Module 5
The Ethics of Managing Pain
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1.1 Bad deaths
often occur as a result of poor pain and symptom management, inadequate communication and the experience of abandonment and isolation. Very often bad deaths occur where there is inappropriate and, arguably, unethical active treatment and when obstacles prevent patients from accessing palliative care.

1.2 Comprehensive pain management
includes not only specialized clinical programs to control physical pain, but also counselling and human support to minimize psychological pain and soul pain, family and community support groups to counter social pain and pastoral care resources to address spiritual pain. These aspects of pain are interrelated and sometimes hard to distinguish. If efforts to manage pain focus on one aspect to the neglect of the others, the patient may not experience genuine relief. This can lead to the patient developing anxiety and concern about the ability of staff to control their pain.

1.3 Family resistance to palliative care
deserves a careful conversation with health professionals to see why they don’t want their loved one to receive such care. At times families can strongly influence health professionals who might think that palliative care would benefit a patient. Doctors and nurses can come under considerable pressure from patients and families who have assumptions and preconceptions about palliative care, such as ‘I’m going there to die’ or ‘I’ll be drugged to my eyeballs’ (Quinlan and O’Neill, 2009, p.31-34). This resistance can abandon patients to unnecessary suffering.

1.4 Good deaths are more likely to occur
when the beliefs, values, preferences and individuality of patients are respected and all pain management services are put in place. The experience of pain can diminish the energy and clarity of thought in attempts to exercise autonomy. Thus, the possibility of autonomy in practice is nurtured and enhanced by the management of a person’s pain. Unrelieved pain experience is the most debilitating part of illness. In characterising a ‘good death’, the absence of pain is central.

1.5 Health professionals may fail to give patients adequate relief from pain
for a number of reasons including: basic ignorance of the magnitude of the doses needed to relieve severe pain, an inappropriate fear of causing respiratory distress, a misplaced anxiety about the hazards of addiction or a fear of civil or criminal prosecution.
1.6 Patients often do not tell health professionals the extent of their pain. The reasons for this vary according to gender, cultural background, religious beliefs, age etc. Patients also say they do not know how to describe their pain so as to get the right kind of help from health professionals. Their pain may be a combination of physical, psychological and soul pain. There are also concerns about being viewed as weak or a ‘complainer’, or the patient may observe that staff resources are low and think that time is simply not available to discuss pain relief.

1.7 The principle of beneficence
or active concern for and promotion of, patient well-being would rank pain relief and management among the most important objectives in caring for patients suffering from painful illnesses. Engaging the patient in discussion about their pain, about their concerns in relation to that pain and about what they hope for is reassuring for any person in the institutional setting of a hospital.

1.8 Slippery Slope concerns apply to many areas of decision-making.
The form of the concern is this. If we take a particular decision, even if it is a good decision, we need to ask: is it likely to lead to another decision which we would not desire or think is good? Slipper-slope concerns in allowing competent patients to decline all life supports would be that we might slowly come to think it is justified to discontinue all life supports for patients lacking competence who seem to us to lack a good quality of life. One of the difficulties with slipper slope worries is that they can frustrate very good decisions out of fear that less desirable consequences will follow.
2. Module 5 Definitions

2.1 Euthanasia:
is a deliberate act or omission whose primary intention is to end another person’s life. Literally, it means a gentle or easy death but it has come to mean a deliberate intervention by one person with the clear intention of ending the life of another. This is often described as ‘mercy killing’ of people in pain with terminal illness. Decisions to withdraw or discontinue life supports are not equivalent to euthanasia if they are validly authorised by a competent patient’s consent or if a clinical decision is made that further life supports, based on all available evidence, would be futile – lacking in benefit for the patient and merely prolonging the dying process.

2.2 Life Prolonging Treatment (LPT):
is any medical intervention, technology, procedure or medication that is administered to provide benefit for a patient and to forestall the moment of death. These treatments may include, but are not limited to, mechanical ventilation, artificial hydration and nutrition, cardiopulmonary resuscitation, haemodialysis, chemotherapy, or certain medications including antibiotics.

2.3 Palliative Care:
a comprehensive approach to treating serious illness that focuses on the physical, psychological, spiritual and existential needs of the patient. Its goal is to achieve the best quality of life available to the patient by relieving suffering and controlling pain and other symptoms associated with the particular illness of the patient.

2.4 Palliative Sedation:
is offered to patients if standard opioids are ineffective in managing their pain. It is used to induce an artificial coma especially in cases in which a dying person is experiencing severe, intractable suffering. The intention in using palliative sedation is to induce a state of decreased, or absent, awareness (unconsciousness) in order to remove the burden of suffering in an ethically acceptable way for patient, family and healthcare providers. The term ‘palliative sedation’ has largely replaced the previously used term of ‘terminal sedation’.

2.5 Physician Assisted Suicide (PAS):
the act of assisting a person to die by providing the means for them to take their own life. A recurring example of PAS is the act of giving a prescription or supply of drugs to a patient who has requested this. The doctor providing the lethal dosage of drugs thus enables a patient to end his or her own life.
2.6 Principle of Double Effect (PDE):
an ethical rule which holds that effects of treatment which would be morally wrong if
brought about intentionally are permissible if they are foreseen but unintended. The
principle is often cited to explain why certain forms of care at the end of life which may risk
and/or hasten death are morally permissible while others are not.
3. Module 5 Background

One of the classic themes of healthcare ethics concerns the moral acceptability of interventions to modify the dying process. Developments in the practice of palliative care give rise to new discussions about the ethical aspects of medical care at the end of life. This module focuses on these discussions.

3.1 Ethical Principles in Pain Management

3.1.1 Respect for Patient Autonomy (See Module 4, 4.2)

The moral principle of autonomy is pivotal in conversations with competent patients when considering options for pain management. The experience of pain can diminish the energy and clarity of thought to exercise autonomy. Thus, encouraging and fostering a patient's understanding and decision making in relation to these options through sensitive information sharing shows interest in the facilitation of patient autonomy. In fact, the possibility of autonomy in practice is nurtured and enhanced by the management of a person's pain (See Module 3).

3.1.2 The Principle of Beneficence

The active concern and promotion of patient well-being would put pain relief and management among the most important objectives in caring for patients suffering from painful illness. Engaging the person of the patient about their pain, about their concerns with that pain and what they hope for is reassuring for any person in the institutional setting of a hospital.

Patients may have difficulties in speaking about their pain and seeking pain relief. This can apply to adults but applies especially to children. Describing pain is not easy and sometimes a patient may think they will be perceived as a complainer and incur the displeasure of staff (McCracken and Keogh, 2009).

One narrative recounted in an Irish hospital setting makes clear that some patients are assertive about their preferred pain relief methods:

‘Recently I became aware of a 90-year-old lady who is in long term care in a residential unit. The lady is as fun-loving and active as her physical abilities allow. She has no relatives and receives weekly visits from the palliative care team. Approximately 6-8 weeks ago the lady decided that she had had enough of the pain medication as it wasn’t helping her and she indicated she would prefer whiskey at night instead. The staff discussed this with her...”
and she remained very clear that this was her wish. The palliative care team was in agreement. Arrangements were made for a supply of whiskey to be on hand and the lady reported that the whiskey in her tea is a far more effective means of pain relief. She said she feels better in the morning as she is guaranteed a more peaceful night.' (Quinlan and O’Neill, 2008, p.26-7)

This amicable result came about not simply as a result of listening but by actively hearing what the patient was saying. The staff was flexible in responding positively to this request for ‘whiskey therapy’. The 90-year-old lady was shown respect and her subsequent contentment showed her delight at this concern for her well-being. The staff’s decision to provide whiskey heightened the patient’s sense of self and allowed sleep and serenity. With this simple method of pain management for this lady, staff showed moral respect for her unique person.

The scenario that follows describes a less fortuitous outcome than in the case of the elderly lady above.

‘An 82-year-old lady with a diagnosis of COPD respiratory failure was being managed by the respiratory team. There were numerous requests from her for pain relief and symptom control. Inappropriate analgesia was prescribed and the patient was unable to swallow. While on night duty at 9.30 pm, I had to contact the Registrar on call and insist on analgesia, anti-emetics and hypocrite to dry secretions and promote comfort. The family were very distressed. The registrar came at 11.30 pm and spoke to the family and infusions were commenced. The patient was only comfortable at 12.30 am. When I looked at the Nursing and Medical Notes, this had been going on for four days.’ (Edited narrative, Quinlan and O’Neill, 2008, p.1)

It would seem that the pain suffered by the 82-year-old lady in this scenario is not all that rare internationally. Cassel, (1999) claims that a great deal of pain is inadequately treated. He explains that, ‘too much suffering is unrelieved and undiagnosed, a situation more common now than a generation ago because current treatments keep people alive long enough to enter the chronic, terminal phase of their illness: the duration and severity of their suffering are thereby increased’ (Cassel, 1999, p.531). He also traces the prevalence of untreated pain, in part, to deficits in physician training which focuses on organs, diseases and aetiology rather than on persons as individuals with their unique fears and hopes.

