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Chapter 2

Ethics in Palliative Care

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"Should you shield the canyons from the windstorm, you would never see the true beauty of their carving".
Elizabeth Kubler Ross

Abstract

In 1959, Victor Frankl considered universal facts of life to be suffering, death and existential guilt and called it the "tragic triad". Life is suffering, as Lord Buddha concluded. Palliative care tries to reduce this suffering which increases even more near the end of life. Severe pain can compromise the quality of life. Ethicist will guard against counter phobic determination to treat pain as health care team undertreats the pain are worried about excessive sedation and concern for hastening death. Palliative care is best for controlling the symptoms in these difficult situations. Even when goals of care are so clear, still there are lots of ethical question. Most common reasons are conflicts in values between physician and patient or patient and his family. There can also be conflict in expectations. Here we have described ethical issues with ethical analysis with few common clinical scenarios to help the reader associate these in their practice.

Keywords: good death, suffering, Ulysses contract, dementia, do not attempt resuscitation (DNAR), double effect, metaphysician

1. Introduction

Medical ethics is a scholarly inquiry regarding which moral values and specific ethical principles will apply in each situation. In palliative care, the goal should be to let the patient maintain their dignity and hope while they are here alive. Afterwards, when the time comes, death should be peaceful, pain-free and without any suffering. If the patient can be surrounded by his loved ones and had time to say Good byes, it is fortunate. Most people will call this a "Good Death".

The duration of symptom management is a very important factor in patient care. Ideally, with an increase in life-span, the expectation would be a prolonged healthy life followed

by a short period of illness and quick death. Along with an increase in healthy phase, the period of the chronic disease is significantly prolonged, followed by slower death. Palliative care is offered to those whose suffering can be relieved by special care while they continue with active treatment of their disease. Palliative care does not require a life expectancy of <6 months. Hospice provides only comfort care when life expectancy is around 6 months. It all started in the 1940s, when Cecily Saunders recognized the need for a place where terminally ill patients can be cared for while maintaining their dignity, functional status, and moral uplift by living well till the time comes. In 1967, after she became a physician, she opened St Christopher Hospice [1]. In 1965, Elisabeth Kubler Ross joined the University of Chicago. In 1969 she published her book "On Death and Dying". Her passion for her work on terminally ill patients, dying, and death took her on the roller coaster ride of her career where she published many books on the topic. She wrote her first book on the mysteries of life and living in 2000 [2]. Attention to the process of dying was pioneered by Dame Saunders and Dr Ross.

2. Ethical issues in palliative care

Usually, most of the ethical inquiries of the day are resolved without going into any principle or theory of ethics. Life will be sacred for some at all cost. Others seek happiness. It is the patient's right to decide for themselves. Other persons may have value to believe the right action is the one which will bring maximum happiness for the most number of people. The sanctity of life makes it our duty to preserve and prolong life, but it cannot be absolute. Rather, it must depend on the situation. If only life preservation will remain the goal, then the suffering at the end of life will be prolonged as well. In another way, some conditions will prolong the process of dying. The principle of utility, when used, will promote happiness in as many persons as possible. It does not include health care provider's own happiness. There can be two kinds of utilitarianism in which action is judged by the principle of utility. Rule utilitarianism applies the principle of utility through a set of rules which will bring maximum overall happiness [3].

2.1. Autonomy for choice of living arrangement

After being in palliative care for a short duration, it was proposed that Mr R L move to a nursing home for continuation of pain medication and getting help in activities of daily living. He refused to go to the nursing home and requested to be discharged home. He asked his wife if she was okay with his decision of not to go to the nursing home and assured her that he would no longer be a burden to her with getting help from the home health services. That night Mr R. L. took all his pills for pain, insomnia, and anxiety along with a bottle of Tylenol. In the morning, his wife found him in deep sleep in his bed, tucked in the blanket, bible on the side table. She removed the blanket to wake him up and saw him dressed in a white shirt and black suit with socks and shoes, like he was going to church. At that moment, she realized that he has gone, indeed.

Ethical issues in this case are:

- Should a patient have control over timing of death when it is imminent anyways?
- Should we respect their choice?
- Should he go to the nursing home, which would have made everyone happy other than him?

