the care provided at end of life, key values that arise include sanctity of life (the fact of being alive is itself deeply valued), quality of life (the fact of having positive experiences and avoiding negative experiences is considered deeply morally significant), autonomy (respecting someone’s preferences in relation to where, how and when they die is, increasingly, considered to be deeply morally significant and challenging).

A second key task of ethics is to evaluate the adequacy of reasons that we give for our actions: it considers, for example, whether the reasons offered to support a particular course of action are based on sound evidence and/or logical argument. Applied to the processes of death and dying, reasons that are evaluated might be the arguments a health professional offers in support of resuscitating an incompetent terminally-ill patient or a parent’s reasons for refusing medical treatment for a severely disabled neonate.

The tasks of weighing ethical values and evaluating different ethical arguments are unlike many other kinds of human tasks. Ethical values are usually not as easy to understand as other kinds of values, e.g., it is probably easier to explain the (mainly) practical value of energy than it is to explain the ethical value of courage. In turn, it is easier to test a person’s blood pressure than it is to determine whether or not they are virtuous.

Moreover, ethical problems are often not as clear as other kinds of problems and resolving ethical problems as definitively is not always possible. The aim of ethics then, is not, despite popular opinion, to take the high moral ground and tell people what to do, but, rather, to offer tools for thinking about difficult problems. Good ethical thinking purposefully seeks out...
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the grey in questions and concerns in order to acknowledge the diversity and complexity of roles, situations and circumstances that arise in human life and relationships.

As complex as ethical situations may be, however, there is still an onus on everyone involved in ethically-challenging situations to resolve any problems that arise in the most sincere, reasonable and collaborative way possible. This means that they must be prepared to review and revise their position in the light of reflection, discussion and changing circumstances. (See Further Discussion for more detail on traditional and contemporary ethical theories).

3.2 Healthcare Ethics

Healthcare ethics is a domain of inquiry which focuses on the moral, or ethical, problems and challenges that arise in healthcare settings. Healthcare ethics addresses these concerns, largely from the perspective of different professional groups, including doctors and nurses, as well as occupational therapists and dentists. It can be further subdivided into medical ethics, nursing ethics, dentistry ethics, etc., but, for the purposes of these modules, the broader term ‘healthcare ethics’ is used. This is because all health professionals and some allied professionals share common ethical concerns about how best to care for patients at the end of life. These concerns arise in all patient/professional relationships, and include worries about breaking bad news, obtaining informed consent and respecting confidentiality. All health professionals also have similar experiences of dealing with challenges in relation to distributing scarce resources, addressing social injustice and dealing with incompetent or immoral colleagues (Holm, 1997).

While healthcare professionals may differ in relation to these issues as a result of their different roles and responsibilities, they nevertheless share much common ground. For example, in end-of-life situations, different professionals have different functions: consultants and doctors are, generally, the lead decision-makers in relation to treatment or nontreatment decisions, while nurses and allied professionals have much of the responsibility for caring for patients and their families through the dying process. However, these functions may also overlap in both directions; nurses and other professionals contribute to decision-making, consultants and doctors contribute to care.

In the past twenty years, the field of healthcare ethics in general has rapidly expanded in an effort to address the seismic moral and metaphysical shifts that have occurred as a result of technological advances at the beginning and end of life. Today, human beings can create life, modify life and prolong life in ways that make the wildest of science fiction stories sound tame. Clinical Ethics Committees, Research Ethics Committees and Commissions are being instituted to attend to the moral uncertainty and moral challenges that accompany such rapid changes. Similarly, the evolution of healthcare ethics can be seen as part of a process of development that involves confronting and addressing these challenges.
Where the healthcare ethics literature has traditionally addressed the ethical challenges which health professionals face during the course of their work, the focus, in recent years, has been on good judgement, collaborative decision-making and professional and personal accountability. In addition, because of the particular nature of this work, human relationships, and the ethical bonds and obligations that they give rise to, are at the heart of the moral realm of healthcare provision. Storch captures this in the following quotation, in which she claims that the ethical life is one that is most deeply lived in relationship with others:

‘[Healthcare] ethics is about being in relationship to persons in care. The enactment of healthcare ethics is a constant readiness to engage one’s moral agency. Almost every [healthcare] action and situation involves ethics. To raise questions about ethics is to ask about the good in our practice. Are we doing the right thing for this patient? Are we listening to this person’s need for pain relief? Are we respecting a family’s grief over their dying child as they struggle to squeeze out a few extra days or hours for the child through alternative therapies? Are we ready to stand up for what we know to be right when we face a situation requiring us to perform a procedure that we are confident is not appropriate and that violates the dignity of another human being? Are we willing to find time to debrief after complex situations to determine how we could have done better, with a commitment to doing everything in our power to prevent similar situations from occurring in the future?’ (Storch, 2004, p.7)

Echoing Storch’s emphasis on human relationships, Arthur Frank, author of the internationally-acclaimed book, The Wounded Storyteller, has posed the question of how health professionals can remain generous in the middle of expanding needs and demands on them and the pressure to deliver treatments as commodities. Frank describes fundamental medicine as:

‘[F]ace-to-face encounters between people who are suffering bodily ills and other people who need both the skills to relieve the suffering and the grace to welcome those who suffer […] Before and after fundamental medicine offers diagnoses, drugs, and surgery to those who suffer, it should offer consolation. Consolation is a gift. Consolation comforts when loss occurs or is inevitable. This comfort may be one person’s promise not to abandon another.[ … ][T]hose who make medicine their work are to find their consolation in being the kind of people who offer such hospitality.’

(Frank, 2004, p.1-3)
4. A Good Death and Dying – A Spectrum of Views

4.1 Defining ‘Death’
When the question is posed, ‘what is death’?, it seems a straightforward question with a simple answer – the cessation of all life functions. But that’s simply a biological definition and it is disputed, i.e., does death occur when the heart stops? When the brain partially or wholly stops functioning? When the question is posed, ‘what is the meaning of death’?, it becomes even more apparent that death cannot be directly apprehended in straightforward scientific terms.

Death is a fact of life, but how one thinks about mortality and the limits of earthly life reflects social, not biological realities (Kliever, 2004). This means that beliefs about death and its significance and value are ‘socially constructed’. Depending on the society in which we grow up, we learn much about dying. We acquire emotions about death and dying and, along with our memories of others who have died, we accumulate anxieties, or develop a sense of acceptance, dread or detachment about dying. Our ‘society’ is the sum of our unique environmental space, our geography, our culture, our religious traditions and family influences. Because the beliefs and attitudes towards dying are ‘socially constructed’ in the sense just explained, a culturally diverse society, such as Ireland is now, reveals a similar diversity of ‘death perceptions and values’.

4.2 Cultural Differences
Culture provides the key medium for comprehending the final boundary between our existence as living beings and the eventual end of that existence. If one is a religious person, he or she might believe that death means the end of existence ‘at least in this mortal sphere’. For example, the beliefs of Muslims hold a promise that death is not the end. ‘They believe that dying is part of living and an entrance to the next life, a transformation from one life to another, a part of a journey, and a contract and part of their faith in God’ (Our Lady of Lourdes Hospital, 2005, p.11).

Similarly, belief in the Catholic religion frames the way in which death is negotiated for many Irish people. As Quinlan (2009a) observes in relation to her research of media representations of death and dying in Ireland:

‘The Catholic nature of much of Irish spirituality was evident. It was evident in the response of one mother to the prognostication of terminal cancer in her young daughter Rachel (Tubridy: 04.02.2008). She spoke of trips to Lourdes, to Medjugorje, to Rome for a meeting with the Pope, in search of a miracle that would save her daughter’s life. She said that they had not discussed
death with Rachel. Rachel was five years old when she died. Her mother said that when Rachel’s siblings asked if Rachel was going to die, her response was: “we hope not. She is very sick but we are praying to holy God. We are praying to him to make her well again.”