‘The diagnosis of suffering is often missed, even in severe illness and even when it stares physicians in the face. A high index of suspicion must be maintained in the presence of serious disease, and patients must be directly questioned […] Often, questioning and attentive listening, which take little time, are in themselves ameliorative. […] The language that describes and defines the patient’s
suffering is different from the language of medicine – there is too often an actual disconnect between our case history and the patient’s narrative […] Physicians are trained primarily to find out what is wrong with the body – in terms of diseases or pathophysiology; they do not examine what is wrong with persons […] when physicians attend to the body rather than to the person, they fail to diagnose suffering.’ (Cassel, 1999, p.531)

3.1.3 Nonmaleficence

The value of nonmaleficence, or ‘Do no Evil’ is closely linked to the objectives of pain management. Lack of adequate pain management causes harm to the patient. The harm, worry and, at times, consequent depression of painful suffering, and accompanying anxiety needs no elaboration beyond the ethical and empirical research on end-of-life care. (O’Shea, Keegan and McGee, 2002; Bon Secours Health System, 2007; German National Ethics Council, 2006) Unrelieved pain is the single factor accounting for patient experiences of a ‘bad death’
4. Resistance to Palliative Care

The discussion in this module shows that pain and suffering are not homogeneous realities and that the practice of thinking beyond the conventional limits of physical pain management serves patients well. Pain relief is one of the most important goals of palliative care where such care is universally understood as a comprehensive philosophy of care which includes pain and symptom management, support for patient and family and the opportunity to achieve meaningful closure to life (Deandrea, Montanari, Moja et. al., 2008). A good death survey has shown that one of the elements in a good dying is skilled pain and symptom management and that lack of such skills ensures a ‘bad death’ (Steinhauser et. al., 2000). If the elements of a good death call for good pain and symptom management, the provision of syringe drivers, the management of nausea and vomiting, and the establishment of good relationships between patients, families and health professionals, then the earlier palliative care can become involved with the patient the better.

4.1 Family Reluctance

The research conducted by Quinlan and O’Neill (2009) shows that adequate pain relief is sometimes not achieved because, for a variety of reasons, family members choose not to have their loved one receive palliative care. As one health professional interviewed commented:

‘I find on the ward that Palliative Care isn’t brought in soon enough. I do feel that, especially with pain management because it’s something I feel very strongly about. I still find that sometimes teams are resistant to involve palliative care for pain control. I don’t know why, I just feel there’s some resistance.’ (Quinlan and O’Neill, 2009, p.35)

Another health professional observed:

‘[W]e would have patients who end up not seeing the palliative service because that’s not acceptable to the family and there’s been backwards autonomy in the first place, I mean that the autonomy has been given to the family – the family decides whether or not the patient is seen by Palliative care. It should never arise [...] and the family say ‘well you’ve got to guarantee me you won’t tell them that they have cancer otherwise I’m not bringing them in.’

(Quinlan and O’Neill, 2009, p.68, see also, p.27)

The role of families in healthcare decision making is a profoundly important issue. If family involvement in decision making is judged to be damaging to the well-being and proper care of a patient, then health professionals cannot, with good conscience, comply with family requests.
The family may tend to claim proxy authority to decide for the patient, especially when the patient either lacks capacity or has declined to be involved in decision-making about pain management. However, there is a mandate here for staff to engage families and report the harm they are doing to their loved ones in denying them pain management or access to palliative care. Failure to seek palliative care often means that pain continues needlessly and the moral obligation of carers to provide for the well-being of patients is not met. Reluctance to use palliative services points to a very urgent need for education in palliative care for health professionals and the wider public (Randall and Downie, 2006).

4.2 Staff Collusion
But unfortunately, there can be unwitting collusion among some clinicians in a family’s refusal to have palliative care for their loved one.

‘There is a patient who is at home who I know from the referring physician and […] this patient is very unwell, needs the type of palliative support that we can offer and our community teams can offer but this patient went home and the doctor whose care they were under agreed not to tell them their diagnosis. They are now at home, the family isn’t telling the diagnosis and the patient isn’t being allowed access to palliative care because, we, palliative service, will not agree, if the patient asks us why this has happened, to not telling them the diagnosis (Quinlan and O’Neill, 2009, p.63). See also Module 2, 6.1.1 and Module 4, 6.4.
Module 5 The Ethics of Managing Pain

5. Dimensions of Pain

Pain is an intriguing phenomenon and we have only begun to understand its complexity. Pain most often is multi-dimensional, consisting of a range of symptoms and types of suffering: physical, psychological, social, spiritual and ‘soul’. In the cases that follow in this module, there is often a combination of different types of ‘suffering’, resulting in each patient’s set of unique pains. The pain experienced in terminal illness is much more than physical. The combination of many dimensions of pain can overwhelm dying patients and weaken their sense of control, sense of purpose and meaning. It can also weaken their sense of connectedness to others. If effective patient care is to ensure pain relief, the patient needs to be seen in holistic terms as integrating emotional, physical, spiritual, cultural and social causes of pain. Michael Kearney uses the phrase, ‘total pain,’ to refer to the combination of the different pain components most often encountered (Kearney, 1996, p.24).

5.1 Physical Pain

Physical pain is the most obvious form of pain and major cause of suffering. It impairs physical functioning, mood, and social interaction. Physical pain serves as a clear warning that something is out of order in the normal functioning of the body. But, since pain affects the whole person, it can easily exceed its function as a warning signal. Severe pain can drive a person to request its removal at any price, even to the point of asking for death for oneself or for others.

5.2 Psychological Pain

Psychological pain often arises when facing the inevitability of death, losing control over the process of dying, letting go of hopes and dreams, or having to redefine the world one is about to leave in terms that never quite satisfy one’s needs. Psychological pain is evident in the mood swings and strong feelings that often accompany terminal illness. (See Case 6.1)

5.3 Social Pain

Social pain is the pain of isolation. The difficulty of communicating what one is experiencing while dying creates a sense of aloneness at a time when companionship is most needed. The unwillingness or inability of others to keep company with the dying by visiting them, listening to their feelings and experiences or discussing the implications of what is happening to them only aggravate the isolation. The loss of a familiar social role is also painful. For example, letting go of the role of being a self-sufficient, caring parent and becoming the one who is dependent and cared-for can be socially and psychologically painful (Ranger and Campbell-Yeo, 2008).
5.4 Spiritual Pain

Spiritual pain arises from a loss of meaning, purpose and hope. Despite society’s apparent indifference to the ‘world beyond this one’, spiritual pain is inescapable and widespread. Everyone needs a framework for meaning – a reason to live. People who are dying often seek a larger landscape of meaning and therefore need to feel part of a community that shares that meaning. Some patients can find meaning and solace in a religious belief.

Spiritual pain endured by those patients with religious belief can arise from: 1) concern and anxiety about their relationship with their God; 2) worry that they might not remain steadfast in their faith while suffering pain and illness; 3) worry about whether a priest or chaplain will be with them when needed to offer spiritual companionship and religious solace.

Issues of faith are frequently mentioned by dying patients as integral to the overall healing at the end of life. This often becomes more important as the patient declines physically (Steinhauser et. al., 2000). As evidenced by research with patients, spiritual pain can cause genuine suffering when patients are either denied spiritual companionship or have it provided without respect for their refusal (Quinlan and O’Neill, 2009, p.32).

5.5 Soul Pain

is a particularly profound and excruciating form of pain. ‘Soul’ is here used in its more classical sense as meaning ‘psyche’ and is without religious connotations (Kearney, 1996, p.57). It is manifested in an all-pervading sense of emptiness, hopelessness and meaninglessness and characterised as anguished, tortured and restless (Kearney, 1996, p.62). Patients experiencing soul pain may request help to become unconscious as seen in the following case. (See Case 6.5)
6. Cases in the Ethics of Pain Management

6.1 Case 1: Psychological Pain of Anticipation – ‘I Dread What May Come’

The following case illustrates the pain that can accompany psychological dread of what is to come.

‘I Dread What May Come’

[...]hen I was in a centre of adult Palliative Medicine, we came across Maurice, a young gentleman of 32, who was referred to us after he had attempted to commit suicide and he had thrown himself into the local river. The reason that he had tried to commit suicide was that he had a diagnosis of cancer which he’d lived with for about eight years at this stage but was developing increasing pain. He was worried that if his pain was so bad at this stage and not controlled, how bad was it going to be when he was closer to death? It was really his fear about symptoms, you know, not being controlled. So he was able to relay all this to us, and we then got his pain under control, relatively easily I suppose, it’s what we do every day, and we were able to reassure him that his pain would never have to be out of control as it had been and thereby his suicidal ideation completely resolved. (Quinlan and O’Neill, 2009, p.34)

6.1.1 Discussion 5

This case looks at the stressful reality of what we term anticipatory pain. Such pain is not uncommon even in ordinary life as we wait for the colonoscopy or go into the nursing home to see our failing elderly parent. What we call anticipatory pain comes under the heading of psychological pain. Psychological pain is indeed a form of authentic suffering. It is not illusory, nor is it simply ‘in the mind’. Anticipating the real probability that one’s manifest pain will increase in severity and regularity as one’s disease progresses can exacerbate psychological suffering. Anticipatory suffering can be excruciating and requires relief using a variety of interventions.

Case 1 is a good news story in terms of the result for this patient and for the health professionals who listened to Maurice’s desperate pleas for relief from his present pain and excruciating anticipatory pain. Maurice was not only saved from his attempted suicide but he was given an opportunity to speak openly about his dread of increasing pain.
He was given relief and hope, through being assured of on-going pain management. This young man’s act of attempted suicide secured for him the therapeutic pain management and compassionate conversations with staff that he needed. Health professionals responded when the patient demonstrated dramatically by means of a suicide attempt that he needed solace, communication, pain management and emotional support (Cassel, 1999).