On a cursory view, it appears that medical system failed him. Once we analyze it ethically, the patient's wishes have been respected following the principles of autonomy and dignity. Principle of justice is evident when he was treated like anyone else with care and compassion. Doctor and nurses gave their advice for him to go to the nursing home but when patient expressed that he would prefer to go home, they did not force him to go to the nursing home. It does not mean that patient will be safe or his decision is the alternative I would suggest but it is where ethics has a crucial role. This exemplifies utilitarianism as he did not spend his savings on a nursing home, making his wife happy. Since he did not have to go to a nursing home, he was happy as well. If he decided to end his life in the isolation of his room without any involvement of others, it was his choice. He did not apparently suffer and as per discussion with his wife, this was a good death for him [4].

The principle of justice proposes equal treatment and care for all those in the similar situation. The goal of palliative care is to relieve suffering. Suffering is a reaction to something which causes pain: physical, mental, emotional, or moral. The reaction depends on the person. The principle of justice demands the similar treatment of persons of similar conditions, but the ethics of palliative care permits discretion on the part of the physician, as treatment is tailored to the patient. St Augustine has described it beautifully in City of God.

> *"… though exposed to the same anguish, virtue and vice are not the same thing. For as the same fire causes gold to glow brightly, and chaff to smoke; and under the same flail the straw is beaten small, while the grain is cleansed… So material a difference does it make, not what ills are suffered, but what kind of man suffers them. For, stirred up with the same movement, mud exhales a horrible stench, and ointment emits a fragrant odor".*

Suffering in the same person can be perceived differently and cause significant challenges in management. In the following scenario, would you agree that the patient is suffering or is the longevity worth this suffering?

2.2. Silent suffering in dementia?

Mr JA had a stroke at the age of 54. For the last 11 years, having lived in a nursing facility, he has suffered more strokes and had advanced vascular dementia for last 4 years. He stopped eating, and, when fed, he would open his mouth but neither chewed nor swallowed. At that time, a discussion was held regarding artificial nutrition and hydration. The patient's Medical Power of Attorney (MPOA), his daughter, insisted on it and was not willing to consider anything further. Having a Gastric (G) tube connected to the nutrition bottle, JA could no longer control his activities as feeding had to be planned around by the nurses' schedule. In the last 4 months, he had pulled out his G tube 11 times, leaving him without food or water for hours until it could be

replaced. To prevent dehydration, he requires Intravenous (IV) fluids during these times. When a nurse comes to place the IV line, he makes it apparent that he does not want the IV placed. To prevent him from pulling the IV line, he is physically constrained by hand restraints.

The medical staff caring for him believed that the patient was suffering. He was not happy with the tube in his stomach, frequent intravenous needle placement, or his hands restraints. His daughter, who came on the weekends to see him, found him completely comfortable and saw no issues with the procedures being done. She always brought chocolate for him, which he enjoyed, and he was always happy to see her.

The ethical concerns would be:

- Was the patient suffering?
- Since he has dementia and may not be capable of informed consent, should the health care team follow his daughter's instructions?

At times, doing nothing is the best discourse, but very difficult in practice. Placing the feeding tube in this case is controversial as it can be a source of suffering, but has been necessary in sustaining the patient's life. Now, the patient can decide about their quality of life and depending on the answer, whether sustaining his life is beneficial [5].

Deciding when to give all options, regardless of benefit, and when not to offer all options is dependent on the analysis of a patient's values, living will, and the benefit/risk ratio. It also depends on whether a surrogate/health care agent is making substitutive judgment or if his/her judgment is according to selfish motives. Jay Katz mentions a case where even useful options were not presented.

"Immediately prior to our meeting, the nephrologist had examined a French peasant who lived some 40 miles outside of Paris and suffered from chronic renal failure. The condition was a rapidly progressive one and would soon lead to death if not placed on dialysis. Yet the patient was not offered this option. Instead, he was told that no medical treatment existed that would help him. When I asked the nephrologist, he reacted with surprise, like the answer was self-evident: 'To say more would have been cruel. Peasants do not adjust well to a permanent move to a large city'" [6].

Ethically speaking, to make a choice for the patient is paternalism, but the physician may justify it as his fiduciary duty to not cause mental suffering. To see the same action by various angles makes it clearer. It is possible that in a few cases, that the "doctor knows best" indeed. The autonomy of the patient will not be respected for the sake of beneficence. At many times, the treatment of a disease causes more suffering than the disease itself.