(Quinlan, 2009a, p.7-8, See Appendix)

The reality of cultural diversity is a recurring theme of the Ethical Framework for End-of-Life Care precisely because recognition of this diversity means recognition of, and respect for, the differing values of patients in the illness and dying processes. Some illustrative examples show what this may mean in practice. In Middle-Eastern societies, it is common to support a border-line existence for patients suffering from persistent vegetative state, maintaining their biological lives in specialised ventilatory-care units. It is as if death must be resisted at all costs. But the Wari people, native inhabitants of the Amazon, do not shrink from the reality of dying, but employ customs that might be shocking to many Western value-systems. Wari people show respect for their dead and salve their grief by engaging in ritual mortuary cannibalism. Western onlookers might be aghast at such behaviour that looks like profound disrespect for the deceased loved ones. However, the value of ‘respect’ is pronounced among the Wari people.

Cultural differences may also challenge some basic assumptions in hospice philosophy, making it more difficult for hospice carers to respect these differences. For example, home death is often considered an ideal in hospice philosophy, and a ‘good death’ is characterised as taking place at home, surrounded by family and/or friends with symptoms and pain under control and spiritual needs identified and met following appropriate good-byes. At variance with this hospice goal, home death (or ‘Hogan’ death to use the Navajo term for ‘home’) may not always be valued in diverse ethnic groups, for whom it is deemed dangerous or polluting to be around the dead. Among traditional Navajo, dying persons were removed from the Hogan dwelling to a separate shed-like room through a special door to avoid the travesty of a death happening in the Hogan, because the Hogan would then have to be destroyed. To ensure that ghosts could not find their way back to the Hogan, family members did not touch the body (Koenig and Marshall, 2004). This task was assigned to outsiders. The Navajo Indian likewise considers advance care planning a violation of their traditional values (Carrese and Rhodes, 1995).

Quinlan’s account of the views of some Irish Travellers indicate that there are culturally different attitudes to death and dying among Irish people also – some Irish Travellers, for example, find common ground with the US Navajo Indians in their view of the place dying:
“The multicultural nature of Irish society was also evident. It was evident in Regina McQuillan’s discussion of Irish Travellers and their experience of hospice. Professor McQuillan said that Irish Travellers, unlike Irish people generally, did not like to die at home. She talked about how Travellers would traditionally leave a place where one of their community died. She detailed how they would burn all of the person’s belongings, even burn the dead person’s trailer. She said that in the history of The Irish Hospice only two Travellers had died in a hospice, both in 1999 and none since. She quoted one Traveller as saying: “Now that we know what kind of place it is, we wouldn’t want anyone to go there. It’s a place without hope, and Travellers can’t live without hope” (Quinlan, 2009a, p.8)

4.3 Individual Differences
In addition to cultural differences, there are also individual differences in the way in which dying is negotiated. For some, ‘a good death’ may seem a contradiction, especially if one does not have the possible comfort and solace of religious belief in an afterlife. Death may signal the end of all that is loved, all that is experienced and all that is possible. The sentiments that reject the very notion of a ‘good death’ are voiced by Dylan Thomas (1945/2003). Expressing a sense of frustration that his father might not resist the illness that beset him, Thomas wrote these words to his father as a moving plea not to give in to ‘the dying of the light’.

_Do not go gentle into that good night,
Old age should burn and rave at close of day;
Rage, rage against the dying of the light._ (p. 239)

Dylan Thomas stressed the importance of affirming life, of fighting the ‘dying of the light’ up until the last breath, and refusing the call to accept death quietly. An opposed view is that of Elizabeth Kubler-Ross (1975), who urges us to move through a number of stages: denial, anger, bargaining, depression and a final detachment which is an ‘acceptance’ facilitating a peaceful demise. On Kubler-Ross’s view, health professionals would be facilitators helping the dying person with the journey through these stages. ‘Since the dawn of human-kind, the human mind has pondered death, searching for the answer to its mysteries. The key to the question of death unlocks the door of life’ (1975, p.1).
Recent research on dying and death in Ireland also gives us some indication of the variety of responses of people living in Ireland when queried about their understanding of a 'good death.' The following features were highlighted by members of the focus groups convened in the course of Weafer's qualitative research for the Irish Hospice Foundation (Weafer, 2009a):

- Fast and peaceful/ to die in your sleep.
- To have your family with you when you die.
- To have control over the time and circumstances of your death.
- To be cared for at home, with adequate medical support.
- No pain or suffering involved.
- To die with dignity and all that entails.
- Your children to be reared and independent.
- When you are old; in accordance with the natural life-cycle.
- With enough time to get your affairs in order.
- With a pint of Guinness in one hand and a model in the other!

In addition, the top three concerns of the respondents in a national survey (n = 667) on the public's reported concerns at the end of life related to family/friends, pain/violent death, and actually dying (Weafer, McCarthy and Loughrey, 2009). This echoes an earlier study on the same theme, in which the three most important aspects of care cited by respondents if they were dying or in the last stages of a terminal illness were: to be surrounded by loved ones, to be free from pain, to be conscious and able to communicate (Weafer, 2004).

Quinlan claims that there is evidence of a culturally-specific Irish attitude to death in Professor McQuillan's observation that 'there is a frankness about death in the UK and the US that is absent in Ireland.' 'We are not,' she said, 'so open about death here.' (Quinlan 2009a, p.7). Indicating that this Irish reluctance to talk about death may be changing, Emma Doyle’s recent research describes the now famous interview by Marion Finucane with Irish author and broadcaster, Nuala O’Faoláin, during which O’Faoláin shared her experience and subsequent struggle, on learning of her diagnosis of terminal cancer. Doyle terms the interview a ‘critical event’ which sparked a ‘national conversation about death’:

"On a Saturday morning in April, many Irish people stopped what they were doing and listened to the voice of a person who was talking about dying. People who missed the interview heard about it from others and listened to it later on the internet or read the transcript in the next day’s papers. This voice moved many to reflect on their own feelings about dying or the deaths of their..."
loved ones and started a national conversation about death. The emotional response of so many people to the narrative of a dying woman serves to highlight how unusual it has become to speak out publicly about death, and the belief of over half the population that death is not discussed enough shows that Irish people were ready to have this conversation. By drawing attention to the lived experience of dying, O’Faoláin began a discussion where previously there had been silence. (Doyle, 2008, p.25)

Doyle refers to one participant in this ‘national conversation’, Terence Cosgrave, whose editorial in the Irish Medical Times points out:

‘[I]f Nuala O’Faoláin has taught us anything, it is that we should put the person who is experiencing the trauma of terminal illness at the forefront […] Their interests should be paramount and we should not let ideology blind us to their wishes - and their rights […]

Doctors know if they treat any patient long enough, it will […] end in failure. But the failure to keep a patient alive forever is acceptable – that is the nature of life. An undignified death – and needless suffering – is a much more catastrophic failure, and one that should be consigned to history.’ (Cosgrave, 2008)

Cosgrave’s editorial is of interest, not just because it underlines the inescapability of death, but also because it focuses on the obligations of health professionals to accompany the dying well. Murray and Jennings (2005) support this commitment to addressing the issue, not of death, but of dying badly. They suggest that in the past, end-of-life-care reform in the US has been excessively driven by the law and that it is time to turn the lens on the need for culture to catch up.

‘The next decades should be, we believe, a time of education and soul-searching discussions in communities and at kitchen tables, as well as in health care settings. […] We must talk about what we dare not name, and look at what we dare not see. We shall never get end of life care ‘right’ because death is not a puzzle to be solved. Death is an inevitable aspect of the human condition. But let us never forget: while death is inevitable, dying badly is not.’ (Murray and Jennings, 2005, p. S57)

Speaking of death and dying, commentators such as Murray and Jennings agree that we have witnessed a basic change in the way we die. With this change has come a rethinking of the goals of medicine and the roles of health professionals. If one accepts that dying and practices surrounding death vary within Irish culture and across many other cultures, then engagement in and awareness of these cultural realities need to be encouraged. Persons
who are not members of a society’s dominant cultural group cannot simply be seen as a challenging ‘other’. Ethnic, social and cultural differences that reveal meaning through end of life rituals generally deserve professionals’ respect, in the form of efforts to become informed and through efforts to avoid harmful stereotyping. The caveat on giving this respect would be if a certain practice sought was clearly limiting another individual’s autonomy or putting another’s welfare at risk (see discussion on Autonomy in Module 4).