The psychological pain for this man has at least three sources.

- He has lived with his cancer diagnosis for eight years and, given to reflecting on this reality, he experiences on-going stressful pain. There is a belief among some patients with a diagnosis of cancer that it is only a matter of time before the cancer cells all go haywire (Steinhauser et. al., 2000). The unique character of the person suffering certainly affects the nature, intensity and stressful nature of this prolonged pain of thinking ‘how will this end, will I die in pain like this? What will it be like?’ (Terry, Olson, & Wilss, et. al., 2006, p.342).

- The second source of psychological pain was the fear and hopelessness that led to his attempted suicide in the local river. Again, the unique personal nature of his ever-present worries about his condition would have drained him of energy both physical and emotional. One difficulty with psychological pain is that the depression associated with it often leads the individual to believe (even subconsciously) that there is no solution. This is the essence of hopelessness and often can only be counteracted by human intervention. Persistent hopelessness is not a normal part of dying; it requires therapeutic attention (Cassel, 1999).

- A third source of psychological pain came for this patient with the measurable increase in his pain. With this increase, Maurice became very frightened and assumed that the cancer was all over his body.

This situation might have been prevented earlier if Maurice's family, GP or a trusted friend had heard about his pain, or had heard his concerns however subtle and encouraged him to seek help. An outpatient drop-in-clinic for patients in need of pain relief, while quite uncommon in Ireland, would provide patients like Maurice with help in reviewing and monitoring his developing symptoms and give him reassurance. With help from hospital staff and on-going sessions with his GP, Maurice might now continue living his days with his illness but in greater psychological security.
6.1.2 Suggested Professional Responsibilities

- Suicide is a cry for help and clear reaction to fear, frustration, sense of isolation and hopelessness. In a conversation with Maurice, hospital team should find out if there was any previous history of suicide attempts or suicide ideation.
- A consultation with the clinician (preferably pain specialist) needs to give Maurice reassurance, as the case indicates, that any developing pain can and will be treated.
- An assessment can be offered to see what medicinal or other therapeutic help can be offered to Maurice for possible depression associated with his anxiety and anticipatory pain.
- A report of Maurice’s attendance in hospital should be prepared and sent to Maurice’s family doctor stating that the hospital clinician advised Maurice to see her within the next couple of weeks.
- Since Maurice’s worries are linked to his fear of dying as pain increases, a careful assessment of Maurice’s cancer condition should be arranged with the oncologist. This assessment can follow with a conversation about his cancer condition and specifically what therapeutic helps can be offered to him.
- This consultation and recommendations for Maurice should be documented for the hospital records so continuity of care can be better ensured if or when Maurice returns to hospital.

6.2 Case 2: Interpreting Children’s Pain – ‘I Never Saw Anyone Suffer Like That in My Life’

Managing the pain of hospitalised children, even very young children, is one of the more profoundly challenging tasks in pain management. The ethical principles of the duty to benefit another (beneficence) and the duty to do no harm (nonmaleficence) oblige health professionals to provide pain management to all patients, including children, who are extremely vulnerable because of the constant developmental changes they undergo and the attendant insecurities of being ill and hospitalized in a strange setting (Kortesluoma, Nikkonen and Serlo, 2008, p.143-144). Evidence also shows that we often underestimate the need to give room to a child’s voice, failing to pay attention to verbal or bodily cues and therefore we fail to promote the child’s incipient autonomy during hospitalisation (Royal College of Paediatrics and Child Health (RCPCH), 2008, p.9). Attentive observations of children by staff and regular conversations with parents can achieve significant insights into the uniqueness of children’s experience of pain (Walco, Cassidy and Schechter, 1994).
‘I Never Saw Anyone Suffer Like That in My Life’

During her last month of life, 4-year-old Madeleine lay on her bed in too much pain to watch her beloved Barney on TV. The little girl’s pain was so great that she cried when her mom touched her, when she tried to speak to her, or when she turned on the lights. Just a few months had elapsed since Madeleine was first diagnosed with leukaemia.

‘I’ve never seen anyone suffer like that in my life,’ said her mother. Madeleine was given chemotherapy with the onset of the disease, and after a relapse, doctors proposed another round of chemotherapy treatments, which, if successful, would prepare her for a bone marrow transplant.

The doctors assured her family that the pain she experienced from the chemotherapy could be controlled.

But when the pain came, and it came within three days after the first treatment, her mother said nothing worked to alleviate it. It took Madeleine 5 minutes just to roll over in bed because each movement was so painful. When the family pleaded for relief for their daughter, doctors seemed slow to act. In addition, Madeleine had a serious bout of pneumonia that went undiagnosed for two weeks. Madeleine’s mother reported that ‘All they were interested in was the cancer and the [white blood cell] counts going up. They didn’t look beyond that.’

On Valentine’s Day 1999, five months after she was diagnosed, Madeleine died.

(adapted narrative from Linsker, 2000)

6.2.1 Discussion 5

The above case illustrates the need for focus, attentiveness and on-going conversation in the relationship between the health professionals, Madeleine and her family. Were parents kept informed by doctors and/or nurses about the meaning of the diagnosis of leukaemia? Did the family understand its severity, the prognosis, how amenable it might be to chemotherapy and what methods of pain management are available? (See Module 2)

The emotional narrative of the mother needs to be heard. It is a narrative based on four years experience of rearing Madeleine and interpreting her pain, her body language, her fatigue, her nausea, her effort to do the simplest thing (Lesho, 2003, p.2429-2430). Here, the mother is the proxy voice for Madeleine and listening to her story of knowing her daughter intimately.
and witnessing her pain is perhaps vital to diagnosing the child’s pain. Through team effort and on-going communication with Madeleine, a strategic plan might have been devised to try and relieve the child’s distress, a strategy that would also require negotiating and engaging with the parents.

The alleviation of children’s pain has been investigated through the eyes of health professionals and parents, but the children’s own perspectives have largely been ignored. Children have their own descriptions and expectations for pain management interventions. The evidence shows that children themselves, perhaps somewhat older than Madeleine, should be regarded as experts on their own pain in order to maximise the options for pain management and provide high-quality care (RCPCH, 2008, p.9). Respecting the incipient autonomy of the small child in the case above calls for a concerted effort to communicate with the child by paying attention to all bodily cues available and any verbal signals provided by Madeleine. By focussing exclusively on her white cell count, the physicians may have focussed on the hopes for curative treatment and failed to diagnose and deal with the degree of Madeleine’s suffering (Lesho, 2003, p.2430).

The ethical values of beneficence and nonmaleficence (Do No Harm) can be combined with the aim of respecting the incipient, developing, autonomy of this small girl as she suffers with leukaemia. Was another round of chemotherapy appropriate here? Was this treatment extraordinary for a dying four-year-old? Perhaps if active treatment for leukaemia stopped, the focus on pain management would yield more comfort and calm for the young patient (Linsker, 2000, p.2).

If the healthcare team had reasons to believe that further chemotherapy and possibly a bone marrow transplant would be beneficial, then this would need to be explained to the family. It seems from the information available in this case, that the level of conversation and communication for understanding was deficient. Adequate pain relief in this case was not achieved and perhaps had even been thwarted by the focus on more aggressive treatment rather than on palliative care. One doctor’s statement may sound a note of truth in relation to this case: ‘As physicians, we are trained to cure, not trained to support the dying patient. We lack training in that and must acquire it on our own’ (quoted in Linsker, 2000, p.1). The desire to cure is powerfully strong and is taught as a primary objective in medical training. In this case of Madeleine, cure was given precedence over care. As carer, her mother, also needed care from health professionals for she failed to understand why white cell counts seemed more important to clinical staff than her daughter’s experience of continuing pain.
6.2.2 Suggested Professional Responsibilities

- A thorough review of this case needs to be undertaken by the healthcare team who managed Madeleine and the concerns of her parents. The objective is to reflect on decisions taken and honest self-scrutiny about the human outcomes. What clinical evidence contributed to decisions taken?

- Team review of the management of Madeleine’s case should consider it a priority to ask whether Madeleine’s mother may have been correct: Was the medical management of this child’s chemotherapy aggressive? If not, an explanation should have been offered to the parents for the recommendation of further chemotherapy and, possibly, a bone marrow transplant.

- Documentation needs to be provided for the records of any diagnostic tests conducted on Madeleine, team consultations, number and evidence basis for chemotherapy sessions and prognosis justifying considerations of a bone marrow transplant.

- Following Madeleine’s death, attention can turn to comforting the grieving parents and efforts made to heal some of the rift in the family-health professionals’ relationship. Can the healthcare team honestly say to the parents that ‘all that could be done was done’?

- The team might take time to reflect on the case and address the question: Was the manner of pain management in Madeleine’s dying deeply regrettable and overtaken by drive to ‘cure’ or ‘keep alive’ at all costs? If so, how, precisely, can a similar situation in the future be improved?
Module 5 The Ethics of Managing Pain

6.3 Case 3: The Principle of Double Effect – ‘I Don’t Want to Die. I Want to Be Without Pain!’

The patient in the following case is explicit about his excruciating suffering and asks for more pain relief.

‘I Don’t Want to Die. I Want to Be Without Pain!’

Paul is a 68-year-old man with metastatic small-cell lung cancer. He is suffering from excruciating bone pain and he is near death. Initially, he responded to a combination of chemotherapy and radiation and had a 3-year remission. His disease recurred four months ago and he decided to choose a palliative approach. Paul’s pain from extensive bone metastases was initially well managed with high-dose, around-the-clock opioids supplemented by radiation and nerve blocks.

