

Ethical Considerations in End of Life Care

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Introduction

In the healthcare world, there is no situation more fraught with emotion, turmoil, and ethical angst than end of life care. Patients, families, and healthcare workers are caught up in this sea of high emotion that can sweep under even the most diligent worker. In fact, some healthcare workers suffer from depression, burnout, and compassion fatigue due to dealing with these scenarios on an all too frequent basis. Truly, death and dying are difficult for any human being to process. For healthcare workers, though, you are expected to deal with it and have a minimal reaction. Not only is that unrealistic, it is dangerous. No matter how many times you have experienced the phenomenon of death and dying in the healthcare setting, it is different every time.

Ethically, end of life issues can be a field of land mines. American culture has definite opinions on when it is okay to withdraw care and when it is not. They are even on board with assisted suicide at times, despite their religion's concrete stance against it. Most religions are staunchly against any type of suicide or anything that even resembles suicide, regardless of the suffering of the patient. In fact, some cultures find the suffering part of the karmic cycle a blessing. In other cultures, we find attitudes that vary with the US accepted norms – some even welcoming death as a wondrous transition. Grief, too, plays a factor in end of life care, and if you want to help people through their grief, you will need to reach much further than Kubler-Ross. Grief is part of the ethical process because it will help you to understand what your patients are experiencing, and it will help you understand why they are behaving the way they are. It is their behavior that brings up most of the ethical issues in end of life care.

But when it really comes down to it, healthcare workers need to know the ethical ramifications of end of life care. There are many justifications for end of life care decisions but often times there will be no perfect solution. Autonomy is often cited as an ethical touchstone for physician assisted suicide. On the other hand, non-maleficence-or do no harm- would be another point of view. End of life care brings challenges and requires difficult decisions. As a healthcare worker, you will need to provide your patients with education about their condition, support for their emotional upheaval, a culturally sensitive environment, and unconditional positive regard for their suffering. This is not as easy as it sounds.

All of the major players have weighed in on the ethics of end of life care, as well. The American Medical Association, American Nurses Association, and the National Association of Social Workers all have positions on the different aspects of end of life care, including physician assisted suicide and euthanasia. If you are a member of any of these groups, it will help you to know where your governing body stands on different end of life care issues.

Historical Perspectives on Death and Dying

Throughout history, humans have attempted to cope with death and dying to the best of their ability. Even early humans faced this unconquerable foe, and they needed ways to explain it to themselves and to others. Ethics, although a modern construction, did have a place in history, but it certainly had a different appearance than it does today. Death was much closer to people who lived before us and tough, ethical decisions did not often arise. Indeed, death was not questioned as closely, and there wasn't the time for the considerations.

Part of this had to do with the simple life expectancy of the people of the era. Since disease and war made dying young common, the question of life and death never really took the weight that it does now. However, that does not mean that people did not suffer. On the contrary, they did, but they did not make the hard choices to withdraw care that face us now. With the advent of new advances to extend life, the history of death and dying has reached a new threshold, and this impacts the ethics for caregivers, family, and patients alike.

Life Expectancy Changes through History

One of the primary tools for tracking death and dying in history is life expectancy. The ethics of dying is not quite as pressing when a person can only expect to live 40 years, and when they are ill, the medical science of the era cannot provide any care to stop the march of the disease. For instance, a white male born in the US in 1850 could expect to live to 38.3 years of age, according to Infoplease. The modern patient would be horrified by such a number, but that was the reality of the time. The ethics of death and dying in this period focused more on caring for those left behind.