Finally, recent years has witnessed intense public debates in many Western societies in relation to the moral and/or legal permissibility of euthanasia and assisted suicide. In countries such as the Netherlands and Switzerland, the notion of a ‘good death’ is linked by some with the notion of a ‘right to die’, i.e., the right to have active steps taken to end a person’s life (euthanasia) or to assist a person in ending his or her own life (assisted suicide). Some of the ethical and legal challenges to which these issues give rise are discussed in more detail in Modules 4 and 7. For present purposes, one important point to note is that neither is permissible under Irish law. Under Irish law, any person who deliberately ends the life of another person is potentially guilty of murder. It makes no difference that the person consented to the ending of his or her life or even that he or she requested that this should happen.

A second point to note is that the focus of the Irish Hospice Foundation, through the HfH programme, is to work assiduously to get a ‘right to die’ understood, not as a right to euthanasia or assisted suicide, but as a claim or expectation on state and institutional provisions to facilitate the most appropriate care and treatment at the end of life. A central objective of the HfH programme is to draw attention to the obligation on state institutions and the Department of Health and Children to assume the responsibility to make resources, policies and physical environments consistent with a ‘good end-of-life care’.

4.4 Elements of Good End-of-Life Care

As illustrated, the diversity of individual values and cultural differences tells us that an agreed consensus on what makes for a good dying may not be within our easy reach. However, if there is no universal agreement about what a ‘good death’ consists of, there is, fortunately, some consensus as to the core features of the care that needs to be provided to those who are dying and their families and loved ones. Drawing on long-established ethical principles, the UK General Medical Council articulates good end-of-life care as that which ‘helps patients with life-limiting conditions to live as well as possible until they die, and to die with dignity’ (GMC, 2009, p.3). Many documents have been published that address the elements of such end-of-life care (The College & Association of Registered Nurses of Alberta, 2005; German National Ethics Council, 2006; Medical Council, 2009; National Consensus Project for Quality Palliative Care, 2009; NCEPOD 2009; New South Wales Department...
of Health, 2005; Sisters of Bon Secours, 2000). Ten general features that recur in these
documents are listed below. They apply equally to those in the end stages of life as well as
those suffering from chronic, long-term illnesses.

**Elements of Good End-of-Life Care**

1. Health professionals with communication skills and sensitivity towards the beliefs and
   practices of diverse cultures and individuals in their understandings of a ‘good dying’
2. Respectful opportunities for the patient’s voice to be heard concerning their dying
3. Provisions for comfort and relief of pain and suffering
4. Due regard for, and provisions made to ensure, patient privacy
5. Respect for the right to refuse treatment or the request for withdrawal of treatment
6. Respect for health professionals’ responsibility not to start, or to discontinue some
treatments when appropriate, with consideration for both patient and family
   preferences
7. A collaborative approach to care: families and the healthcare team work together for
   patients who lack capacity, taking into account their previously expressed wishes
8. Non-discriminatory care: decisions are dependent only on factors relevant to the
   patient’s medical condition, values and wishes
9. Transparency and accountability: decisions are fairly made and the decision-making
   process is clear to all concerned and accurately recorded
10. Hope for the one suffering and loved ones, sustained by reassurances from health
    professionals that all that can be done to achieve a peaceful end of life will be done
5. What Ethics is Not

5.1 Ethics is More than the Law

Laws are rules that govern certain human activities which are prescribed by a constitution (in Ireland), legislators and courts and the court system. They are binding on everyone and are enforced by penalties, such as fines or imprisonment. Law and ethics overlap because many illegal actions are, often, also unethical, e.g., killing the innocent or stealing. In turn, many ethical actions are also obligatory in law, e.g., paying taxes.

But there are also important differences between the law and ethics. For example, there are many actions, such as infidelity, lying and cheating, which would be considered unethical but are not usually enforced by law. Equally, there are many ethically praiseworthy actions such as being kind, saving a drowning person and working for charity that we are not legally obliged to perform.

Laws and ethics may also conflict: people might judge laws such as those permitting euthanasia to be unethical, while they might view legally-prohibited actions, such as abortion, as ethically acceptable. The law can also lag behind the moral standards of a society, or it may be used as a tool by a ruling class or dictator, for example, in some societies, laws may enshrine racism or discriminate against women. When this happens, social reformers usually appeal to more general ethical standards of equality or justice in order to have such laws repealed. In short, ethics and law overlap, but ethics offers a set of tools and values against which the appropriateness of laws can be evaluated.

5.2 Ethics is More than Religion

Different religions offer moral training, e.g., the Sermon on the Mount or the teachings of Confucius. In addition, religious leaders remind their followers of values, such as generosity and compassion, and, sometimes, provide good role models, e.g., Gandhi or Christ. Moreover, many eminent moral thinkers (such as Immanuel Kant [18th century German philosopher] and Charles Taylor [contemporary Canadian philosopher]) are also theists who critically explore the faultline between ethical theory and moral theology.

However, the texts and teachings of the various religions are ambiguous and the interpretations of their leaders often differ on important issues such as war, family planning and the role of women in society. As such, judgements have to be made as to what weight to assign them. This is all the more apparent in pluralist societies where individuals, not simply Catholics, Protestants, Hindus or Jews, must share more commonly-held values that appeal to people of different and no religious persuasion. In short, ethics and
religion overlap, but ethics appeals to more general rules and values than are expressed by religion and does not rely for sanction or legitimacy on the existence of a deity or transcendent being.

5.3 Ethics is More than Popular Opinion

Popular opinion is the view that is perceived to be generally held in a society. It is determined by the media and/or social analysts on the basis of surveys, polls, and interviews or the responses to radio or television programmes. Ethics and popular opinion may overlap, in that popular opinion expresses views on moral issues and it may be a useful indicator of important social concerns.

But there is also much disagreement. Popular opinion is considered to be unsatisfactory as a means of determining what the right thing to do is in any circumstance, for a number of reasons. The main one of these is that popular opinion is often volatile, reactionary and unreflective, e.g., the majority of people who are polled immediately after a harrowing case of child abuse and murder may call for the, arguably unethical, death penalty. A second reason why popular opinion is not a satisfactory determination of right action is that determining popular opinion is fraught with difficulties – which poll/survey/interview counts as truly representative? In short, popular opinion and ethics may overlap, but ethics is more reflective and critical and appeals to more general rules and values than are expressed by popular opinion.

5.4 Ethics is More than Professional Codes

Professional codes, such as the Medical Council’s (2009) Guide to Professional Conduct and Ethics for Registered Medical Practitioners and the An Bord Altranais (2000) Code of Professional Conduct for each Nurse and Midwife, express the ethical and professional standards of professionals, such as doctors and nurses. They are inherently ethical in that they express the aims of these professions and they enumerate the ethical obligations that these bodies of health professionals expect of their members. Ideally, codes function to help professionals in deciding what is the ethically acceptable course of action to take when ethically-worrying challenges arise (e.g., issues concerning patients’ rights or safety). In turn, these professional bodies, through their Fitness to Practice Committees, may penalize any member who is deemed to have failed in their professional duties.

However, while codes are themselves ethical in nature, they are inevitably incomplete; they cannot provide precise guidance for every single situation that may arise. Moreover, some professionals and patients may disagree with the duties imposed in certain circumstances (See Module 4 and 6 for a discussion of the views of the Irish Medical Council and An Bord Altranais and the Irish Supreme Court in relation to the status of Artificial Nutrition and...
Hydration). In short, ethics and codes of ethics overlap, but ethics takes a broader view and offers tools that enable individuals to critically consider the aims, duties and implications for practice of their professional codes.

5.5 Ethics is More than Hospital Policy

Hospitals and other clinical settings usually have a range of policies on issues such as patient confidentiality, informed consent, resuscitation and the allocation of resources. Like professional codes, it is reasonable to assume that these policies are ethically sound, but this is not always the case. For example, hospitals may have policies which deny access to certain procedures, such as heart transplants and infertility treatment, to groups of people on the basis of their age or family status, and this might be considered ethically dubious or, at least, debatable. In short, while hospital policies may be ethical in general, health professionals need to take a critical stance in relation to the obligations and constraints these policies place on them as employees.