Paul prepared for death through talks with his partner, Tom, and clergy and felt he had no remaining ‘unfinished business’. In the end stages, he weighed 80 pounds, was bed-bound, and his pain averaged 8 points on a 10-point scale. Paul had always loved life and even now did not want to die but he told his doctor and the nurses on duty that he was willing to accept the risk of an earlier death which might come from further increasing doses of opioids.

After a palliative care consultation, his doctor increased his total opioid doses by 25% each day until the pain was adequately controlled, or, if sedated, until he would appear comfortable. On the third day after this dose increase, Paul became very sleepy but arousable. He appeared relatively free of pain. The doctor shifted an equi-analgesic amount of opioids from oral to transcutaneous administration because Paul was unable to swallow reliably. Tom was with him as he became unresponsive, appearing comfortable, neither restless nor struggling. Paul remained in that state until he died 2 days later.

(Adapted narrative from Quill, Coombs Lee and Nunn, 2000a, p.490)

6.3.1 Discussion 5

In this case the doctor and Paul were both willing to accept the likelihood of an earlier death as a result of the increased opioid dose. This was a foreseeable possible consequence of increasing the pain dosage. However, the health professionals caring for Paul reassured him that his suffering was severe enough to warrant taking the risk of a hastened death due to depressed respiration. The intention here to increase pain medication was consistent with the aims of palliative care: the compassionate and beneficent relief of Paul’s suffering.
Principle of Double Effect (PDE)
One ethical rule, originally formulated in the Catholic tradition during the twelfth century, and used in moral reasoning in defence of providing pain relief methods without incurring accusations of killing, is the principle of double effect (PDE).

The PDE permits an act which is foreseen to have both good and bad effects, provided:

a. the act itself is good or at least morally neutral (the act of providing pain relief);
b. the good effect must be primary intention and not the effect of shortening a patient’s life. The possible earlier demise of the patient is said to be ‘foreseen’ but not explicitly intended or desired.
c. the good effect is not caused by the bad effect (the relief of pain was not caused by Paul’s dying but by adequate pain medication); (See Case 4)
d. a proportionate reason exists for causing the bad effect (shortened life justified by need for relief from pain);

According to the ethical rule known as the ‘principle of double effect,’ effects that would be morally wrong (dying) if caused intentionally are permissible if foreseen but unintended. This principle is often cited to explain why certain forms of care at the end of life that result in an earlier demise are morally permissible and others are not. So, according to the principle, administering high-dose opioids to treat a terminally ill patient’s pain may be morally acceptable, even if the medication hastens a patient’s death. By contrast however, the principle does not authorise practices such as physician-assisted suicide, voluntary euthanasia and some instances of foregoing life prolonging treatment.

The discussion of this case should clarify that there are some relatively uncomplicated clinical situations in which the PDE can help clinicians overcome a hesitation to prescribe sufficient dosage of pain medication for a particular patient’s suffering. The following text defends the use of the PDE when providing pain relief:

‘[T]he intensive use of painkillers is not without difficulties, because the phenomenon of habituation generally makes it necessary to increase their dosage in order to maintain their efficacy […] Is the suppression of pain and consciousness by the use of narcotics […] permitted by religion and morality to the doctor and the patient (even at the approach of death and if one foresees that the use of narcotics will shorten life? Yes. If no other means exist […] In this case, of course, death is in no way intended or sought, even if the risk of it is reasonably taken; the intention is simply to relieve pain effectively, using for this purpose painkillers available to medicine. (Edited from O’Rourke and Boyle, 1993, p.223)’
An expansion of Case 6.3 might allow us the license to eavesdrop on an invented conversation among members of the team. Such eavesdropping may help in clarifying some distorted views of the PDE.

“One intern, Colum, said he knew the principle of double effect and said “we seem concerned here but, we’re not wishing or aiming for Paul’s death but we can’t let him suffer in pain this way. I know this is ok.” However, another colleague, Clare said, “yes, it’s true that we’re not giving this increased dosage to kill Paul but, I have to admit that, under the circumstances, dying without pain for Paul would be a blessing, not a bad thing. If that were to happen, how do I know that the increased medication dosage I provide is not really my way of achieving Paul’s death? Could I clear my conscience that I have not killed Paul?”

This exchange may not always be verbal or explicit. However, research indicates that these sentiments often cause health professionals to wonder about the clarity of their intentions and motivations in providing pain relief (Quill, 1993). Many clinicians have learned of the principle and, when administering pain medication, their ‘lesson in PDE’ sometimes resurfaces, causing them to wonder whether they are doing the ‘right’ thing and if they are being honest about their state of mind and intentions.

Returning to the scenario between Colum and Clare, if Clare thinks that Paul’s passing may be a blessing, why should this be a source of concern or anxiety? This is a thoroughly normal thought in the presence of anyone who is suffering from serious illness. ‘God would be good to take him’ is a common utterance. It is not our compassion that brings about the person’s death? Qualms of conscience expressed by Clare are not trivial and call for understanding from the medical team. If persistent qualms or scrupulous worries about excessive opioid provision are left to take hold of one’s moral reasoning, the result is serious under-treatment of pain in suffering patients which is a concern of many health professionals when writing of pain management.

‘The more severe and intractable the patient’s pain, the greater is the justification for risking an earlier death. Thus, the amount of opioid pain reliever that is given and the rapidity with which it is increased must be in proportion to the amount of pain and suffering. Some physicians have been reluctant to use sufficient doses of opioid pain relievers, even when their patients are dying, in part because of fears (both ethical and legal) about contributing to an earlier death. The rule of double effect has helped some physicians to overcome this hesitation. Yet other clinicians remain unwilling to prescribe sufficient doses in part because they do not distinguish morally or psychologically between actions performed with the intent to cause death and those performed with the foreseen possibility of causing death.’ (Quill, Dresser and Brock 1997, p.1769-70; See Further Discussion of PDE)
Utilising the concepts of adequacy and proportionality in making decisions about pain management prove helpful in the clinical setting and do not embroil one in the difficult task of making clear and distinct intentions that are, in fact, often unclear and ambiguous (Woods, 2007, p.40).

Adequacy and Proportionality
Palliative treatment relies on the twin concepts of adequacy and proportionality in order to try to verify the intention of a doctor or nurse and consider whether they are consciously and knowingly trying to cause the patient’s death.

Utilising these concepts, an intervention like managing a patient’s pain is justified when and if:

- the particular treatment used (type of medication and dosage) is adequate for the relief of pain in the case of this particular patient and,
- the particular treatment used is proportionate in its effect to the symptoms this particular patient is experiencing
- a patient’s pain is responsive to opiates, then the appropriate aim is to stabilize the patient on a regime that keeps them comfortable with minimum side-effects
- a patient experiences pain, while taking morphine, then the aim is to increase the dose progressively until the patient’s pain is relieved (dose titration).

With this recognised method, even a large dosage of morphine can be proportionate to a particular patient’s pain experience (Woods, 2007, p.130-131). This manner of providing pain relief contrasts starkly with cases in which patients were administered a disproportionate dose of an opiate without on-going reference to the patient’s level of comfort or tolerance for the drug. The latter would not be morally justified under the condition of proportionality of treatment to the patient’s pain. It is possible, with attention to adequacy and proportion, to ensure that a person can be kept pain-free and conscious on a dosage of morphine, which would likely be fatal to a person naïve to the drug, indicating that even a large dosage of morphine can be proportionate and therefore morally justified (Woods, 2007, p.131).
In conclusion, the ethical justifications for providing the pain relief which ran the risk of hastening Paul's death are five-fold:

a. Competence is evident: Paul was clearly competent when expressing his wishes to increase the pain medication.

b. Imminently dying: Paul was unambiguously and ‘imminently dying’ and the relief of his pain is a widely-acknowledged moral good to aim at even while recognising the prospect of hastening death.

c. Consent is given: Paul consented to this pain management decision and was clearly heard to say he wished to have an increased dose of medication administered

d. No desire to die: The case describes Paul’s love of life even as his health diminished. Paul was not seeking death and nor could he be accused of seeking ‘euthanasia’ by the back door through his request for pain management. He understood the possibility of an earlier demise as a consequence of increasing the medication dosage and yet he agreed to this. The companionship of family and clergy gave Paul solace in his dying moments (Terry et.al, 2006)

e. Adequate dosage to relieve this pain: The healthcare team attending Paul were not complacent about the increase in Paul’s dosage. They had discussed the dosage of opioids required to keep Paul comfortable though they were aware that Paul would probably suffer an earlier death. In spite of this, they believed that the increased dosage was justified.

6.3.2 Suggested Professional Responsibilities

- The healthcare team should document the series of palliative decisions taken in Paul’s case since the process and outcome proved sensitive to both patient and family needs. Included in the documentation should be Paul’s understanding and consent to the pain management recommended.

- Palliative care specialists are a necessary resource in critical care settings and, if such a specialist is lacking, a recommendation for this resource should be made a priority. The assistance of a palliative care specialist insured a compassionate, and expert response to Paul’s pain. It was adequate and proportionate to the needs of Paul.

- A provision of comfort and privacy is essential when a patient is in their dying days. Family and clergy need that space as much as the dying patient for whom noises in the environment can be especially stressful.

- It was fortunate that Paul remained conscious until near his death thus facilitating solace and companionship with the priest and family.