2.3. Iatrogenic pain

89-year-old JL, a man with a pressure ulcer on his sacral area and both heels require dressing at least once a day. He cries with pain whenever he is turned for dressing changes. It appears that the dressing hurts him as he can be turned other times without any outcry. The patient's life expectancy is limited as his albumin has dropped to 1.2, hemoglobin 8, and total cholesterol 92. Nursing staff feel that the patient is in pain when they do his dressings and want to

decrease the frequency of dressing. But the doctor is concerned about sepsis if he is not provided with the standard of care.

An ethics consultant or palliative care physician can conduct an interdisciplinary meeting and discuss goals of care as well as safe and judicious use of pain medications that is enough to control pain.

When a medication is given for one effect which is needed by the patient, but the dosage that is needed to produce that therapeutic effect can cause other serious effects, that is, suppression of breathing or even death, it is known as "double effect". Intention is important for the double effect to apply.

Resuscitation may not be medically indicated even though patient and MPOA have not given permission for "Do not resuscitate" orders.

2.4. Simply dead

84-year old Mrs ND had been in palliative care for 11 days with aphasia, dysphagia, and inability to turn. Otherwise, she could move in bed although too weak to stand. Physical therapy transferred her to a wheelchair where she could sit for several hours every day. She had a gastric tube, Foley catheter, and inhaled oxygen. Apparently, she suffered from hypoxic brain injury. Since she did not communication in any way, it was hard to assess her decision making capacity. Her daughter, the MPOA refused to make her Do Not Attempt Resuscitation (DNAR) as she believed that her mother will recover from this episode. This morning Mrs ND was found to be breathing rapidly with fever of 104°F on morning rounds by the nursing staff. They called 911 and transferred her to the nearest hospital. However, as she was being transported she stopped breathing. As they had already reached the emergency department, she was handed over to the ED physician who called for the code cart. She was pale and pulseless without a heartbeat and not breathing, and the pupils of both eyes were dilated and fixed. She had a fever of 104° last night prior to transfer. It appeared that she had died on the way to the hospital during transfer. What should the physician do?

Choices for the physician:

a. Declare her dead

b. She is full code, so he should try resuscitation.

c. As she is full code, she should be intubated even if there is no response.

Mrs ND could have been in a skilled nursing home and receive extensive physical therapy, but her daughter wants to keep her comfortable while getting physical therapy, allowing only as much as Mrs ND could tolerate comfortably.

Though, legally, she has the right to resuscitation unless the physician is sure of futility. In this case, calling code is okay. CPR and, if qualified, defibrillation is acceptable, but if there is no response, then intubation will not be necessary. The physician fulfills the patient's and

daughter's goal of care to keep Mrs ND comfortable by granting her a peaceful death. He did not accelerate or hasten death, but when the situation presented itself and there were no chances of recovery, there was no use of intubation or pacemaker. The physician called the chaplain and her daughter. The daughter was appreciative that the physician attended to her mother promptly and did what was best for her mother. This was a difficult decision to make, but the physician knew that the patient had all the signs of death and, given her previous brain damage, she would not tolerate this anoxia for so many minutes. Hence, he let her go peacefully. Sometimes when middle ground is chosen between paternalism and autonomy, it is known as "mutual autonomy". [7]

2.5. Ethics of dementia in palliative care

Dementia is one diagnosis that looks just right for palliative care. There are no goals left in life except to live happily till the end. Agitation or frustration can be an occasional problem when a person cannot express themselves. Many patients with dementia qualify for hospice and palliative care and in fact, improve in this nurturing environment. Sadly, only 20% of referrals to hospice/palliative care is for non-cancer patients [8]. On average, stay of patients with dementia is shorter than their cancer counterpart. Dementia is not recognized as terminal illness as the patient does not go to the doctor, patient is unaware of the problem Caretakers maintain their hygiene and keep them well fed, not an easy task.

> I want to tell you how much
>
> I miss my mother.
>
> Bits of her are still there.
>
> I miss her most when
>
> I am sitting across from her.
>
> Candy Crawley

In modern facilities, there are various activities for these patients. When person starts withdrawing from social activities, one should suspect depression or increasing neurocognitive deficits [9]. Ethics is vital for managing these patients as it is common to have a controversy over what is best for the patient.