5.6 Ethics is More than Authority

Doing what you are told just because you have been told to do it has always been viewed as ethically suspect. This is because, while people in authority may often mean well and often give ethically sound orders and requests, this is not always the case. That obedience is not an excuse for harmful actions was confirmed in law in the Nuremberg trials, when doctors, nurses, guards and collaborators were found culpable for their part in Nazi war crimes. Similarly, health professionals are ethically, professionally and legally obliged to question instructions and requests that put patient safety and/or rights at risk. No matter the source of authority, individual health professionals are responsible, and held accountable, for their own actions. In short, while figures in authority, such as managers, consultants and Directors of Nursing, may mean well and may direct health professionals to do the right thing most of the time, individuals are, nevertheless, accountable for what they do themselves.
6. Ethical Theories

An ethical (or moral) theory is an effort to interpret moral life and moral intuitions in a more or less formalised way.

6.1 Traditional Ethical Theories

Traditional ethical theories, such as Utilitarianism, Deontology and Virtue Theory, are termed ‘traditional’ because they have been part of the canon of moral philosophy for many centuries.

6.1.1 Utilitarianism: Producing the best consequences

Utilitarianism – sometimes referred to as ‘consequentialism’ – is a moral theory which emphasises the consequences or outcomes of an act rather than the act itself. Good outcomes or consequences are those that yield overall benefits, pleasures and happiness for the greatest number of persons affected by an action. Good outcomes of actions also diminish overall suffering or harm. Any action that produces benefit, pleasure or well-being is a ‘useful’ action – useful as conducive to the greater good.

The choices or actions that contribute to maximal happiness or well-being have instrumental value. Instrumental values refer to something useful or important for achieving some goal or purpose, or, as a means to some end.

The utilitarian goals of maximising pleasure, happiness, or well-being are contentious. There is no consensus about the meanings of these valued goals or human ends. It seems clear that different people view pleasure, happiness and well-being with considerable disagreement. Diverse cultures might disagree even more profoundly.

The nineteenth century philosopher, John Stuart Mill, defined in his ‘Happiness theory’ an understanding of happiness which he believed would be universally accepted:

‘According to the Greatest Happiness Principle, the ultimate end, with reference to and for the sake of which all other things are desirable (whether our own good or that of other people), is an existence exempt as far as possible from pain, and as rich as possible in enjoyments, both in point of quantity and quality’ (J.S. Mill, [1859], 1991, p.142)

The ultimate end sought by the utilitarian is a life described by Mill, rich in many pleasures of intellect, emotion and sensibility, and spared in terms of suffering and pain. Both quantity of rich experiences and quality (range and depth) of experiences mattered in Mill’s account of utilitarianism.
Utilitarians do not focus on the importance of motives for choosing when locating the moral quality of an action. Almost any motive is acceptable for a choice which delivers a positive outcome and best overall results. Saving a drowning man is always good, whatever the motivation of the rescuer. I might be doing this to get my picture in the paper and maybe get some reward from the man I save, yet this doesn’t take away from the good result. Feeding starving people who have no subsistence is a good act, and it matters not whether one’s motive is primarily to get nominated for the Nobel Peace Prize or whether it arises from a deep obligation to suffering humanity.

Utilitarian theory is a prospective moral theory. It is forward-looking, going beyond the choices of the individual to the outcomes of those choices. Utilitarians think that the consequences of an action are the effects which the individual could have reasonably foreseen, on the basis of information or understandings available to him or her.

Three-Step Action Formula
Utilitarianism might be construed as offering a three-step action formula for action:

1. On the basis of what I know, I must project the consequences of each alternative option open to me (e.g., taking different kinds of actions or taking no action).
2. Calculate how much happiness, or balance of happiness over unhappiness, is likely to be produced by anticipated consequences of each action or none.
3. Select that action which, on balance, will produce the greatest amount of happiness for the greatest number of people affected (see Yeo and Moorhouse, 1996, p.45).

6.1.2 Deontology: What duty asks of us
What makes a ‘right’ act right? The utilitarian or consequentialist answer to this question is that it is the good outcome of an act which makes it right. Moral rightness or wrongness is calculated by determining the extent to which the action promotes values such as pleasure, well-being, happiness, etc. To this extent, the end justifies the means. In many respects, deontological moral theory is diametrically the opposite of utilitarianism.

The name of the German philosopher, Immanuel Kant (1724-1804) is identified with the moral theory known as deontology. Kant was adamantly opposed to the idea that the outcome of an action could determine its moral worth. For deontologists, it is not consequences which determine the rightness or wrongness of an act, but, rather, the intention of the person who carries out the act. The emphasis is on the correctness of the action, regardless of the possible benefits or harm it might produce. Deontologists maintain that there are some moral obligations which are absolutely binding, no matter what consequences are produced.
As a ‘rationalist,’ Kant believed that we can use our reason to work out a consistent set of moral principles which apply in all possible situations and cannot be over-ridden. One way of describing these deontological moral principles is to say that they are ‘non-negotiable’ and cannot be argued away by persuasion, or counter-reasons.

Unlike utilitarianism, according to which the value of moral actions is determined by their instrumentality for achieving the greatest overall benefit, deontology regards good choices as intrinsically valuable, that is, valuable in and of themselves. Whether or not they bring about good consequences is not essential to their moral quality. Kant aimed to establish a fundamental point about morality: that there is such a thing as non-negotiable morality; in other words, there is a domain of laws which apply to our conduct and from which we cannot exempt ourselves. The laws governing our conduct are derived from a supreme or highest principle, which Kant calls the categorical imperative; this is a command that admits of no exceptions and must be obeyed by all of us, insofar as we consider ourselves rational beings.

One Step Action Formula
Kant formulates the categorical imperative in different ways but it is easiest understood as a universal rule which tell us how we ought we to live if we are to live an ethically good life:

1. Act in such a way that I could imagine all other persons doing the same thing in the same circumstances.

The challenging test for us when we choose to do something is that we are required to act, not out of self-interest, but because we believe it is the right act to do for anyone in the same situation. So, if we are deciding to lie in order to escape a difficult task, then we must be ready to allow everyone else to lie for the same reason. If we are stealing rare lilies from our neighbour’s garden to bring to a friend in hospital, we need to be ready for our neighbour in turn to steal rare roses from our garden for her friend. Kant believed that this requirement of universality places necessary constraints on our conduct.

Here, it is clear that Kant does not entirely ignore consequences. We take them into account in order to consider our choices. We ask: what would be the consequences if everyone acted on the principle I want to follow? So, to answer that, we need to imagine the consequences for our world if everyone acted in a manner which is contrary to the duties spelled out above. We cannot discount consequences, but good outcomes will never make an immoral action moral. Our motives – whether we act with a ‘good will’ according to the categorical imperative – determine whether we are persons of moral character or not.
Deontological morality is grounded in human motivation, and not merely in consequences. Even a person with a mean and bitter disposition who has to work hard to be sympathetic towards suffering people can, nevertheless, with effort, exercise their will and do the right thing in spite of their negative inclinations. They do the right thing, not because they will be praised, or rewarded, or gain immortal life, but simply because it is the right thing to do. A Kantian deontologist cautions us to be wary of our natural inclinations – whether they are negative or positive. Because we are kindly or compassionate by temperament does not give us an edge on being moral. It may make it easier to do good for other people, but that is not the yardstick Kant uses. People who have negative inclinations by temperament are considered much more praiseworthy if they succeed in doing the right thing!

Kant was a rigorous moralist and a religious believer. However, he argued that religion and the possible rewards of immortality could not form part of his argument that morally praiseworthy actions must have universal worth. We cannot presuppose that the presence of certain religious beliefs will make people moral. Nor can we rely on the presence of good inclinations, feelings or sentiments in people to make them moral. We need to look to the disciplined will.