- When Paul dies, attention and care can be given to his partner and other family members, asking if there are other ways they might be helped at this time.
6.4 Case 4: Proper Use of PDE or Euthanasia? – R v. Cox

Reflecting on the key concepts of adequacy and proportionality can offer a health professional moral assurance or raise serious questions about legitimacy when giving large doses of opioids in the treatment of a patient’s extreme suffering and intractable pain. The following case reflects a compassion to relieve pain but at the price of a lethal injection.

R v. Cox

In 1992 Dr. Nigel Cox, a consultant rheumatologist, was convicted of attempting to murder Mrs. Lillian Boyes, one of his patients. Mrs. Boyes had been terminally ill with rheumatoid arthritis; she suffered from septicaemia and had abscesses and ulcers on her limbs. Her heart was calcified, her lungs were malfunctioning. She had gangrene and a number of fractures of the lumbar spine. There is no doubt that Mrs. Boyes was in excruciating pain. Dr. Cox had administered heroin in an effort to alleviate her suffering but to no avail. It was then that he injected her with potassium chloride and she died shortly thereafter.

Many people praised Dr. Cox for his humane act and expressed hope that they might be treated similarly by their doctors if in equally severe pain during the final stages of terminal illness. It is clear, however, that the criminal law in the UK views his behaviour quite differently since he was charged with murder and, the body having been cremated before a conclusive cause of death could be established, convicted of attempted murder.

(Edited case from Ferguson 1997, p.368)

6.4.1 Discussion 5

The case of R. v Cox [1992] is a helpful illustration to show that it is sometimes possible to have objective evidence of the intention to hasten death. As the case explains, Dr. Cox was convicted of attempted murder when his patient, Lillian Boyes, died following an injection of potassium chloride. A fundamental question that was asked at the time was: Were all other avenues of proportionate pain relief exhausted? It does not seem so.

‘Cox was convicted of attempted murder because his chosen means, potassium chloride, had no analgesic effect and had no therapeutic uses in the circumstances, thereby falling short of one of the sufficient conditions of a justified act. Dr. Cox may have tried but could not claim that potassium chloride had a double effect.’ (Ferguson, 1997, p.368)
One does not give an injection of potassium chloride to alleviate pain unless it is administered to alleviate pain by inducing death. Had Dr. Cox killed Lillian Boyes with an opiate that was given in very high doses, then it is highly unlikely that his action would have resulted in a conviction (Woods, 2007, p.130). In this case, the evidence that Dr. Cox used potassium chloride makes it clear that what he clearly intended was to relieve Lillian’s pain by means of ensuring that her life ended. (see 3rd condition of PDE)

Case 4 is a clear case of euthanasia because if the intended goal is to relieve the patient’s profound suffering, potassium chloride may work by causing death but it fails to fulfil the criteria of adequacy and proportionality which would give evidence of moral justification for the action. Potassium chloride is not an opioid for treating the suffering arising from rheumatoid arthritis.

There is a significant moral difference between ensuring that the natural process of dying is made as comfortable as possible and actively precipitating someone’s death by employing known lethal means. The former is clearly compatible with a health professional’s commitment to preserve life and relieve suffering – the latter is not.

The crux of the difference lies in the intention behind the act and use of appropriate and proportionate means consistent with that intention. It cannot be accepted as a policy guideline that doctors can consider death among their range of treatments to relieve suffering. This would make doctors equal to a profession of executioners (Thomson, 1999, p.81-82). (For a discussion of ethical and legal positions on euthanasia see Module 6, sections 7.2 and 7.3).

6.4.2 Suggested Professional Responsibilities

- The case of Lillian Boyes raises a fundamental question for discussion: Is adequate and specialist pain management available in acute care hospitals in Ireland? If not, how can a hospital address this important resource deficiency?

- Ensure that a palliative care specialist is available for consultation and advice in acute care settings where pain management is meeting with little success.

- Discuss with the palliative care specialist whether palliative sedation would be an appropriate pain remedy in the case of Mrs. Boyes. (See Case 5 following)

- In attempting to manage the pain of a patient, attention to the adequacy and proportionality principles are essential. Applying these principles requires that the healthcare team know the extent of pain suffered by the patient in order to respond adequately. Assessments need to be put in place to get to know patient’s depth of pain.

- Encourage patients not to be timid and to let health professionals know if their pain is not being relieved. Many patients fear if they speak up about their pain they may come to be known as a crank or constant complainer.
6.5 Case 5: Palliative Sedation – Soul Pain

As part of the skills and services of palliative care, health professionals need strategies for responding to the troubling problems of patients who develop intolerable suffering despite receiving excellent care. Comprehensive palliative care is highly effective but survey data show that 5% to 35% of patients, even in hospice programmes, describe their pain as severe in the last week of life, and 25% describe their shortness of breath as ‘unbearable’ (Coyle, Adelhardt, Foley et. al., 1990). Understanding each patient’s unique situation is the crux of palliative medicine and moral response.

Pain is usually understood as a sensation caused by physiological phenomena and so is deemed treatable with pharmacological agents such as opioid, hypnosis or other mechanisms. However, pain is not simply physiological. With analgesics one can relieve a great deal of pain but might not touch the ‘soul suffering’ an individual may experience. Michael Kearney understands soul pain as: ‘[t]he experience of an individual who has become disconnected and alienated from the deepest and most fundamental aspects of him or herself’ (Kearney, 1996, p.60). The holistic experience of the dying that is ‘total pain’ combines physical, emotional, spiritual and social dimensions of pain. Soul pain finds emotional expression as fear and behavioural expression as the ‘fight’ of an agitated struggle to find a way out of the awful situation. Observing a patient in this ‘total pain’ puts impossible demands on carers of patients to do something, anything: ‘Can’t you see I’m in agony?’ (Kearney, 1996, p.62).

Kearney explains that when a patient is in soul pain, this is accompanied by an all-pervading sense of emptiness, hopelessness and meaninglessness. In such situations, the clinical team may recommend ‘palliative’ or ‘terminal’ sedation – sedation to unconsciousness – until the patient dies, a decision which relieves the patient of his or her complex physical and psychological experience of the unique suffering termed ‘soul pain’.

The following case illustrates respect for the uniqueness of Maura in administering palliative sedation for her soul pain.
Maura was a music teacher in her early fifties known by all students and friends as ‘bright, brusque and breezy’. A malignant tumour invaded the nerves in her leg and was treated with radiotherapy and painkillers. Yet, this did not relieve Maura’s suffering, profound and deep soul pain. Maura was anguished, terrified, agitated and would not settle. Eventually her defences ‘cracked in an eruption of uncontrollable fear, paranoia and pain. She writhed about in her bed as she groaned, hyperventilated and cried out, wide-eyed, for someone to help.’ These symptoms were treated with a morphine infusion but no medical workup was done and no antibiotic treatment was given. As the dose of morphine was increased to try and relieve symptoms, the patient became delirious and agitated. When the dose was decreased, Maura became more lucid but was very uncomfortable. She asked the doctors and nurses to help her escape from her agony.

The team offered to sedate her to the point of unconsciousness and then withhold further treatment including intravenous fluids. The patient was reassured that the sedative dose would be increased until she appeared to be resting comfortably and that it would not be cut back until she died. The healthcare team, the patient and her family reached the consensus that this was the best of the available options. It would allow Maura to achieve the death that she saw was good for her without violating the law or forcing her to suffer unnecessarily. She was given a midazolam infusion which was titrated upward until she achieved a sedated state and was then maintained at that level. She died within 24 hours. (Edited case variation from Quill, Coombs Lee and Nunn, 2000a, p.491 and Kearney, 1996, p.22-24)

### 6.5.1 Discussion 5

Palliative sedation, also known as ‘terminal’ sedation, is sometimes provided in end-of-life care, e.g.

- in end of life weaning from ventilator support
- in the management of refractory symptoms at the end of life
- for psychological or existential suffering (also termed ‘soul pain’)

However, it is important to understand that it is not always restricted to end-of-life care. It may sometimes be used as a temporizing measure in trauma, burn, postsurgical, and intensive care.
In these cases, while patients are sedated; all other life prolonging measures are carefully maintained with a view to patients eventually recovering consciousness and recovering from their illness.

However, a small percentage of patients who are receiving care, such as Maura in Case 5, reach a point where their anguish, suffering and restlessness become severe and unremitting despite the unrestrained palliative efforts. Where the patient is close to death – a matter of hours, days or at most a few weeks – the following process is an option that is considered a last resort.

*In the context of far-advanced disease and expected death, artificial nutrition, hydration, antibiotics, mechanical ventilation and other life prolonging interventions are not instituted and are usually withdrawn if they are already in place. These measures are withheld [...] because they could prolong the dying process without contributing to the quality of the patient’s remaining life* (Quill and Byock, 2000, p.409).

Such was the decision in the case of Maura. The decision to administer palliative sedation to patients whose death is imminent is based on clinical reasons but it clearly has ethical implications.