> Time, you enjoy wasting is not a wasted time.
> Marth Troly-Curtin, Phrynette Married

Mr V was transported to geriatric nursing home as he was increasingly isolated, inactive, stayed bed-ridden, avoiding eye contact, and hardly speaking. Physical therapy tried the Merry Walker on him, and he suddenly realized that he could move on his own, making him very happy. He needed supervision while using the Merry Walker, hence he could only use it for 30–60 minutes per day. When the social worker and nurse noticed the change in Mr V's personality, they discussed the matter with visiting family members. Consequently,

his family requested that he should be permitted to use the Merry Walker for a longer duration. The concern of restraints did not bother Mr V or his family, as he feels safe in the cloth restraint which goes across his chest. Increased risk of fall while using the Merry Walker is a concern, but, as the patient is already at high fall risk, it is uncertain that the Merry Walker increases this risk. This cloth restraint is strong and cues the patient to only move forward facing. Since the family is willing to assume both the risks, is it ethical to put advanced dementia patient in a Merry Walker with group supervision and can family be permitted to assume these responsibilities?

When the clinician accepts either the patient's or health-care proxy's decision, it shows respect for the patient and the doctrine of self-determination for which Justice Cardozo wrote: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body" (1914) [10].

Here, the physician must agree to the same risk that the patient is willing to take although the physician does have the autonomy not to be forced to recommend a device in suboptimal conditions. It is of note that the therapist initiated the use of this device, and it benefitted the patient tremendously. According to ethical analysis, the benefit-risk ratio clearly tilts toward benefit; hence, the Merry Walker may be prescribed under group supervision with the consent from a surrogate to whom risks and disadvantages of the Merry Walker have been described in detail [11].

Here, many people will turn to the Law for a solution. The law appears clear and unambiguous in its answers. On the other hand, Law keeps changing with time and jurisdiction, and it has not defined all our activities as lawful or unlawful. Law can demand morally wrong actions, that is, doctors in Nazi Germany [12]. Regarding this case, at least one law suit has been filed against the Merry Walker.

Ethics consult appear unique until it is broken down into values and principles. As in this example, the ethical question is: can a surrogate consent for risk taken by the patient when he uses the device? This question was answered by court in a case of Karen B Quinlan when his adoptive parents were permitted to withdraw life support based on substitutive decision. As for the clinician's side, a person in palliative care is there for quality of life, and if the Merry Walker makes him energetic and happy without discomfort, prescribing Merry Walker with group supervision should be within the clinician's comfort zone.

While interest in caring for the dying has been increasing in the medical field, avoidance of death and dying is the norm for society in general, resulting in 29% of persons dying in the hospital and the average terminal admissions lasting 7.9 days in 2010 [8]. Focus on prolonging the life became so intense that humane physician Dr Walby had to make way for Dr House on Television.

> "When the world says, 'Give up', Hope whispers, 'Try it one more time'".
>
> Anonymous

2.6. Different set of goals

Mr L was transferred from acute care to a long-term care community center with diminished mobility. While in acute care, he was hooked up to intravenous lines and only received passive movement therapy. Active movement physical therapy was started, but the patient was not interested. After 2 weeks of physical therapy, the patient could transfer himself from the bed to wheel chair with minimal assistance. He did not start walking with a walker as he used to do before, but he was happy to move in his manual wheel chair. He showed no interest in physical therapy and was in pain during exercises. He was started on a dose of Tylenol prior to exercise time which helped, but he remained tense during exercises and walking with physical therapist. As he has not achieved his functional goal of walking with a walker, should one continue physical therapy despite his obvious dislike for it?

Palliative care provides comfort care to the patient under the principle of *Primum no nocere*. Non-maleficence is the most important principle out of four guiding principles of ethical decision making. The case of Mr L makes a case of slow improvement. If the physical therapy is continued, as it has been optimized, and the patient is in pain during therapy, there is no reason to continue physical therapy now. The counter argument to this approach is that by providing physical therapy, the outcome and expectations may be different for the provider and the patient. Small improvements in endurance where he can stand on his own by holding the side of the bed for half a minute may mean a lot to him as he can then use a bedside commode. A small step for the provider can be a big difference in quality of life for the patient. This will advocate for the continued physical therapy.