Before concluding this discussion of deontology, it is important to note that deontologists are alive and well today. Religious believers would often consider themselves as deontologists, in their acceptance of some actions as categorically right and others wrong. The religious belief might, additionally, appeal to revelation for an understanding of which actions are right and which are to be avoided. The often uncompromising positions held by religious believers may not reflect stubbornness or closed-mindedness, but may instead demonstrate the Kantian conviction that consequences – no matter how good – cannot make evil actions good. A review of some of the positions presented in Modules 2 and 5 illustrate the contemporary deontological perspective most clearly.

6.1.3 Virtue Theory: Challenging the adequacy of rule-based theories
The ancient Greek philosopher, Aristotle, (384-322 B.C.) first wrote a detailed discussion of virtue morality in the Nichomachean Ethics. ‘Virtus’ he understood as strength. Correspondingly, specific virtues are seen as strengths of character. But, many years after Aristotle’s death, virtue theory came to be over-shadowed by the development of utilitarianism and deontology.

In the past fifty years, however, virtue theory has resurfaced as a major moral theory. But why is that so? Virtue ethics has been restated and reinvigorated in the years since 1958 by philosophers such as Philippa Foot, Alasdair Maclntyre and Elizabeth Anscombe. They and many others became disillusioned with the promises of mainstream theories.
They argue that how we ought to live could be much more adequately answered by a virtue-based theory than in terms of calculating consequences or obeying rules.

Moral Virtue: Centrality of motives
A virtue is a trait of character which is socially valued and a moral virtue is a trait which is morally valued. Courage might be a socially-valued trait, but it only becomes moral courage if the context is a moral one. Moral virtue is a disposition to act, or a habit of acting in accordance with moral ideals, principles or obligations (Pence, 1991).

Aristotle distinguished between external performance and internal state. This is the difference between right action and proper motive. An action can be right without being virtuous, he said, but the action can be virtuous only if performed on the basis of the right state of mind of the person.

Virtue, then, is closely aligned with motives. We do care how persons are motivated. Someone who gives donations to mental health research and is motivated by personal concern or sympathy for suffering people meets with approval, while someone acting the same way in order to be able to proclaim generosity as a feature of their character would not obtain our endorsement. Persons who are properly motivated – not just in carrying out a single action, but by disposition or habit, persons of virtue – don’t simply follow rules, but have a morally-relevant motive and desire to act as they do. Virtue theorists think that basic instruction and an emphasis on the right motives and desires will guide us, not only in terms of what to do but who to be (Frankena, 1998, p.291-296).

The person of morally good disposition is properly motivated. To be properly motivated, says Aristotle, one must experience appropriate feelings. Aristotle explains:

'We may even go so far as to state that the man [woman] who does not enjoy performing noble actions is not a good man [woman] at all. Nobody would call a person just who does not enjoy acting justly, nor generous who does not enjoy generous actions, and so on.'

(Aristotle, 1955, p.42)

Aristotelian virtue theory cautions us away from a negative view of morality that mainly requires us to do what we really don’t feel like doing. Anne Thomson speaks of the critical role of emotions in developing a moral disposition of fair-mindedness. This focus on the centrality of cultivating proper feelings and emotions as ingredients of virtuous action stands in stark contrast to the suspiciousness about feelings associated with Kantian deontology (see Thomson, 1999, p.143-152).
Character is More Important than Conformity to Rules
Virtue theorists think that their views supplement deontology and utilitarianism by offering a more comprehensive moral theory, which acknowledges our common intuitions that motives do make a difference to the quality of our actions and that appropriate feelings facilitate virtuous behaviour.

Writers in the field of health care ethics suggest that efforts to replace the virtuous judgements of professionals with rules, codes or procedures will not result in better decisions and actions. For example, some believe that, rather than always appealing to government regulations or international conventions to protect subjects in research, the most reliable protection is a researcher with a character marked by informed conscientiousness, responsible sensibility, and compassion. The thesis is that good habits of character are more important than conformity to rules, and that such good habits are most likely to lead to behaviour consistent with rules.

The position is that virtues should be inculcated and cultivated over time through educational interactions, role modelling, moral mentoring, and the like. Gregory Pence contends that the right kinds of desires, feelings and motives are the best protectors of patient well-being (Pence, 1991). Almost any healthcare professional can successfully evade a system of rules. Pence argues that we should create a climate in which healthcare professionals desire by virtue of strong habit not to abuse their subjects. The educational process for healthcare professionals provides a context for modelling the virtues of good nurses, good doctors and good allied health professionals. Where adequate role models are lacking, little progress can be made by further exhortations to become a ‘good (virtuous) nurse’, or a ‘good (virtuous) doctor’.

This last point stresses the argument that we do not make moral decisions as isolated persons in a social vacuum. It is rather in families, schools or communities that natural affection, shared concerns, spontaneous sympathies and expectations for the virtues arise.

6.1.4 Compatibility of Virtues and Principles
The rule-governed theories of utilitarianism and deontology are not at odds with virtue theory; rather, they are compatible and mutually reinforcing. Persons of good moral character sometimes have difficulty discerning what is right and recognise that they need principles, rules and ideals to help them choose right or good acts.

“One often cannot act virtuously unless one makes judgements about the best ways to manifest sympathy, desire and the like. The virtues need principles and rules to regulate and supplement them. As Aristotle suggests, ethics involves judgements like those in medicine: Principles guide..."
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us to actions, but we still need to assess a situation and formulate an appropriate response. This assessment and response flows from character and training as much as from principles.’

(Beauchamp and Childress, 1994, p.67)

If we are to progress as moral agents and justify our actions in the eyes of those affected, this need to explain and justify requires that we translate our virtuous claims into an explanation of the values, duties or principles on which we base those claims. To do this, we may need to say why we consider it compassionate behaviour to lie, why we believe that it is fair to break the confidence of patients, or why we think it is loyal to keep silent when speaking out would correct wrong-doing. This requirement to justify our moral decisions reveals the intricate connection between virtue theory and the rule-governed theories discussed earlier.

6.2 Contemporary Ethical Theories

While utilitarianism, deontology, and virtue theory have been in place in the canon of moral philosophy for centuries, they have not remained fixed and static as theories. Volumes have been written which critique elements of these theories, sharpening them for greater clarity and, attuning them more to the fullness of human living. In addition, insights into moral living come in fresh forms, breathing new life into the traditional moral canon. This is the case with contemporary ethical theories such as principlism, narrative ethics and feminist ethics. In these we find new insights that attempt a number of tasks:

1. To offer developments of, and improvements on, essential features of traditional theories
2. To fill in the dimensions of human living that were often omitted or understated in traditional theorising.
3. To acknowledge that the challenges of moral development require that we move from a realm of moral abstractions to concrete situations. This allows us to see whether or how much the resources of moral theory help to guide our decision-making.

6.2.1 Principlism

What is known as the principlist approach to ethical decision-making has dominated western healthcare ethics for the last twenty years. It emerged with the publication of several well-known texts in the 1970s and 80s. One of these was the Belmont Report which identified basic principles that would underlie and guide the regulation of research involving human subjects (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). Three books published around the same time outlined and defended a principlist ethical framework, written by Tom Beauchamp and James Childress (1979), Robert Veatch (1981) and H. Tristram Engelhardt (1986).
Of these three, the account developed by Beauchamp and Childress in their book, *Principles of Biomedical Ethics*, is the most well known. This principlist model (hereafter called the PBE model) is an ethical decision-making process which negotiates between fundamental principles, on the one hand, and the unique nature of specific moral situations on the other.

These principles oblige the healthcare professionals to behave in certain ways in relation to patients.

1. The principle of autonomy obliges healthcare professionals to respect the views, choices and actions of the individuals in their care. *(See Module 4)*
2. The principle of nonmaleficence obliges healthcare professionals not to harm patients. *(See Modules 5 and 6)*
3. The principle of beneficence obliges healthcare professionals to act for the benefit of, or in the interests of, patients. *(See Modules 5 and 6)*
4. The principle of justice obliges healthcare professionals to treat people in their care equally and to ensure that resources are distributed fairly.