As medical science improved, the life expectancy did the same. In 1900, a newborn male could live to be 48.23, and in 1920 the same newborn white male could live to be 56.34. As medical science learned to treat conditions, the life expectancy increased. In 1940 when antibiotics were first used, the life expectancy spiked to 62.81, showing that medicine does, indeed, have a powerful effect on death and dying. It then, has a powerful effect on the ethics of it, as well. The current life expectancy is 76.3 as of 2011, and this long life has changed the modern

perspective on dying. We are not close to it anymore, and we don't know how to manage it when it arises – as it always has and always will. [1]

Historical Views on Death and Dying

The medieval views about death and dying would shock the modern layperson. Since it was so prevalent and could happen at any minute, the medieval person dealt with death by preparing for the afterlife. It was important to live a good life now, to follow all of the strictures of the church, so that a good life could be had after death. This provided comfort to the living, and shaped most of how those in this period approached their own mortality. Death was nothing more than passing into God's waiting hands if the person was a good Christian. [2]

The Renaissance and Reformation, though still close to death, mark a change in the approach to death and dying. It brings the discussion into a more secularized point of view due to the latest approach of medical sciences. Although the medical technology was nowhere near that of the present, people of this time saw dying as something that possibly could be overcome for a time. In addition, the memorialization of the deceased became an important point of the post-death process. [3]

When history reached the Victorian period, death and dying hit a new high. Yes, death and dying were still common. The medical technology still didn't exist that would make the ethics of end of life care so vital, but the Victorians took mourning and death to a new level. Elaborate funeral services, expensive coffins, and long periods of mourning were just some of the mores that this era employed to remember the dead. Death was only a breath away, and those who were lost were sometimes worshiped, as evidenced by Queen Victoria's inability to let go of her husband Prince Albert when he died in 1861. [4]

As history progressed, views shifted from the religious to the secular. Although death always remained close, the memorialization of death changed until it became a sentinel event in the lives of all the person it had touched. This part of the Victorian mindset has stayed with us into the modern era and greatly affects the ethics of end of life care.

Medical Advances in Extending Life

Once we reach the modern area, medical technology takes over and completely changes how death and dying are perceived. Where once death was a close companion, it is now something novel. Where once you could expect your loved one to die young, you can expect your loved ones to live into old age. These are the medical advances in history that have changed the landscape of death, and thereby changed the ethics of end of life care.

Date	Medical Advance	Effect on Patient Care
1670	Bacteria discovered	Possibility of treating patient illness
1796	Vaccines first used	Prevented small pox
1846	First use of anesthesia	More comfortable and complex surgeries
1876	Asepsis	Patients surviving surgeries more frequently
1882	Germ theory	Patients are infected by germs and can be treated
1893	Open heart surgery	First successful in treating heart problems surgically
1928	Antibiotics	First medication to fight germs discovered
1948	Defibrillator	First time heart rhythm affect by electricity
1949	Ventilator	First time machine can breath for patient
1952	Polio vaccine	Using vaccines to combat pandemics
1953	Heart lung machine	Used to keep patients alive during open heart surgery
1960	CPR developed	Increased out of hospital survival rates

Of course, this list is not exhaustive, and the history of medicine in the 19th, 20th, and 21st centuries is well beyond the scope of this course. However, it is interesting to see how the increase in medical technology means the increase in the questions that now arise when approaching the ethics of death and dying. For instance, ventilators are often helpful in keeping patients alive, but they can do so indefinitely. It is then an ethical question as to whether this tool should be removed, what the circumstances are, and what the family wants and needs. If this technology did not exist, neither would the question, and it is the question of what to do about the ventilator that leads to the ethical debates that cause so much thought.

US Cultural Attitudes toward Death and Dying

In the modern period, with the medical technology available to patients, the questions regarding death and dying are more complicated. It is not just a question of choosing a mourning period, but now we must choose when to withdraw care, when to initiate hospice, and when everything possible has been done for a patient.

The Pew Research Center has done extensive research into the culture views of Americans on death and dying, and their statistics help to pull back the curtain on how Americans feel about death. As with all statistics, these cannot possibly represent the individual, but they can give the caregiver an overview of how an ordinary American may react when faced with the concept of death, dying, and end of life care.

However, it should be noted that the survey done by Pew is purely hypothetical. When it is the caregiver's loved one and the situation is dire and the stress is high, thoughts change. No matter

what they felt before, emotion cannot possibly fall into the statistical paradigm that gives us an overview of this complex set of ethics.