> One thing is certain and the, rest is lies.
>
> Omair

Death appears in many guises. To some, it is a relief from chronic pain and suffering. To others, it may be sudden and unexpected [13]. It could be traumatic and shocking. When activities of daily living can be performed without assistance, one need to be able to get out of bed or chair, use the toilet, bathe, groom, dress, eat, and walk. Most people will lose Independent Activities of Daily Living which are: shop, cook, do laundry for himself, maintain housekeeping, take medications for himself, make phone calls, travel, and handle his finances.

> There are all kinds of futures.
>
> There is a hoped-for future,
>
> there is a feared future,
>
> there is a predictable future,
>
> and there is an unimagined future.
>
> - Werner Erhard

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2.7. Ethics of Ulysses' contract

Mr S is 63-year-old lawyer who had been very successful in his personal life and career. He had been living with amyotrophic lateral sclerosis (ALS) for last 3 years. Three years ago, he could still walk though awkwardly, both his arms dangled with no strength. He realized that accelerated pace of ALS is going to be devastating. On his next visit to the doctor, he requested no resuscitation and no life support or sustaining treatment in any circumstances. He wanted to be sure that he would never be on respirator. His doctor suggested Ulysses contract so even if he would like to change his decision about life support, only his current wishes would be honored. S asked his doctor to help him take his life. His doctor explains the law and offered him palliative care through inpatient hospice. Even though he is not eligible in conventional sense for hospice, his doctor helps him with the admission so that he can achieve a good death prior to intense suffering and saves him from committing suicide.

> Ulysses also known as Odysseus is famous for his brilliant plan of escaping from the Sirens. Songs of the Sirens were beyond humans resolve to stay away and that's how always resulted in shipwreck at the sharp rocky island of Sirens. To save himself Ulysses asked his men to tie him to the ships mast and put wax in all the sailors' ears so that they could row but not hear. Ulysses contract is used to ensure implementation of previously carefully thought plan and not get influenced by the future weaknesses. There are many ethical questions and it should not be used widely [14].

Mr S was feeling increasing isolation, loss of interest of his treating team, and had lost all hope. He was requiring more assistance from his wife, she did it cheerfully without complaining. When they discussed what was coming, she remained optimistic. For the patient's good, he was referred early than normally indicated due to this unique situation of knowing the progression of disease. Hence, he feels lonely even when surrounded by his friends and family. The physician facilitates the transition for patient to achieve his goals.

Basic knowledge of ethics should be the requirement for all clinicians, more so for people working in an Emergency Department (ED). Though there are lots of venues to get into urgent decision making for life and death, there is nothing like a patient brought by ambulance, alone who is in respiratory failure. Patients on palliative care usually do not end up at the emergency department. On rare occasions, a doctor may ask a patient to go to ED as a terminally ill patient reflects their defeat to maintain health and by having no magic bullet to fix things, causes avoidance of the patient. Knowing the duration of suffering brings desire to do more in the physicians like in child birth, traumatic injury or post-operative pain [15].

> Choose your future and take action. Be the hammer, not the nail
>
> - Jonathan Lockwood Hui

2.8. Validity of advance directives

Mr P was brought to the emergency department by ambulance. He was 87-year-old, comes with pneumonia and end stage chronic obstructive pulmonary disease. There was a Do not intubate order, had not been touched in last 10 years. Patient was not receiving care here in last 10 years. Patient had been brought alone and patient was responding only to pain. His son, his health care agent arrived shortly. Patient was under palliative care, he had progressively worsened and was now in respiratory distress. The physician offered intubation, the patient was unable to speak and his health care agent asks for comfort care. What should the physician do?

Ethical dilemma arises when patient's autonomous decision is causing him harm. In this scenario, it may cost his life. If he had refused the use of invasive device, he should not get one. Doctors are trained to try to conquer death so it is hard on him to not intubate and save him. Physician has a decade old written directive from patient. Ethical question is, whether it is ever justifiable to overrule a patient's refusal for his own good? [16]. Son agrees with his father's wishes. Principles involved here are: Patient's self-determination, patients' bill of rights, physician's duty to do good and first do not harm. Even if physician intubated him, chances of meaningful recovery were very less. Then physician also violates patient's request as well as decision of his health care agent. If recently he changed his mind and wanted intubation, then Mr P did not get that chance. End of life issues can be complicated. Physicians are discouraged to make unilateral decisions even in complex situations or when they have irreconcilable differences with patient and/or surrogate.