A good deal of the Principles of Biomedical Ethics text is taken up with an analysis and discussion of each of the four principles in terms of their nature and scope. In particular, the specific rules which are supported by these principles and which permit, prohibit or require particular kinds of action are delineated. These include rules governing truth-telling, confidentiality and informed consent *(Beauchamp and Childress, 2001, p.57–112).*

What is special about the four principles, according to Beauchamp and Childress, is their universal or objective nature. These principles, according to Beauchamp and Childress, have been drawn from a ‘common morality’, beyond tradition, and beyond the vagaries of individual character and culture, the set of norms that ‘all morally serious persons share’ *(2001, p.3).* This common morality ‘contains moral norms that bind all persons in all places; no norms are more basic in the moral life’, and the notion of international human rights is invoked as an example of such universal norms *(2001, p.3).* Having grounded their four principles, they justify their particular choice of principles by pointing out that these four have been presupposed by traditional ethical theories and medical codes throughout history.

The most immediate way to decide on the merits of a proposed course of action, on the Principles of Biomedical Ethics (PBE) model, is to determine whether or not that course of action obeys the moral rules derived from the four principles. For example, on this view, a healthcare professional might consider that it is, generally, morally required to provide a patient with information about their illness because this action obeys the moral rule ‘Tell the truth’ which is, in turn, derived from the principle, ‘Respect patient autonomy’.
In morally difficult situations, however, where there is a conflict between principles, or between principles and particular judgements, the PBE model stipulates that none of the principles is privileged. In any given situation, each principle must be specified and weighed relative to the particular context in which it is applied, and informed by generally accepted background theories of human nature and moral life. Following John Rawls, this weighing and balancing is described as a process of reflective equilibrium and the principles are described as *prima facie* rather than absolute (Beauchamp and Childress, 2001, p.398). This expresses the idea that any principle is, on first impression, morally obligatory, but that it may be modified or overridden in certain situations.

In the case of Joanna, the patient with Alzheimer’s in Case 4 of Module 2, for example, a nurse might initially believe that telling Joanna the truth about the death of her son might be the morally correct thing to do. However, on consideration of the concrete circumstances of the patient, she might reconsider. In this case, it could be argued that it is her particular judgement in relation to what Joanna might find meaningful which prompts her to reconsider whether the principle of autonomy, or some other rule, such as nonmaleficence, should be the focus here.

On this understanding, the processes of moral deliberation are akin to scientific processes: plausible beliefs and possible decisions are considered and accepted, rejected and modified on the basis of reflection and experience. Also, analogous to the scientific goal of achieving theoretical consistency and unity, the aim of reflective equilibrium is to unify all one’s moral beliefs and background commitments.

In positive terms, the PBE model provides a method of supporting ethical decisions that has a strong justificatory force. Put simply, on this view, the force of the imperative, ‘Respect autonomy’, derives from its grounding in universally-accepted norms, and not in the subjective viewpoint or intuition of the individual professional.

Moreover, even in situations of doubt and uncertainty, such as in the case of Joanna in Module 2, the deliberative process which comes into play appeals to reasoning strategies and goals which are also considered objective, not intuitive or subjective. In addition, the course of action that would be considered the most successful, on this view, would be one which manages to meet as many of the relevant principles as possible.

The challenge in Joanna’s case is to respect her autonomy, while at the same time acting in her best interests.
6.2.2 Narrative ethics

While different shades of principlism have dominated the healthcare landscape in the last twenty years, an increasing number of theorists have begun to turn their attention to alternative approaches to describing and understanding the various elements of moral life (McCarthy, 2003). One such approach deploys narrative concepts and methodologies drawn from literary criticism and philosophy as tools of moral understanding and assessment. In common with contemporary thinkers in other disciplines (e.g. anthropology, philosophy, cognitive psychology and history) who have turned their attention to narratives, narrativists in the health care arena argue that the first person narrative, or personal story, is a rich medium for qualitative data about the unique lives of individual people. Further, for some of these theorists, the narrative is not only an important form of communication, it is also a means of making human life, and specifically the moral life, intelligible. While they deploy narrative tools in different ways, all of these thinkers are engaged in ‘narrative ethics’.

Martha Nussbaum (1992), for example, views literature as a vast resource of moral knowledge and a means of sensitising people to the responsibilities, obligations and challenges of a full moral life.

Alternatively, the narrative approaches of Albert Jonsen and Stephen Toulmin (1988) and John Arras (1991) take a casuistic turn and resolve ethical dilemmas by comparing each new situation with others and with paradigm cases. These authors argue that local, contingent moral rules and maxims to guide action can be derived from paying attention to the morally relevant similarities and differences between cases.

More recently, Rita Charon (1994) has suggested that our understanding of healthcare situations will be greatly enhanced if we pay attention to their narrative elements, e.g., the function of the narrator – who tells the story? – the development of plot – how the story unfolds – and the relationship with the audience – who hears and interprets the story? In addition to supporting Charon’s view, Tod Chambers (1999) has sparked a lively debate in the healthcare ethics community by arguing that the task of reporting cases is, itself, not a neutral enterprise. This is because, he argues, the process of describing any set of events involves making decisions about which pieces of information to include or exclude and making choices about the way different facts are presented. For example, take any of the modules in this framework and consider how the case scenarios are narrated: from the patient’s, professional’s or family’s point of view? Or from an observer point of view? Consider the difference that this might make to what is left in and left out of the story that is told. Because narrative ethics is in the early stages of development, there is, as yet, no ready-to-hand canonical position that best expresses its central tenets. Even so, what follows
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is a rough sketch of a plausible and defensible account of narrative ethics. It is also one which highlights the tensions between narrative ethics and principlism and exposes the congruities and incongruities between these supposedly competing positions.

On the narrative view, when ethically challenging situations arise, it is the whole journey of an individual’s life as he or she conceives it which is privileged (Nelson 1997, p.2001). Howard Brody, for example, sees the practice of healthcare as in part ‘a storytelling enterprise’ (Brody, 1987, p.xiii). For Brody, actions are made meaningful in the context of an individual life story. As such, it is difficult to isolate any given decision or choice, to uncouple it from the whole person who acts and evaluate it in terms of abstract and general rules. In healthcare settings, this means that the patient’s own account, where it is possible to hear it – of their illness, their preferences, their needs – is considered profoundly important. However, not any tall tale will do and personal stories are tested against various criteria, such as the stories of others and the medical chart.

This idea of testing personal narratives against various criteria can be likened to the way in which the principlist model tests its principles through the application of the process of reflective equilibrium. In the case of the PBE model, the four principles are prima facie privileged, but may be subsequently modified. On the narrative view, it is first-person narratives which are prima facie privileged; however, like principles, they can be challenged and modified in the process of a ‘narrative reflective equilibrium’. Recalling the Socratic ideal, Paul Ricoeur describes the final story or account of a life that emerges from such evaluation as ‘the fruit of an examined life’ (1988, p.246-247).

In recent years, a narrative approach of this kind has contributed to discussion and debate in relation to surrogate decision-making in end-of-life situations. For example, it informs one of the recent recommendations of the US Council on Ethical and Judicial Affairs, which suggests that, when it comes to making decisions for incompetent patients, one of the tasks of a surrogate decision maker is to consider ‘how the patient constructed his or her identity or life story’ in order to enable a decision about a proposed course of treatment which continues the story ‘in a manner that is meaningful and consistent with the patient’s self-conception’ (Council on Ethical and Judicial Affairs, 2001). In addition, the Council argues that it is precisely the fact that a number of different options might be consistent with a person’s life story which makes the narrative approach so attractive, because it avoids having to predict only a single course of action as compatible and, therefore, morally acceptable.