*The question of withdrawing artificial nutrition and hydration is often difficult to address with the patient and family because nutrition has such a high symbolic value. Withholding food can be perceived as neglect, abandonment, or hastening death.* (Lesage and Portenoy, 2001, p.124)

Ethical concerns and challenges arise in cases where the clinical decision is that the patient will be sedated until his or her death. In many cases, the patient has already ceased artificial nutrition and hydration (ANH), antibiotics and other life prolonging therapies before sedation is applied (Kahn, Lazarus and Owens, 2003). In other cases, life prolonging measures may be withheld during palliative sedation. Failure to keep the reasons for a decision on sedation distinct from the reasons for ceasing all life prolonging measures can lead to concerns that the decisions taken together amount to camouflaged euthanasia or physician assisted suicide (PAS). (See discussion of euthanasia and PAS in Module 6, section 7)
The following text emphasizes the need to keep the decisions distinct:

‘[T]erminal sedation can be distinguished from euthanasia and, furthermore, is an ethical alternative to euthanasia in countries where the general ethos is against euthanasia [...] sedation ought to be considered a valid option at the end of life [...] but I believe that the distinction between sedation and euthanasia is much harder to sustain when other decisions, for example, to withhold hydration and nutrition are not considered as distinct decisions in their own right.’

(Woods, 2007, p.127)

In brief, Woods is stressing the reasoning that, when considering palliative sedation for a patient, there need to be clinical reasons why withholding other life prolonging therapies (LPTs), such as ANH, are also indicated.

Reasons for this may be that LSTs such as ANH:

• have been refused by the patient when competent and not under sedation
• are futile – may not provide any benefit for the patient and do not contribute to the quality of the patient’s remaining life
• intensify the patient’s suffering
• may prove too stressful or burdensome for the patient’s system to bear


In the two decisions, (sedation and withdrawal of LPTs), it is not only essential that clear reasons for each be thought through but the process involved in making the decisions with accompanying clinical and ethical reasons needs to be documented. The need to document decisions of this nature can contribute to clearer, more reason-based decision-making.

Palliative Sedation Remains Controversial
It is important to stress that palliative sedation still remains a highly controversial practice among acute care clinicians. Palliative care specialists are also concerned about the widening of indications that are cited for its use. The case of Maura discussed here poses one of the more problematic indications for palliative sedation: existential or soul suffering.

‘Perhaps the most controversial indication for sedation is unresolved psychosocial or existential distress. As palliative care physicians we must reflect on whether the role of medicine is to relieve all human suffering. Suffering is an essential part of the human experience and may have meaning for patients and families […] refractoriness should be determined only after repeated
evaluations by a skilled clinician who has a professional relationship with the patient. This implies that a single psychiatry consultation to rule out depression or anxiety is insufficient. Involvement of a social worker, chaplain, and ethicist, including evaluation of the family and social circumstances may also be needed before decisions are made. Existential distress is perhaps the most important place for intermittent or respite sedation: time for rest and reorganization may resolve some of the distress. (Hauser and Walsh, 2009, p.578)

Extensive on-going debate about the medical and ethical indications for palliative sedation continues. Some authors express worries that the use palliative sedation and discontinuation of ANH by a consenting, competent patient may, in effect, be physician assisted suicide. Proponents of palliative sedation continue to clarify that ‘the purpose of the medications is to render the patient unconscious to relieve suffering, not to intentionally end his or her life’ (Quill and Byock, 2000, p.561). On this understanding some commentators claim that the Principle of Double Effect would apply in the careful use of palliative sedation. (See Case 2 for a discussion of PDE)

Three features of Case 5 give evidence of moral reasoning in the clinical judgment to use palliative sedation as a last resort to ease Maura’s ‘soul pain’. Are these sufficient? Do these reasons show that, with Maura’s comprehension of and consent to palliative sedation, the case seems to be a clinical and ethically based decision to withdraw further life prolonging treatments and provide adequate pain relief?

a. Maura’s symptoms reveal genuine ‘soul pain’ – the case narrative illustrates ‘soul pain’ as it is described by palliative care physicians and patients alike (Kearney, 1996).

b. Competence to arrive at consensus: Maura appears competent and sufficiently lucid to participate in the consensus reached in conjunction with the healthcare team and her family that this method of relief from suffering is the best of the available options for her suffering even though it involves the withholding of nutrition and hydration.

c. Requesting help – exercising autonomy of choice: Some may worry that Maura’s appeal to her doctors and nurses to help her escape from her agony may be a request for assisted suicide. However this worry might be alleviated with the realisation that a competent patient in the throes of terminal illness can, with moral legitimacy, exercise their autonomy and decline life support therapies? One burning question for patients and professionals making such a decision in an Irish context is the status of nutrition and hydration – should it be considered as simply another medical treatment or should it be understood as universally obligatory basic care? (See Module 6, section 6.5 for more detailed discussion of ANH).

The European Association for Palliative Care have carried out an extensive review of the use
of palliative sedation in clinical settings (Cherny, Radbruch and the Board of the European Association for Palliative Care [EAPC], 2009). The following are only a few of the problem practices cited as cause for concern about mis-use of palliative sedation.

Problem Practices in Use of Palliative Sedation

There are a number of ways in which patient care can be undermined by the injudicious, abusive or unskilled use of sedation. There is, unfortunately, strong data indicating the prevalence of abuse but little is known about the prevalence of substandard sedation practices. The following four practices are problems in the use of palliative sedation and undermine the credibility of therapeutic effectiveness when used ethically and expertly.

Abuse of palliative sedation: This occurs when health professionals sedate patients approaching the end of life with the primary goal of hastening the patient’s death. This has been called ‘slow euthanasia’. Indeed, some physicians administer doses of medication, ostensibly to relieve symptoms, but with a covert intention to hasten death. Others, on request from patients would use palliative sedation as a method of performing assisted suicide.

Excess dosage of pain medication, for example, can compromise physiological functions such as spontaneous respiration and haemodynamic stability. These duplicitous practices represent an unacceptable and often illegal deviation from normative ethical clinical practice (Cherny et. al., 2009, p.581).

Injudicious use of palliative sedation: This occurs when sedation is applied with the intent of relieving symptoms but in clinical circumstances that are not appropriate. This means that the patient indications are inadequate to justify such a radical intervention. What accounts for injudicious use of palliative sedation?

1. Instances of inadequate patient assessment where potentially reversible causes of distress are overlooked.
2. Before resorting to sedation, there is a failure to engage with health professionals who are experts in the relief of symptoms despite their availability.
3. The situation of an overwhelmed physician resorting to sedation because he or she is fatigued and frustrated by the care of a complex symptomatic patient.
4. Situations in which the demand for sedation is generated by the patient’s family and not the patient him/herself. The family may be emotionally distressed watching the suffering of their relative (Cherny et. al., 2009, p.582).
Substandard clinical practice of palliative sedation: Examples include inadequate communication with the patient and/or family to ensure understanding, the goals of the care plan, anticipated outcomes and potential risks.

In addition are substandard clinical practices of inadequate monitoring of symptom distress or adequacy of relief; inadequate assessment of psychological, spiritual or social factors that may be contributing to the patient’s distress; use of inappropriate medications to achieve sedation (i.e., opioids). *(See under Further Discussion for several other important EAPC guidelines)*

### 6.5.2 Suggested Professional Responsibilities

- Health professionals must be carefully trained in the methods and management of palliative sedation or have a palliative care expert give advice on use for a specific patient. It is advisable to get a second opinion regarding the decision to use palliative sedation with a particular patient.

- A diagnosis of a terminal condition must be given with a life expectancy of days to weeks.

- Competent patients must give informed consent based on conversation, information and reassurance.

- A documented advance directive must be sought if the patient needing sedation lacks capacity or competence.

- In the absence of an advance directive, the patient’s family must be consulted to determine what is in the best interest of the patient. Discussion with the family should include an open discussion about the advantages and concerns associated with palliative sedation.

- Where appropriate, open discussion with family around the withholding of life prolonging therapies should take into account the emotions and religious beliefs that may underpin perspectives on these procedures.

- In sedating the patient, the family should be present if possible; nasal oxygen should be provided as well as a single room in a quiet part of the hospital *(Quill and Byock, 2000; Royal Dutch Medical Association, 2005)*.

- The reasons why a decision might be taken to discontinue life prolonging therapies if these are to accompany palliative sedation should be documented separately.

- The family should be supported in their bereavement and reassured that nothing more could be done to provide a good dying for the patient.

- The healthcare team should facilitate discussion of any member’s reluctance or queries in the use of palliative sedation.

- The European Association for Palliative Care recommended framework for the use of sedation in palliative care should be considered and reviewed.
7. Module 5 Further Discussion

7.1 The Ambiguity of Clinical Intentions in Pain Management

Palliative care consultant, Dr. Timothy Quill, has written extensively on pain management, the principle of double effect and ambiguity of intentions. Quill claims that a common belief that our intentions are always clear, uncomplicated and transparent is a serious mistake. It is a mistake especially because many doctors and nurses realise that their intentions in pain management decisions are often complicated, and are not transparent or clearly obvious to them.

Nurses and doctors may believe that the lack of clear and uncomplicated intentions might mean that, in truth, they are aiming for the death of a patient, or committing euthanasia. On the other hand, believing strongly that euthanasia is not only illegal but unethical; they may seriously under-treat pain and suffering to avoid this even when a patient is dying (Quill, 1993, p.1039). Indeed, uncertainty about intention should not discourage the potentially lethal use of drugs, provided that that use is strictly governed by what is necessary to palliate in a given case.

More than anything we may need to move away from an idealized ethical perspective which argues that intentions must be clear and distinct if we are going to be sure of our moral propriety. If we probe intentions in much of human life we find that they may be ambiguous, complex and often contradictory. It is useful to consider a quotation from Quill, on this point, because it provides food for thought, and helps tease out the complex reasons why many health professionals continue to under-treat pain and suffering. It explains the multilayered complexity of human life, the life that any person seeking to act morally must live. Quill writes of the ambiguity of intentions in treating suffering patients while urging realism in the process of moral reflection.