Good-life till the end is good death. Death is individual. A person may just want his bed and his dog at the time of death. Another person may want to be at the beach. Yet another person may wish for a day without any pain on the day of death.

> Also, I would like a doctor who is not only talented physician, but a bit of metaphysician too. Someone who can treat body and soul.
>
> Anatole Broyard

2.9. Autonomy vs beneficence

A 47-year-old male patient requests to go home without ventilator. He has been ventilator dependent for many years. He has paralysis below T10. Now, he has decided that he does not see any benefit in prolonging life when all he can move is his upper body. Nurses tried to tell him that he will get anxious without any medication in hand, Patient was asking to do withdrawal of life support as he is reaching home, so he can die peacefully at home without any tubes. It was decided that a hospice nurse will go along with the patient and give medication according to his needs, she will be in contact with his doctor all this time. Bioethics is in agreement with achieving the patient's goals.

Pain control remains a challenge even for palliative care. It is commonly noticed that patients require higher opioid dose than their usual dose. It is ethical to give enough pain

medication to control the pain while keeping an eye for a placement making sure that intravenous line is indeed in vein and not blocked so that the dosage increase should increase the effectiveness of pain medication. Dyspnea or air hunger should be treated with anxiolytic or morphine. Again, the dosage required may be way higher on occasions, so far it is documented clearly about symptoms, and what is the goal, there is no ceiling for the dosage. If intention is to control pain and dyspnea, increased dosage of these medications may diminish respiratory drive to the point of death, this is known as double effect, not physician-assisted death.

> *"We want autonomy for ourselves and safety for those we love. That remains the main problem and paradox for the frail. Many of the things that we want for those we care about are the things that we would oppose for ourselves because they would infringe upon our sense of self"* [17].

2.10. Vegetative state and choice of surrogate decision maker

Mrs NC was an elegant mother of four, now living alone at the house since her children had moved out and her husband had died in line of duty 15 years ago working in armed forces. One day, while speaking to her daughter, she suddenly started having gurgling noises and the phone fell from her hand. Her daughter called 911 and went to emergency department. Mrs NC was breathing on her own, eyes closed, no deformity of face, laying on her back. A quick physical by the emergency physician elicited no response to cortical functions, her brain stem reflexes were present. After magnetic resonance imaging (MRI), Electroencephalogram (EEG) and vascular studies over next week by the neurologist, she was found to be in vegetative state. She had no advance directive. Having no treatment to reverse damage, palliative care was consulted. Palliative care physician arranged a multidisciplinary meeting that evening. Three children could come. They discussed the goal of care, and it was agreed that Mrs NC did not believe in life support when there are no chances of recovery. She would receive comfort care and no artificial food and water. Her eldest son who came back from his trip was shocked to see his mother just waiting to die, he demanded that everything should be done for her including gastric tube for feeding and to move her out of hospice. What should palliative care do?

If patient does not have decision making capacity the surrogate decision maker should be selected from this list in order of priority:

Health care agent or Medical power of attorney

Court appointed Guardian

Spouse

Adult Children

Parents

Adult siblings

Next close relative or friend

Minor variations can be there according to jurisdiction

Her daughter Nancy lives a block away, while her daughter Julia lives across the town but stays with her mother on weekends. Her son John lives a few miles away but he takes her for groceries, appointments, shopping, and takes her out for dinner. Her eldest son Dennis was traveling for his work at the time of his mother's admission. What should be the order of the preference? Eldest to youngest, boys first then girls or the one who does the most for their mother? The ethical answer is none of the above. All adult children have equal weightage. In the case like this when there is difference of opinion, a family meeting should be called and the question posed is what your mother would decide if she could for herself? Everyone agreed that she would not want to live like this. No change was made and the patient passed away in her sleep by the time meeting was over [10].

Most palliative care physicians handle the stress well. Occasionally, a patient comes along who requires lot more care but his suffering continues. In these cases, a physician maintains their integrity and silently continues to suffer. Moral distress is defined as "the pain or anguish effecting the mind, body or relationships in response to a situation in which the person is aware of a moral problem, acknowledges moral responsibility and makes a moral judgment about the correct action, yet as a result of real or perceived constraints, participates in perceived moral wrongdoing" [18]. Biomedical ethics protects palliative care physicians from significant moral dilemmas but adds some as well.