Finally, the task of moral justification for narrative ethics is not, primarily, a unifying one. Rather, its focus is on acknowledging and embracing the multiplicity of, often contested,
meanings that are available in any given situation. What is key for this narrativist account is the idea that many different voices and readings of moral situations and individual lives are possible. And, generally, narrativists focus, less on trying to reduce competing perspectives to a commonly shared view and, more on involving as many people as possible in the dialogue. Anne Hudson Jones summarizes this view as:

‘In ideal form, narrative ethics recognizes the primacy of the patient’s story but encourages multiple voices to be heard and multiple stories to be brought forth by all those whose lives will be involved in the resolution of a case. Patient, physician, family, healthcare professionals, friend, and social worker, for example, may all share their stories in a dialogical chorus that can offer the best chance of respecting all the persons involved in a case.’ (Hudson Jones 1998, p.222)

In turn, for narrativists, relational virtues such as empathetic listening and support are privileged. In the course of such privileging, these virtues are reworked to acknowledge and accommodate the narrative view that, in some senses, difference is irreducible. For example, Howard Brody radically reconceives the moral demands of ‘empathy’ in the following passage:

In a culture that prizes autonomy and independence, we may fondly imagine that most people are whole and intact, unlike those who suffer from disease[...] Charity tends to assume that I start off whole and remain whole while I offer aid to the suffering. Empathy and testimony require a full awareness of my own vulnerability and radical incompleteness; to be with the suffering as a cohuman presence will require that I change[...] Today I listen to the testimony of someone’s suffering; tomorrow that person (or someone else) will be listening to my testimony of my own. Today I help to heal the sufferer by listening to and validating her story; tomorrow that sufferer will have helped to heal me, as her testimony becomes a model I can use to better make sense of and deal with my own suffering (Brody, 1987, pp.21-22)

On Brody’s view, the demand of empathy does not require us to ‘step into another’s shoes’ in order to understand their pain. It does not presuppose that it is ever possible to fully understand another’s pain. The other person is always ‘other’ to us, their difference persists, resisting assimilation under the umbrella of mutual understanding. Instead, empathy demands that we bear witness to our own vulnerability and lack so that we stand, not as whole to part, or healthy to ill, but as a ‘cohuman presence’. On this view, the healthcare professional cannot offer patients the reassurance that they know and understand them, only the acknowledgement that they have listened and heard. On this view too, they cannot be untouched by a patient’s pain and vulnerability, there is professional engagement, not detachment.
6.2.3 Feminist Ethics

Feminist ethics considers the impact of gender roles and gendered understandings on the moral lives of individual human beings and draws attention to the power and power differentials inherent in moral relationships at individual, societal and organizational levels. Feminist ethics, in short, is the application of feminist theory to understanding the ethical realm: it critiques traditional ethical frameworks from a feminist perspective such as those already discussed; deontology, utilitarianism and principilism.

The diversity of theoretical starting points when tackling the subject of ethics makes it difficult to identify or talk about a single ‘feminist perspective’ in ethics. However, what each of these approaches share is a common concern with the marginalisation and disempowerment of women in sexist societies and a transformative concern to change those societies for the better (Murphy, 2004). In addition, as Sharon Murphy points out:

‘Given their sensitivity to the oppression of women, feminist perspectives also often share a sensitivity to the oppression and marginalisation of other social groupings based on age, race, class, sexual orientation, etc. With this sensitivity comes an interest in feminist ethics in analysing how moral authority and the status and power that goes with it, has traditionally been constructed, aligned and divvied out, moral authority and moral agency having traditionally been inequitably distributed among different social groups, with women in particular being deemed less morally capable than men.’ (Murphy, 2004)

In general, feminist ethics has widened the scope of health care ethics to include consideration of the social, cultural and political dimensions of moral decision-making in health care settings. Susan Sherwin makes this point in the following way.

‘Medical and other health care practices should be reviewed not just with regard to their effects on the patients who are directly involved but also with respect to the patterns of discrimination, exploitation, and dominance that surround them.’ (Sherwin, 1992, p.4-5)

Contemporary moral philosopher, Margaret Urban Walker (1997, 1998), critiques ethical frameworks such as deontology and principlism, which, in her view, represent morality as a set of compact codes of impersonal statements guiding the actions of individuals. She replaces these, with a moral framework that represents morality as a process, rather than a set of prescriptions or outcomes. For Walker, morality and politics cannot be pulled apart and individuals are not the bounded integrated decision-makers that traditional moral approaches seem to presuppose. Rather, who we are and how we decide upon a
course of action at any given time must be understood contextually. Morality, for Walker, is a socially embedded process which determines what is morally significant, who is assigned responsibility for decision making and who is permitted and enabled to participate (Walker, 1998).

In short, feminist ethics:

• recognizes human interdependency and vulnerability
• pays attention to the needs of concrete particular individuals in their specific situations
• validates traditionally feminine virtues such as nurturance and empathy
• affirms the importance of being actively concerned with the welfare of others
• widens the scope of health care ethics to include consideration of the social, cultural and political dimensions of moral decision-making in health care settings. (See discussion on Relational Autonomy in Module 4)
7. Module 1 Further Discussion

7.1 The ethical map
The subject of ethics can be divided into three broad categories:

7.1.1 Meta-ethics:
• Examines the meaning of moral terms and concepts and the relationships between these concepts.
• Explores where moral values, such as ‘personhood’ and ‘autonomy’, come from.
• Considers the difference between moral values and other kinds of values.
• Examines the way in which moral claims are justified.
Meta-ethics poses questions of the following kind: What do we mean by the claim, ‘life is sacred’? Are moral claims a matter of personal view, religious belief or social standard, or, are they objective in some sense? If they are objective, what make them so? Is there a link between human psychology and the moral claims that humans make?

7.1.2 Normative Ethics:
• Offers theories or accounts of the best way to live. These theories evaluate actions in a systematic way, i.e., they may focus on outcomes or duties or motivation as a means of justifying human conduct.
• Includes ethical theories or approaches such as utilitarianism, deontology, virtue ethics, principlism, narrative ethics and feminist ethics.
Normative ethics poses questions of the following kind: Are there general principles or rules that we could follow which distinguish between right and wrong? Or: are there virtues and/or relationships that we can nurture, in order to behave well?

7.1.3 Applied Ethics:
• Applies the insights of ethics to social practices.
• For example, environmental ethics considers issues relevant to the relationship between human beings and the natural world, e.g., global warming, animal welfare, limited resources.
• Healthcare ethics is the branch of applied ethics which applies ethical reasoning and standards to the world of healthcare and to the ethical challenges which healthcare professionals, allied professionals, patients and families engage with.
Applied ethics poses questions of the following kind: What should I do in this particular situation? How should we organise society? What do healthcare professionals owe patients in their care? What do humans owe animals and the environment?
While these might be described as three branches of ethics, they often overlap in the course of deliberating about ethical challenges. Anyone with an interest in the issues that arise in end-of-life care – whether they are professionals working in the area, or patients, or their families – may find themselves doing some work in applied ethics. This is because they are concerned about specific ethically-challenging situations in healthcare settings and, perhaps, the specific duties of their profession or family role. However, in addressing these concerns, they may also have worries about how to evaluate their own actions or the actions of others (normative ethics). They may need to explore the meaning and the implications of particular ethical claims, for example, they may worry about the extent of their obligation to preserve life if they hold the view that life is sacred (meta-ethics).
8. Module 1 Summary Learning Guides

8.1 A Good Death and Dying

- Death is a fact of life, but beliefs about death and its significance and value are socially constructed.
- Culture and religion are key mediums for understanding the boundary between life and death.
- Recognizing cultural diversity implies the need to challenge basic assumptions and to recognize and respect the different values of patients in the illness and dying processes.
- Individuals also differ in the values they hold about dying and death. Research indicates that many people are concerned about family and loved ones being without pain and being able to communicate.
- If there is no universal agreement about what a ‘good death’ consists of, there is some consensus on the core features of good end-of-life care.

8.2 Defining Features of Utilitarian Moral Theory are:

- The moral quality of our decisions is determined entirely by the beneficial consequences following on these decisions.
- Good consequences are understood broadly to mean outcomes such as pleasure, health, well-being, justice, happiness, satisfaction of preferences etc.
- Moral responsibility is both positive and negative – covering both our actions and our failure to act.

Motives as morally neutral
- Motives for actions are not relevant for the moral evaluation of that action.
- Motives are simply instrumental means for achieving good ends. Ends justify means.
- How ought we to live our lives?
- We ought always, in our choices, to work to maximise good consequences and minimise undesirable outcomes.
8.3 Defining Features of Deontological Moral Theory are:

- Actions are intrinsically right or wrong depending on whether right principles motivate them.
- Consequences must be considered when making a choice, but they can never be decisive in measuring the moral quality of an action.
- Natural inclinations (positive or negative) might make moral behaviour more or less difficult but they are not part of the moral appraisal of a person.