Views on Withdrawing Treatment

Most Americans have mixed views on withdrawing treatment. This means that the treatment is already in progress, such as a ventilator, and it is removed, allowing the patient to pass away naturally. About 66 percent of Americans feel that some situations may call for this, while 31 percent are of the opinion that physicians should do everything they can to save a patient's life. [5]

When considering themselves, 57 percent of Americans would want treatment withdrawn if there was no hope of recovery or if extreme pain was involved. [6] In addition, 52 percent would want care withdrawn if they were not going to get better and had to depend on someone else for help. [7] However, 35 percent would wish for the medical team to do everything possible to keep them alive, regardless of the circumstances. [8] No real pattern can be derived from these numbers because the definition of a “condition that won't get better or will cause pain” is vague. Most laypeople also do not realize what conditions can cause these symptoms and are only thinking in extreme situations – which are not the only situations that meet the definition.

Religious Impact on End of Life Care

It may be obvious to note, but end of life care is strongly affected by the religious beliefs of the persons in question. For instance, 65 percent of white Catholics would stop medical treatment for an incurable disease, compared to 72 percent of white “mainline” Protestants and 62 percent of evangelical Protestants. [9] However, that is not the whole story. Black Protestants – 61 percent – and Hispanic Catholics – 57 percent – would want all measures taken to prolong their lives, regardless of pain or prognosis. [10]

Preparing for Death

Unfortunately, not many Americans are preparing for death. Although four in 10 adults have thought about their deaths, only 27 percent have given serious thought to how the end of their lives will play out. [11] What this means for the end of life caregiver is that there may be many patients who are sick without a clue as to what they want for their deaths. This is indicative of the American cultural view of death. It is not polite conversation, and it is something that is often swept under the rug. Even when people are grievously ill, they often resist the conversation about their own deaths. This is evidenced by the fact that 22 percent of Americans over 75 have not written down or even spoken to loved ones about what their wishes are for their deaths; three in ten of these respondents describe their health as fair or poor. [12]

Some other considerations include wealth versus poverty. Those in higher economic classes tend to have more plans for their own death. Of course, older people have more concrete plans than those in younger generations. White persons are more likely to have directives than those who are black or Hispanic. Those without directives usually want everything done to save them instead of withdrawing care, and about half of adults have experienced someone in their social circle who have experienced the ethics of end of life care. [13]

Wishes Made Known

There are three general scenarios about end of life care that are usually discussed. One is to tell the doctor to stop treatment if the pain is intense or there is no cure for the disease (57 percent). The second is they would want to withdraw treatment if they became a burden on someone else (52 percent), and the third is they want care withdrawn if they are unable to perform day to day activities (46 percent). In all three scenarios, there are also percentages of respondents who would want everything done despite the case presented. [14]

Hospice Care and Who Should Decide

Two thirds of American adults say that sometimes patients should be allowed to die while three in ten feel that doctors should do everything to save a life. [15] Again, religion plays a part in deciding who should be allowed to die. White Catholics and mainline Protestants feel that most patients should be allowed to die, while black Protestants, on the majority, feel that everything should be done to save a patient. [16] Surprisingly, cost also figures into the end of life care question. About seven in ten respondents feel that medical care often “creates more problems than it solves,” strongly indicating that letting the patient die would be preferable simply from an economic standpoint. [17] However, 62 percent say that medical technology saves lives and leads to better quality of life for patients. Even these people, though, indicate there should still be a time when a patient should be allowed to die. [18] In addition, 78 percent feel the closest family member should be the one who decides if the patient should be allowed to die if the patient is unable to make the decision themselves. [19]

Multi-cultural Views on Death and Dying

Judaism

Judaism is an open religion, often comprising many beliefs. If someone identifies as Jewish, they may or may not follow all of the laws set out by the religion. For instance, some people of

the Jewish faith keep Kosher, and some choose not to. The same umbrella of thought also applies to end of life care, so it is important for the practitioner to tread carefully. One example that is completely against Judaism is assisted suicide in any and all forms. It is considered murder under any circumstances because the Jewish viewpoint is that any life, even the most minuscule part of that life, is valuable and important to cherish. This thinking also informs the rest of end of life care and can lead to ethical problems with determining when to withdraw care or compose a living will.