"Multi-layered intentions are present in most, if not all, end-of-life decisions. To understand physicians’ reluctance to stop life-sustaining treatment once it is started, or to prescribe adequate amounts of narcotics to patients who are dying and in severe pain, we would do well to look beneath the sanitized intentions espoused by many medical ethicists to the actual experience of doctors and patients.

- If we do not clarify the ethical and legal status of such actions as prescribing barbiturates to terminally ill patients, with their inherent complexities and contradictions, then most physicians will remain too fearful to help patients with these delicate deliberations.
• If we do not acknowledge the inescapable multiplicity of intentions in most double-effect situations, physicians may retreat from aggressive palliative treatment out of fear of crossing the allegedly bright line between allowing patients to die and causing their death.

• Our current ethical thinking and legal prohibitions reinforce self-deception, secrecy, isolation, and abandonment at a time when the exact opposite is needed.

• Perhaps a key to humanizing medical ethics and the law, as well as clinical medicine, lies in being more forthright and explicit about our intentions and responsibilities in working with dying patients.’ (Quill,1993, p.1040)

7.2 Ethical Concerns over the Use of Palliative Sedation
Four concerns of an ethical and clinical nature merit scrutiny when deciding on palliative sedation.

7.2.1 Fear of Euthanasia
Recall that the intent of palliative care is to relieve suffering, even if treatments for pain relief hasten death. Intent matters in law and ethics, with the rule of double effect stating that foreseeable adverse consequences of treatment are acceptable only if they are unintended, i.e., not the explicit aim and goal of the treatment. For many palliative doctors it is a matter of great importance to draw a clear distinction between palliative care and euthanasia (Douglas et. al., 2008, p.390). However, research that examines the intentions of doctors in palliative care settings is fraught with difficulties:

‘In particular, one needs to be sure that the distinction between intention and foresight has been recognized by respondents who report their own actions. Furthermore, intentions in the setting of end-of-life-care may be multiple and ambiguous, and respondents may have limited insight into their own intentions, or may recall them inaccurately, particularly in light of societal pressures that approve some intentions and disapprove of other.’


7.2.2 Suppressing Patient’s Consciousness
This concern arises in relation to the perceived importance of maintaining consciousness and awareness – even when one is suffering and dying. The question is whether it is justified to control, curtail or reduce considerably the experiences of awareness for a dying person, as happens in some cases of deep sedation. The emphasis here is on the importance of sustaining a level of mental awareness in order to allow for communication with loved ones, family or healthcare staff. On this view, the aim of maintaining a patient’s awareness to the greatest degree possible should temper when and how sedation ought to be used.
Without awareness a person cannot avail of opportunities for reconciliation. Likewise, without awareness the patient may feel that they are being abandoned (Woods, 2007, p.126; Craig, 1994).

Woods reassures on this point:

‘Even if a patient were to be deeply sedated, they would still be cared for with respect and dignity; with someone watching over them, turning them, keeping them clean, going to the bedside, quietly and discreetly, to observe and so on.’ (Woods, 2007, p.126)

In addition, for some religious believers, consciousness may be considered a necessary condition of spiritual reconciliation with oneself or one’s god. In this regard, the following statement on pain relief from a religious perspective claims that health professionals need to take special care in considering suppression of pain and consciousness through sedation.

‘Is the suppression of pain and consciousness by the use of narcotics [...] permitted by religion and morality for the doctor and patient (even at the approach of death and if one foresees that the use of narcotics will shorten life)? If no other means exist and, if in the given circumstances, does not prevent the carrying out of other religious and moral duties. Painkillers that cause unconsciousness need special consideration’ (cited in O’Rourke and Boyle, 1993, p.223).

The text concludes:
‘It is not right to deprive the dying person of consciousness without a serious reason’ (cited in O’Rourke and Boyle, 1993, p.223).

The fundamental emphasis on respecting the values of the patient when making clinical decisions arises here. Where patients either explicitly request the therapy of sedation or consent to it when it has been explained to them by a health professional that it is necessary in order to relieve suffering, anxiety and restlessness, then health professionals can proceed with confidence that it is one way that they can facilitate the autonomy and choice of the patient who is suffering.

Woods urges health professionals and families not to substitute their own values for those of a competent patient or one who has left an Advance Directive about their wishes. He claims that palliative sedation should remain a morally justified option for the patient who is competent to choose it.

‘Deliberately aiming to alter the experiences of the patient is a legitimate goal in the use of sedation [...] the possible meaning that people may find in their experiences of coping with
challenging situations is boundless. However, whatever the meaning this experience may have for a person, it is the meaning he or she alone finds in the experience that endows it with value [...] Individuals may find meaning in suffering, and the principle may be a sound one, but to claim that there is virtue in the suffering of a person if they find no meaning or value in the experience is a corruption of the virtue. The patient’s own testimony should be the main reference point when adjusting the pain relief’ (Woods, 2007, p.125).

7.2.3 Fear of the Slippery Slope

A further concern about palliative sedation is that one may too easily mount the slippery slope which involves a move from employing it as a method for alleviating the pain of those who are terminally ill to employing it in treating depressed patients or those who have simply lost meaning in life. Where some health professionals could justify its use with patients who are unambiguously dying, they could not morally defend its use for profoundly depressed patients who are not ‘terminally ill’ or near death but seek escape from their chronic and profound suffering.

This concern voices a legitimate worry about the use of palliative sedation to treat profoundly depressed patients who are not terminally ill but nevertheless seek escape from profound suffering. The concern about using palliative sedation when a person is not ‘terminally ill’ is very much debated since it is widely agreed that alleviation of suffering is one goal of medicine. If this is the case, it is not clear why such relief from suffering should be limited to the imminently dying. However, if sedation for chronic depression were considered, it is not morally justified also to discontinue all life supports unless there is clear evidence of a competent patient’s refusal of such supports.

Out of respect for patient self-determination, such discontinuation of life supports would need serious consideration. The serious problem here is that a patient who is acutely or chronically depressed may lack the capacity to decide on life prolonging treatment or palliative sedation. A decision to use alternative therapies for depression would be essential and a psychiatric consultation with the patient advised before depression is cited as a condition warranting palliative sedation.

7.3 European Association for Palliative Care Guidelines

To ensure consistency in practice and also to allow for the on-going review of pain management decisions, the European Association of Palliative Care (EAPC) published a decision-making framework in 2009. The 10-item framework incorporates an extensive literature review of the practice of palliative sedation. Expert peer review of the initial draft was invited from a wide range of palliative care clinicians both within and outside of the EAPC.
Some of the points provided in this framework are discussed above under Case 5 where palliative sedation was used. Two other significant points which are rarely stressed in such guidelines documents include the needs of carers – family and medical professionals.

### 7.3.1 Care and Informational Needs of the Patient’s Family

Families need extensive support to understand the decision-making process, and be clear about the goals and expected outcomes of palliative sedation. Identifying a family spokesperson (preferably one chosen by the patient) may help communication, especially for large, geographically scattered or conflicted families.

> ‘Without effective communication families may be left with feelings of profound confusion, guilt or remorse, which complicate their subsequent bereavement. For these reasons, evaluation and decision-making by a multi-disciplinary team skilled in palliative care is essential prior to initiating [palliative sedation]. (Hauser and Walsh, 2009, p.577).

Further advice is offered from the EAPC to improve compassionate care and attention for family of patients undergoing palliative sedation.

> ‘A patient’s family often experiences profound distress. If the patient is hospitalised, all efforts should be made to provide privacy for emotional and physical intimacy. To promote the family’s sense of well-being and peace, consideration should be given to the aesthetics of the care environment including an opportunity to sleep in the room or nearby.’

(Cherny et. al., 2009, p.587)

The health care team should counsel the family in the ways that they can continue to be of help to the patient: by being with, talking to and touching the patient, providing mouth care, managing the atmosphere of the patient’s care (providing patient’s favourite music, scents, saying prayers or reading to the patient).

Families of sedated patients need to be kept informed about the patient’s well being and what to expect. This includes appropriate notification that death is approaching and what can be expected in the dying process.
7.3.2 Care for the Health Professionals

Health professionals and healthcare staff may also express profound distress when a patient is sedated. This is particularly true if there is discord regarding the appropriateness of the intervention and in situations when the process is protracted. Staff distress can be mitigated if there is development of a culture of sensitivity to the emotional burdens involved in care. Sharing information and engaging in multidisciplinary discussions can offer the group or individuals opportunities to express their feelings. This context can be therapeutic for staff distress and address any confusion about the procedure of palliative sedation (Cherny et al., 2009, p.588).

"Staff need to develop awareness of their own preferences about care of the dying, and the potential role of frustration, sense of failure and burnout in decision-making. Individual physician person and professional factors may influence the practice of [palliative sedation], including prevalence, determination of refractoriness, level of sedation used, and drugs employed (Huaser and Walsh, 2009, p.577).

7.4 Critics and Proponents of the Principle of Double Effect (PDE)

7.4.1 Critics of the PDE

Critics have criticized the principle of double effect because:

a. The analysis of intention used in the principle is problematic and inconsistent with other analyses of human intention. According to modern psychology, human intention is ambiguous, subjective, multilayered and often contradictory. The principle of double effect does not acknowledge this complexity (Quill, 1993, p.1040; Bennett, 2001; Davis, 2001; Foot, 2001; Marquis, 2001). In addition, the PDE claims that where there are two outcomes of an action, one good and one bad, the doctor must focus on the good end that she or he intends and realise that the other bad effect is not intended but only foreseen.