Clinical Scenario:

> "Student must learn that there are areas of experience where we know that uncertainty is the certainty".
>
> James B Conant [6]

Providing care to those with rare diseases which are devastating to the person and family yet do not follow typical path of morbidity and mortality. Typical markers of impending death do not appear until very late.

Under the care of Doctor Mims, Ms. SM had stayed in a mental health lock down facility for 5 weeks. **The doctor** was pleased with the control of her volatile mood, depression, and anxiety, but now calm she is focused on leaving this controlled area. Hence a palliative care consult was placed for inpatient care but was not approved. Ms SM was diagnosed with Huntington's Chorea for the last 4 years. She was doing well until last year when she started to exhibit unpredictable, unprovoked burst of aggressive behavior, limiting her choices for living. She needed strong antipsychotics to calm her down. She started to lose her balance and needed help in ADLs. Her appetite remained good and she did not lose weight. She was not meeting the criteria for palliative care and hospice. In general, indicators for imminent death are weight loss, pressure ulcers, signs of nutritional deficiency, anemia and/or uremia, which are not present in Ms. SM.

Here the issue is that this patient will benefit from comfort care early on to save suffering from the now predictable down spiral course of the disease. Huntington's Chorea is a rapidly progressive neurodegenerative disease with autosomal dominant transmission. Bioethics is

used for justice by ensuring palliative care to the individuals according to their need. A strict policy criterion does not work in all institutions or for all patients. The patient values were to maintain her dignity and independence and did not want life support if her disease advances. Concerned about the disease and with the 50% possibility of transmitting to the next generation, she did not marry and had no children. She had worked full-time in her adult life and had left her assets with her mother, showing the good relationship between the two. The criteria for palliative care in Huntington's Chorea are a little different. A patient qualifies for palliative and hospice care when they start to require:

Assistance for ambulation and other activities of daily living ADLs, like dressing

Loss of control over urination and defecation

Difficulty in communication

Despite having dementia, a person with Huntington's disease usually recognizes a familiar song, prayer, church, and minister of long duration. The focus should be at quality of life at the end stage of the disease. After a short delay, the patient was admitted to palliative care, where she stayed until her death.

Cure few, treats most, and comfort always. The goal of medicine is healing of sick. Healing includes cure of physical inflictions along with psychosocial and/or spiritual needs. The cure

Huntington's disease is an autosomal dominant disease transmitted by one of the parents. Problem has been mapped to short arm of chromosome 4, where sequence of Cytosine-Adenosine-Guanine (CAG) is repeated. Normally CAG is repeated 11–34 times, median being 19. When it is repeated 35–39, it is diagnostic of Huntington's Disease. Severity of the disease proportionately increases with the number of repeat sequence [19].

of ailment is ideal. When a cure is not possible, the physician continues to treat to minimize the impact of disease. When death is imminent, the physician comes by to assure his presence, reassure peaceful transition, to acknowledge patient's relevance in life and emphasizing his company till the end. Before the advent of clinical ethics and the expansion of bioethics, death was not talked about, as it would not happen if not mentioned [20]. Now and for the last 40 years, the patient gets to choose the type of care he wants at the end of life. The patient gets to decide which life sustaining treatment he will like if needed. Now, the presumption is that the patient understands the condition and options well enough to decide on his own [21]. Most of the patients would ask their clinicians for advice. The therapeutic relation between doctor and patient is unique and physician has a fiduciary duty to safeguard interests of his patients.

In conclusion, ethics is an integral part of end of life care, same as palliative care and hospice. Ethical scenario described above only cover few issues. One important ethical topic in palliative care is difference between withholding and withdrawal of care. Though they seem similar, in practice, it is easy not to start life support as opposed to withdrawal. Philosopher Dan Brock gives a very nice example. A man is being taken in ambulance and in one version wife reaches the Emergency department at the same time as her husband and shows do not

attempt resuscitation (DNAR) order, physician provides comfort care only. In second version, wife gets caught in traffic and gets late to emergency room, her husband is intubated at the time, she shows the same DNAR order and physician refuses to extubate him to let him die. As Brock explains: do not the very same circumstances that justified not placing the patient on ventilator now justify taking him off of it?