Judaism believes that all measures should be taken to sustain life. This means heroic measures are called for, such as antibiotics, life support, and so on, to maintain the patient's life. Again, this reflects the precious nature of life in the culture. However, when the patient is considered brain dead, it is acceptable to remove care, but determining brain death is often difficult in the view of many Jewish people. There are often treatises on the subject. Writing living wills is similarly fraught with problems because they may be applied too early or when the patient is in pain. Pain is not an acceptable reason to withdraw care, and if the patient's pain was better managed, their decision may be different. When dealing with a Jewish patient at the end of their life, it is important to remember that they may have views that conflict with orthodox traditions and that the dearness of life is the most important point to their decision making process. [20]

Islam

Islam focuses on allowing Allah to determine the time of death and discourages the patient from asking for death. In fact, it is seen as a cleansing for the patient to suffer as that washes the sins from the believer and allows them to be one with God more fully. In Islam, it is important that the family and friends of the patient visit. This is looked upon as a duty of the faithful and is said to be akin to prayer for them to visit in the mornings and stay until the evenings. Being at the deathbed is important, too, and doing good deeds for the patient is looked upon favorably as a sign of respect for the patient and for Allah.

The Interfaith Leadership Council Of Metropolitan Detroit states, "It must be understood that, as long as the heart is beating and the brain is functioning any decision taken to end one's life due to pain, suffering or other reasons is against Islamic principles and considered suicide; an act forbidden in Islam. Muslims believe that all human life is sacred and only God determines its life span." [21] For this reason, life support is only withdrawn when these two aspects of life are absent. Suicide, in this form, is strictly forbidden. Turning off life support is allowed in brain death scenarios, but ending life through the use of medications is strictly forbidden.

Hinduism

One of the primary tenets of Hinduism is karma, and this affects the overriding feelings Hindus have about suffering. Karma is the notion that suffering in this world means that the patient will be born into a better life following their death. For this reason, some patients may choose to allow themselves to suffer pain or avoid taking meals. In many cases, they will strictly refuse to take pain medications, regardless of how much pain they are experiencing, depending on how devote a Hindu they are. They may try to perform good deeds to increase their karmic standing in this life and help to make their death meaningful. It is important to respect the need for the Hindu patient to live a “good life” at the end so that their reincarnated life may be one that they are pleased with.

In end of life decisions, the eldest son is usually the one who is the decision maker. It is believed that life should not be aggressively pursued by medical means unless the person will be living a good life, full of the ability to pursue their karmic function. Hindus also do not believe in suicide as this is a “bypassing” of the karmic debt owed in this lifetime and could lead to a poor incarnation in the next life. However, younger patients are often aggressively treated because they have yet to pursue their karmic debt in this lifetime. The important thing to remember about this culture is that suffering is not considered something to avoid but something to embrace as part of dying a good death. [22]

East Asia

East Asian views on death and dying are fundamentally different from those in western culture. Whereas the west often turns to thoughts of heaven and God to ease passing, East Asian cultures often tend to turn to family. It is very important to those in the east to have a family, and not having children is problematic for this culture. In fact, a son who does not care for his aging and elderly parents is considered disrespectful to his cultural background. It is important for family members to keep memories of the deceased after their deaths and perform rituals to honor them.