Motives for acting:
- The motive one has for acting is morally decisive.
- The moral motive for any action is to choose always out of respect for the moral law.

How ought we to live?
- We ought to work conscientiously to become persons of good will.
- A good will observes the rule of universality.

8.4 Principlism claims that:

- Basic commonly-shared principles – autonomy, nonmaleficence, beneficence and justice – and the specific action-guiding rules that are derived from them are central to the ethical decision-making process in health care situations.
- In any given health care situation, any decision or course of action is morally justified if it is consistent with the relevant principles, rules, background theories and judgements in particular situations.
- The success of any chosen course of action, on the part of the health professional, can be measured by the degree to which it achieves an overall cohesion of all of the elements of the decision-making process.
8.5 Narrative Ethics claims that:

- Every moral situation is unique and unrepeatable and its meaning cannot be fully captured by appealing to law-like universal principles.
- In any given health care situation, any decision or course of action is justified in terms of its fit with the individual life story or stories of the patient. The credibility of these, in turn, is determined on the basis of narrative reflective equilibrium.
- The objective of narrative reflective equilibrium is not necessarily to unify moral beliefs and commitments, but to open up dialogue, challenge received views and explore tensions between individual and shared meanings.

8.6 Feminist Ethics

- is the application of feminist theory to understanding the ethical realm as one in which women are treated as moral equals.
- considers the impact of gender roles and gendered understandings on the moral lives of individual human beings, especially, the moral lives of women.
- is sensitive to the power/power differentials and politics inherent in moral relationships.
- highlights the contextual socially embedded nature of moral decision-making.
9. Module 1 Activities

9.1 Consider the list of key elements of good end-of-life care. Are there other elements of a ‘good dying’ that you think should be included? Explain why.

9.2 Read again the description of what ethics is and ethics is not. Consider the examples of statements in the table below and categorise them as one (or more) of the following:

- Law
- Hospital policy
- Professional codes
- Public opinion
- Authority
- Religious belief

State also whether you think the statement is

- ethical, i.e., it involves doing the right thing
- unethical, i.e., it involves doing the wrong thing
- non-ethical, i.e., it does not have ethical content; it does not refer to ethical values or reasoning.
You might find it helpful to discuss the examples with a friend or colleague.

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<td>a. Competent over 16s can consent to medical treatment and care.</td>
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<td>b. Cough mixture A is a more effective expectorant than cough mixture B</td>
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<td>c. Healthcare professionals have a duty to intervene in an emergency</td>
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<td>d. The Patient's Charter informs patients about their rights</td>
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<td>e. Patients ought to be informed if they have a serious illness</td>
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<td>f. Consultants' orders should be followed</td>
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<td>g. People have a right to refuse treatment even if it results in their death</td>
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<td>h. Hospital environments should be clean and aesthetically pleasing</td>
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<td>i. 80% of doctors agree that cannabis is therapeutic, therefore, it should be legalized</td>
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<td>j. All human life is sacred</td>
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(adapted from Gallagher, 2005)
You may find that many of the statements can be categorized under more than one heading. For example, a) the issue of consent for over 16s is addressed in Irish law but it might also be expressed in hospital policy. You may also consider that it is an ethically good thing to respect the treatment choices of over 16s.

On the other hand, b) the claim that cough mixture A is a more effective expectorant than cough mixture B is a factual (non-ethical) claim. Evidence from clinical trials or practice may prove this claim true or false. It would only become an ethical (or professional and legal) concern if a professional prescribed the least effective expectorant for reasons of personal gain, rather than in the best interests of their patient.

The statement relating to professional duties in emergency situations, c), may be a familiar one drawn from your professional code. You may agree or disagree as to whether it is reasonable and ethical to expect professionals to always intervene in emergency situations, even when they are ‘off-duty’.

Statement d) concerning the Patients’ Charter is likely to be a matter of hospital policy, but it may also reflect Constitutional rights and law and articulate the commitment of a health organisation and its employees to deliver ethically appropriate care.

The obligation to inform most patients if they have a serious condition, e), is usually articulated in professional codes, as well as in hospital policies and laws. It is also considered to be an ethical obligation because truth-telling is generally viewed as a means of affording patients control over information that concerns them, as well as ensuring their participation in decisions affecting their treatment and care.

Statement f) relates to following orders, obeying the directives of others. The important point here is that professionals need to approach such directives critically and ask if they are ethically sound and clinically and technically appropriate.

That a patient has a right to refuse medical treatment even if it leads to their death, g), is a widely held belief of the Irish public (it is a matter of public opinion [Weafer, McCarthy and Loughrey, 2009]) but it is also viewed as an ethically sound claim that has been underpinned by legal decisions, hospital policy documents and professional codes.

The statement h) may appear, at first sight, to be non-ethical, that is, more a matter of aesthetics (concerned with appearance and beauty), than ethics. However, it has been argued on the basis of a recent survey of over 2000 nurses in the UK that the physical
environment contributed to the promotion and diminution of dignity in care (Royal College of Nursing, 2008). The physical environment is, therefore, an ethical issue, as it influences whether people feel valued or not valued.

Statement i) relates to a poll or survey. We do not know exactly which doctors were asked, how many doctors were surveyed, or whether the sample was representative. Moreover, even if this group of professionals holds this view concerning the therapeutic benefits of cannabis, it does not follow that, i, they are correct; ii, that their views should trump the views of other individuals or groups, or, iii, that there might not be other practical/ethical/legal arguments against the legalization of cannabis.

The final statement j) is a religious claim that links human life with the divine. Some would also argue that the claim can be understood in secular terms to mean that human life is of supreme value, or at least, that human life has a deeply significant value. Understood in these terms, the claim is both religious and ethical (modified from Gallagher, 2005).

9.3 Consider the saying that describes utilitarian morality:
‘the end justifies the means’. Some commentators think that this policy allows morally reprehensible acts to be committed with the aim of achieving good ends.

a. On the basis of your experience, do you think that this habit of carrying out unjust or dishonest acts as means to achieve good ends is so unusual?

b. What about a doctor’s evasion to avoid breaking bad news to a very depressed patient? What about prescribing antibiotics for flu symptoms at the request of a patient?

c. What does the fairly common occurrence of such events tell us? That utilitarianism is well-suited to human behaviour?

9.4 Review Kant’s rule of universality
a. Can you give examples where you think this rule should not or could not be observed?

b. Do you agree with Kant that the consequences of our actions are not fully in our control and so should not count in the moral appraisal of our actions?
9.5 The concept of virtue might seem a bit vague, open to multiple interpretations and unhelpful for giving practical guidance.

a. How do you understand the idea of ‘virtue’? Consider someone whom you think is ‘virtuous’. How would you describe them? What kinds of behaviour or attitudes of the person would you offer as moral indicators of virtue?

b. Does a ‘good’ doctor or nurse have certain characteristic ‘virtues’? If you had to write a short essay on ‘The Caring Professional: a Life of Virtue’, what would you have to say? If you believe that virtue is not relevant as a focus in healthcare, try and explain why.

9.6 Consider again the four principles of the PBE approach.
Taking each principle in turn, can you think of examples from practice which illustrate the need for health professionals to respect each principle?

9.7 Read again Brody’s account of empathy on page 35.
Do you think it is an accurate representation of the patient/professional relationship? Consider the strengths and weaknesses of his account.

9.8 Feminist theory highlights the significance of power structures and hierarchies in moral situations. These elements of power seem intractable and yet they are found in educational settings, in health care contexts and indeed in families. In the context of health care, hierarchies of authority seem resistant to change. But are they?

a. Consider a situation where some moral disagreement occurs on in a health care setting where power imbalances are at play. These power factors greatly diminish your opportunities to speak, to offer suggestions for resolution of a moral disagreement. What do you do? What would you suggest be done if asked by a colleague or friend of yours?

b. It seems that power structures and health care hierarchies are culturally relative. Do healthcare organisations in some countries suffer more from power imbalances than others? If so – how do you explain these cultural differences?
10. Module 1 References and Further Reading


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