Critics claim that this distinction between intended and only foreseen effects of an action is unconvincing. We cannot splice up our mental ‘intentions’ in this way. What we foresee is likely to happen must be included in our over-all intention for an action.

b. The principle is ‘absolutist’ in the rigour with which it specifies kinds of act that are ‘evil’ or ‘bad’. The evil of aiming for ‘death’ is seen to be a prohibition without exception. For some, death is not seen as evil in all circumstances.
c. The principle may be paternalistic. This is because the absolute prohibition against taking human life can be interpreted to mean that a doctor cannot accept a request from a competent, terminally ill patient who seeks to end suffering through the cessation of life prolonging therapy. This interpretation would endorse a strong form of paternalism that is difficult to harmonise with respect for patient autonomy (Quill, Dresser and Brock 1997, p.1768-1771).

7.4.2. Proponents of the PDE

a. The PDE has desirable effects on clinical conduct.

‘The principle has reassured clinicians that prescribing high-dose opioids for pain in terminally ill patients is morally permissible and that is all to the good.’

(Quill, Dresser and Brock, 1997, p.1770)

b. Theory is faulty but PDE is correct. Proponents acknowledge that PDE is based on an inadequate theory of human intention and actions. But they claim that we do not have to accept the theory of intention and action regarding foreseen but unintended consequences. Proponents believe they can concede deficiency in theory of action and yet argue that the fundamental thrust of PDE is correct: When the positive goal of alleviating human suffering, is at stake, then the obligation of the doctor is to take adequate action that is proportionate to the needs of the suffering patient. This would always assume the action is within the law of the jurisdiction of medical practice.

c. Many physicians embrace it as a better option than active euthanasia or physician-assisted suicide both of which are often motivated by poor pain relief. It is not a trivial matter that the PDE may be useful as a way of justifying adequate pain management and other palliative measures for dying patients.

d. The PDE is not perfect but it is a coherent doctrine of moral justification and, unfortunately, suffers from being misunderstood. These proponents make considerable effort to explain their position. One misunderstanding is the idea that PDE is absolutist in prohibiting some actions categorically. These proponents say that PDE does not specify what makes an immoral act immoral. Traditional teachings or ethical views have handed down certain actions as prohibited but any ethical theory that allows that there are kinds of acts which are good and bad could be consistent with the PDE and could make use of PDE (Boyle, 2001, p.7-20; Woods, 2007, p.129-135)
8. Module 5 Summary Learning Guides

8.1 Effective Pain Management is the Primary Objective in Patient Care

- Pain experience is cited in empirical studies as a central element in a ‘bad dying’, whereas successful pain relief is a primary element in a ‘good dying’.
- Unrelieved pain can cause depression and hopelessness.
- The experience of pain in illness can distract from all other factors in one’s life. Pain can diminish an individual’s capacity for clarity of understanding and the possibility of companionship.
- Pain can hinder the ability to participate in conversations about one’s treatment decisions.
- The encouragement and facilitation of patient autonomy is frustrated if pain management is not effective.

8.2 Principle of Double Effect (PDE)

- The PDE is one way for reasoning through the moral complexity of pain management.
- Accounts for actions which have two effects: one intended good effect (relief of pain) and one not specifically sought or willed (earlier death).
- An effect that might be morally wrong if caused intentionally (taking someone’s life) is permissible if foreseen but unintended.
- Human intentions are complex and ambiguous. As a result, a person cannot always be completely clear or certain about the cluster of intentions they hold when deciding on pain management methods for a patient.
- The PDE does not authorise practices such as physician-assisted suicide or euthanasia.
- The PDE helps health professionals to overcome a hesitation to prescribe a sufficient dose of pain medication for a particular patient’s suffering.
- Clinical evidence about the sincerity of one’s intentions can be facilitated if one observes the criteria of adequacy and proportionality. To be morally justified, a particular medication and dosage must be adequate for and proportional to this particular patient’s pain.
- The PDE can be a helpful tool in decision-making but it is not a moral calculus to ensure ethically correct decisions if the decision-maker is using the PDE in a cynical way.
8.3 Palliative Sedation

- Sedation to unconsciousness may be used as a temporizing measure in trauma, burn, postsurgical and intensive care.
- Called ‘terminal sedation’ by some and ‘palliative sedation’ by others, this refers to the administration of high doses of sedatives normally given to patients who are imminently dying and are not expected to recover from sedation.
- Can be indicated when a patient is suffering severe and intractable suffering often called ‘soul pain’
- Soul pain. = the experience of anxiety, restlessness and hopelessness in a person who has become disconnected and alienated from the deepest and most fundamental aspects of themselves.
- If palliative sedation for the dying patient is administered, the decision may be taken to discontinue all other life prolonging measures as well. The reasons must be documented but the central rationale is that these life support measures often do not improve the quality of the patient’s remaining life and may be more stressful than beneficial.
- Competent patients (often involving family in the conversation) may consent to palliative sedation and discontinuation of all life supports.
- Where patients lack capacity and have not left an Advanced Directive stating their wishes, the clinical staff and family must discuss the adequacy and proportionality of palliative sedation for the relief of their loved one’s pain and consider the factors that make this decision in the ‘best interests’ of the patient.
- Compassionate care and understanding for the bereaved family members remain important features in the humane use of palliative sedation.
Module 5 The Ethics of Managing Pain

9. Module 5 Activities

9.1. Review Case 1
and reflect on the experiences of Maurice with a diagnosis of cancer and suffering increasing pain.

a. What are particular features of ‘psychological pain’?

b. What measures might have been taken by health professionals to prevent this patient’s ‘anticipatory pain’?

c. Maurice explained that he attempted suicide because he dreaded the continuing intensification of pain that had already begun. What clinical evidence would you look for to validate whether, in addition, the man may be depressed and need help for that affliction?

d. The reassurance to the patient that his pain would be managed brought relief. Given that Maurice is an out-patient, how can the staff now ensure effective pain management for him?

9.2 Re-read the particulars of Case 2

a. Consider yourself the nurse or doctor in charge of Madeleine. Specifically, how would you deal with the mother’s concerns about Madeleine’s continued pain? Consider jotting down a conversation you might have with Madeleine’s mother.

b. Although Madeleine is very young, how can the health professionals try to discern her level and quality of pain? Provide a few concrete suggestions as to how you would proceed.

c. Madeleine’s mother is particularly annoyed with what she sees as an erroneous clinical focus on white cell count and further administration of chemotherapy while greatly minimising the need for effective pain management. Do you think the mother was correct and deserves to be heard? Write a few notes on how you would respond to the mother’s annoyance and concerns for her daughter’s suffering.

d. On a scale of 1-10, how would you rate the acute care hospital provisions (space, privacy, pain management, decoration etc.) for the care of seriously ill children?

9.3 Reflect back on the particulars of Case 3.
In this case, Paul is suffering from end-stage metastatic, lung cancer and the health professionals involved recommend palliative care.

a. From your experience of managing pain for patients, do you think that Paul would have had equally effective relief from his suffering if he had not chosen a palliative care approach?
b. Discuss your own experience of caring for terminally ill patients like Paul. Would you find that it is a common occurrence to have a conversation with a patient about the risk of an earlier death following adequate pain medication? Explain.

c. In situations like this case scenario, how would you go about determining the patient’s competence or capacity to consent?

d. Paul was comforted by the presence of family and clergy. Explain how you might provide solace and companionship for a patient who is not so fortunate to have this emotional and spiritual support.

9.4 Case 4

is presented as an apparently clear example of euthanasia. Consider the details of the case and wonder:

a. Considering that Dr. Cox has, with stated compassion, relieved Mrs. Boyes of excruciating suffering, what is it about the action of Dr. Cox that you think makes it morally objectionable in law? What is the law protecting here?

b. Would the Principle of Double Effect work as a moral defence in this case?

c. Do you think that Euthanasia is ever morally (if not legally) justified? Why or why not?

d. If you were the doctor or nurse in care of Mrs. Boyes, what alternative to an injection of Potassium Chloride would you have offered her to ensure pain relief?

9.5 Re-read Case 5

and reflect on the treatment offered Maura for her soul suffering.

a. Do you consider that the provision of palliative sedation was ethically warranted as a response to Maura’s request ‘to relieve her from her agony’?

b. Consider the query about whether relief of unresolved psychosocial or existential distress falls within the role of medicine. Discuss with your colleagues whether the provision of palliative sedation to Maura was warranted. Try to write down your reasons why or why not.

c. Maura exercised her autonomous request to be released from suffering by agreeing to this process of palliative sedation. With such a serious degree of suffering, how would you ensure that Maura’s capacity to make this decision is intact?

d. Discuss with your colleagues whether they think that this method for managing suffering is equivalent to physician assisted suicide? Explain.
9.6 Recall the empirical research discussed in this module where Quinlan and O’Neill document clinical and family scepticism about referring patients to palliative care.

a. What reasons would you give to explain the reluctance of health professionals to refer patients for palliative care?

b. Try and explain why some families are very reluctant to refer their loved ones for palliative care even though it would mean diminished suffering and improved quality of life?

c. Do you think this sceptical attitude toward palliative care is mistaken? If so, what are your reasons?

d. Using your creative thinking in the interest of better pain management, what would you do to try and moderate or correct this scepticism about palliative care?
10. Module 5 References and Further Reading


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