Family members are encouraged to participate in the care of the dying member of the family as a show of respect. Elderly patients want to know their children and family are around them at this time, and it serves as a great comfort to them to know they will be remembered. The patient may also appear to be stoic, facing death without any emotion at all. It should also be noted that many of the East Asian religions, such as Buddhism and Taoism, are primarily atheistic, and rely on the spirits of their ancestors to usher them into their new lives. Importantly, “Eastern” and “Asian” are broad terms that comprise a large region of the world, and many religions are included in this overview. Therefore, ask questions about how your patient prefers to approach the question of death and dying before making assumptions based on their region of origin. [23]

Overview of Grief Paradigms

Psychoanalytic Grief Models

Grief, like many other psychological issues, went through its infancy period starting with Freud and psychoanalysis. Freud thought that there was a “normal” course of grief and an “abnormal” course of grief. This was built on by others in this early stage and comprises several key theories put forth by those who followed Freud’s theories, such as Erich Lindemann. It was thought that in the early stages of abnormal grief, the patient may experience:

- Somatic problems
- Obsession with the loved one
- Guilt
- Hostility
- Strained relationships
- Unexplainable behavior

In some cases, the bereaved may even show some of the symptoms of the loved one in the last stages of their life. Certain physical conditions, such as ulcerative colitis, self-destructive behavior, and depression were also part of the grief. The only cure was to release the patient from the emotional “bondage” from the deceased.

These theories were not tested. The first empirically tested theories were put forth by John Bowlby. He proposed a theory that included several steps and focused on the relative intensity of the loss. For instance, the closer the attachment to the deceased, the greater the grief experienced. The first step usually comprised some sort of shock and extreme anger or disbelief. It was thought that this was a defense mechanism against the unbelievable strain of the grief. The second stage was yearning, characterized by depression, anxiety, and sorrow. In the third stage, the bereaved experienced despair while moving to stage four where they begin to reorganize their lives. These theories led to further models as more research continued. [24]

Second Generation Models

Colin Murray Parkes, a student of Bowlby, took the same steps, but added one very important factor: the shifting nature of grief. He envisioned grief as a series of pictures that faded in and out. When the grief picture faded in, then the steps his teacher suggested would follow in a loose fashion. However, the picture would sometimes fade out again, and the patient would experience a lessened feeling of grief. These shifting patterns, in and out, are an important concept to remember with grief because it explains why so many people experience grief strongly for many years after the event.

William Worden, another second generation practitioner, described how therapists could help patients through their grief. Perhaps the single most important distinction is the shift from “grief process” to “grief tasks.” Instead of making grief a list to race through, tasks are items to work with. The first task is to accept the reality of the death, which may not even occur until well after the death has occurred. Of course, there is intellectual acceptance of the loss and emotional acceptance that is much more difficult to overcome. The second task is to work through the pain of grief, such as depression, anxiety, fear, and anger. The third task is adjusting to a reality in which the deceased is missing, including both externally and emotionally. Finally, the fourth task, added later, is to emotionally relocate the deceased and move on with life. [25]

Continuing Bonds

The theories behind grieving took another route in the 1990s with the continuing bonds paradigm. In all of the theories that came before, there was a sense that the bereaved should break ties with those they lost, that they should put them in a small box and leave them in the past. However, when the bereaved are asked about their loved ones, they often speak about them in the present tense. Instead of putting them on an emotional shelf, the relationship to the deceased seems to change and continue despite the fact that they may have been dead for years. For instance, many children who grieve for their parents still talk to them. Some talk about the deceased in the present tense. Some decide to donate money to charities in the name of the deceased or to conduct birthday parties for them every year. Instead of breaking the bonds, the bond actually continues, and in some cases, it grows. [26]

Dual Process

Another model to consider is the dual process model. In this case, it can explain why some bereaved patients can vacillate between crying uncontrollably and then become fixated on something else entirely. As the name suggests, they are experiencing two separate phases of grieving. One is the loss orientation phase in which the bereaved will demonstrate crying, suffering, and other forms of outward pain cues. The other phase is restoration orientation, and this refers to times when the bereaved seems “normal” and is focusing on caring for other items, such as money matters, funeral arrangements, and so on.