In writer's view, if doctor and patient will have long-term relationship, same doctor will manage inpatient and outpatient, the relationship will solve most of the problems of end of life care. Problems arise when patient has no faith in the doctor and doctor does not have a clue about patient's values. Both of these need time to develop, and time is one thing dying patient does not have.

Note the view expressed in this chapter do not represent those of US federal government or the Department of Veteran Affairs and are purely my own personal views. All cases are fictionalized, although inspired by a combination of real cases seen in clinical practice by myself or others.

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References

[1] Drought TS, Koenig BA. "Choice" in end-of-life decision making: Researching fact or fiction? Gerontologist. 2002;**42**(Spec No 3):114-128

[2] [Internet]. 2016. Available from: https://www.nhpco.org/history-hospice-care [Accessed: 2017-07-07] History of Hospice Care, National Hospice and Palliative Care Association, 3-28-2016

[3] Sugarman J, Sulmasy DP. Methods in Medical Ethics. 2nd ed. Washington, DC: Georgetown University Press; 2010;112-117

[4] Benjamin M, Curtis J. Ethics in Nursing: Cases, Principles, and Reasoning. New York: Oxford University Press, Inc.; 2010

[5] Gunderman RB. Is suffering the enemy? Hastings Center Report. 2002;**32**:40-44. DOI: 10.2307/3528523

[6] Jay Katz J. The Silent World of Doctor and Patient. Baltimore: Johns Hopkins University Press; 2002. p. 186

[7] Pellegrino ED, Thomasma DC. For the Patient's Good: The Restoration of Beneficence in Health Care. New York, Oxford University Press 1988;142-147

[8] Tang VL, French CJ, Cipher DJ, Rastogi P. Trends in hospice referral and length of stay at a veterans hospital over the past decade. The American Journal of Hospice & Palliative Care. 2013;**30**(5):432-436. DOI: 10.1177/1049909112453642

[9] Congedo M, Causarano RI, Alberti F, et al. Ethical issues in end of life treatments for patients with dementia. European Journal of Neurology. 2010;**17**(6):774-779. DOI: 10.1111/j.1468-1331.2010.02991.x

[10] Faden RR, Beauchamp T. A History and Theory of Informed Consent. Oxford: Oxford University Press; 1989. p. 123

[11] A Different Take on Walkers—Alzheimer's and Dementia [Internet]. 2011. Available from: http://www.alzheimersreadingroom.com/2011/04/different-take-on-walkers.html [Accessed: 2017-07-07]

[12] Kantor JE. Medical Ethics for Physicians-in-Training. New York City: Springer; 1989. pp. 1-6

[13] Christiaan Bernard C. Good Life Good Death: A Doctor's Case for Euthanasia and Suicide. Englewood Cliffs: Prentice Hall Trade; 1980

[14] Ulysses Contract Mindfulness Map | Putting Wisdom to Work book [Internet]. Available from: http://policypillars.com/self-help-tools/13-pillar-power-personal-growth-work-sheet.html [Accessed: 2017-07-07]

[15] Novack DH, Plumer R, Smith RL, Ochitill H, Morrow GR, Bennett JM. Changes in physicians' attitudes toward telling the cancer patient. JAMA. 1979;**241**(9):897-900

[16] Dewolf Bosek MS. When respecting patient autonomy may not be in the patient's best interest. JONA'S Healthcare Law, Ethics and Regulation. 2007;**9**(2):46-49. DOI: 10.1097/01.NHL.0000277199.78814.fb

[17] Gawande A. Being Mortal. Metropolitan Books, Henry Holt and Company, New York. 2014;p. 106

[18] Rushton CH, Kaszniak AW, Halifax JS. A framework for understanding moral distress among palliative care clinicians. Journal of Palliative Medicine. 2013;**16**(9):1074-1079. DOI: 10.1089/jpm.2012.0490

[19] Ropper A, Samuels M, Klein J. Adams and Victor's Principles of Neurology. 10th ed. New York City: McGraw-Hill Education/Medical; 2014. p. 1076

[20] Blinderman CD, Billings JA. Comfort care for patients dying in the hospital. The New England Journal of Medicine. 2015;**373**(26):2549-2561. DOI: 10.1056/NEJMra1411746

[21] Quill TE, Miller FG. Palliative Care and Ethics. USA: Oxford University Press; 2014. Difficult decisions near the very end of life, Truog Robert. pp. 188-189

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