The loss orientation phase is difficult emotionally, and eventually, the bereaved “cries themselves out.” If they are in restoration orientation, that doesn’t mean that they are hiding their feelings or running from them. It may mean that they have simply not had the loss phase, and can’t take anymore at this point, or will have the loss phase in due course. It is up to the

bereaved in how they manage the shifting nature of their phases, and staying in the restoration orientation phase in public or for a while is not necessarily a red flag. [27]

Transformational Theories

The most current thinking in grief theories is perhaps the most uplifting and positive one. It is one that states that personal growth rises from the ashes of grief. When children who have lost siblings or parents are asked how the loss has impacted their lives, they respond that it has made them stronger, more loving toward their family, and that they grew up faster. Whether they wanted to or not, the grief they experienced changed their lives, and most of the time, it changed it for the better. This is where the transformational grief theories point.

When the death first occurs, there is a time of no hope, but as time moves on and the grief begins to transform, hope blossoms again. It changes the person. However, it should be noted that some people never get past their grief and never experience personal growth from the experience. It is not that the grief and death is a positive experience, though. On the contrary, the grief acts more like a conduit for continued self-exploration and personal growth that changes the person's ideas about themselves and about the world that they live in. [28]

Professional Obligations in End of Life Care

Education

The first priority for the medical professional in end of life care is education. Most patients and families are bewildered at this stage in their journey, and they need help. Of course, it is one thing to teach about advance directives, but it is infinitely more difficult when attempting to teach about withdrawing care, hospice, and right to die. You may want to devise a checklist to go over to make sure that you hit all points in the educational profile that you need to. For instance, have all family members present; explain all salient options; explain medical terminology.

When educating patients about end of life care, you will find that they may feel like you are the enemy. This may feel counterintuitive, but you are the one who is telling them that their loved one is going to pass away. Educate them, too, on the process of care, on your role, on what the next steps will be. Of course, educate them on anything that comes up, and tailor your education to the people you are speaking to. Some families may understand exactly what you are talking

about; some families may have no idea. Take time to think about how you approach education at the end of life, and be sure you organize and prioritize your care.

Emotional Support

The family and patient will need emotional support at this time, and it falls to medical professionals to give it. Depending on your role, you may be called upon to give varying degrees of emotional support. Therapists, social workers, case managers, nurses, and the like may be asked to be bedrock emotional targets for families in crisis. This can be difficult for family and caregiver alike. The most important point to remember, besides education, is presence. Being present for a family in crisis means that you are there and assisting them through the grieving process.

This is why it is so important to understand the grieving process and to apply it to the family in front of you. Even before the loved one passes away, you may see flashes of the grief cycles, such as shifting between loss phase and recovery phase. There may be shock and disbelief, or there may be something else entirely. To the point, you should be there, present, to help them through whatever emotional upheaval they present. If they need a shoulder to cry on, then you can lend them yours. If they don't need you, then that is fine, too. Always offer, though, and continue to, in case they change their minds.

Cultural Sensitivity

We all come from our own background and cultures. Nearly everyone has lost someone, and it may be tempting to tell stories about how we overcame the grief of similar losses to those in the midst of grief. Although your intentions may be good, this is not a helpful item to offer. No two people grieve the same way, and this is where a caregiver needs to be sensitive toward the people who are grieving. In the standard US culture, there are stock phrases and behaviors that are acceptable, such as hugging and crying.

However, in some cultures, these same actions are not in line with their beliefs. Although they may accept your condolences, it is much better to have a sense of what is correct in their culture. For instance, Hindus may actually have some happiness that their loved one has passed because they feel their loved one has moved onto a better life. Instead of falling back on stock phrases, learn the culture of those you are likely to deal with and act according to their wishes. Even for those that you don't know, simply stating, "I'm sorry for your loss. How can I help?" is an acceptable form of sensitivity.

Unconditional Positive Regard

Sometimes, patients and their families will say and do things that may shock and hurt you. Although you should not willfully allow these things to pass by without checking their behavior, you still need to take a stance of unconditional positive regard with those who are grieving. What does this mean? Unconditional means just that. It means that you don't base your views of the person or family on their behavior. No matter how they are acting, it doesn't change your regard of them because they are only doing what they know how to do. They are grieving the only way they know how.

Positive is probably the hardest part of the statement. It is difficult to stay positive when you find yourself confronted with a family that is causing a scene or fighting over care. Again, as the caregiver, it is your job to stay positive with them. Whether or not you personally feel they are behaving in a positive manner is another matter, but professionally, you need to give them your positive regard. You need to help them through this time, and viewing them through the lens of negativity will only make things worse for all involved.

Unconditional positive regard, then, means that you unconditionally accept the grief that your patient or family is going through. You regard them with a caring, positive nature, and play the role of the helper. There are no conditions because there are no limits to the behaviors of grief. There is only positivity because negativity will only lead to more suffering. Your regard of them in this way can make the difference between how they start the grieving process. If you approach the family with unconditional positive regard, it can help them to see that someone cares, and that can propel them down the road toward a better way to deal with their grief.

Common Statements Surrounding End of Life Care

Statements from Patients

It sometimes helps to know what sort of responses to expect from patients, families, and other healthcare workers when talking about end of life care. Patients may have the ability to speak, especially in the case of hospice, but many times they may be non-verbal. Expressing the fear of dying is quite common in patients, especially with statements like, "I don't want to die," "I don't know why this is happening to me," and "I hope that I go to heaven." However, many patients, especially those who have been dying for an extended time may express feelings of acceptance, such as "I am ready to leave when the time comes."

They may also express fear of pain, such as, "Please don't let me hurt." In this case, health care workers can provide reassurance and pain management. Patients may speak of their family, too,

worrying about how they will live without them, if they will remember them, and if they left everything in order. Fear can be the overriding emotion for the patient, but denial and acceptance are two other emotional states that may find expression as well. Some patients may lapse into a fatalistic state and say, “I just don’t care. I want to die and get it over with.” Such statements may require further evaluation and assessment by the health care team.

Statements from Families

Family members may say things that are wildly inappropriate because their fear is usually very close to the surface. They do not have the sanctuary of death to move toward, but must face a life now without their loved one. It is not uncommon to hear, “Why aren’t you doing more?”; “Is my loved one really going to die?”; and “Please help me because I can’t take this.” Although you may think your focus would be on the patient, you may find that you are helping the family through the end of life process far more. They are the ones that may not understand, and they are the ones that are usually feeling the most fear.

Like the patient, families may be very concerned with pain issues and may want to know if their loved one is suffering. It helps to assure them that they are getting the pain management they need and to demonstrate the administration of the pain medication. Another issue may be the refusal to accept that the inevitable will occur, that everything will turn out okay. It is important to help the family understand when recovery is not expected. You can provide education and facilitate discussions with the physicians. Of course, acceptance is a process and will take time. Preparation is important and even the most prepared family members will still need support when their loved one passes away.

Statements from Healthcare Workers

Healthcare workers are usually professional enough to keep their statements private and away from family and patients. However, it helps to know what your coworkers are saying to debrief with them. Perhaps you can all help each other. Some statements you may hear are: “Why doesn’t she just go already?”; “That family just doesn’t understand that we are doing everything we can.”; and “I can’t believe we are still supposed to code this patient when they are clearly dying.” It can be frustrating for a healthcare worker to assist in an end of life scenario, regardless of what position they hold. All of these statements are valid and they reflect the many emotions that workers can feel when providing end of life care.

The best choice is to let these feelings out. If they are kept in, it can lead to compassion fatigue, burnout, and depression. However, the statements should not be made in front of family or

patients, and they should not affect the care that is given to either. It seems obvious, but sometimes healthcare workers can be overheard. This is why debriefing should only happen in a secure room – not in the hallway or at the station – and should be conducted in a quiet voice. It is important for healthcare workers to be able to safely process and share feelings with one another.

Key Ethical Principles

Arguments for End of Life Care Issues

The ethical issues for and against end of life care can be argued convincingly for either side. They can apply to any type of end of life issue from creating an advanced directive to withdrawing care. The first ethical principle associated with end of life care is autonomy. Patients have a right to make care decisions about themselves, and no one should be able to tell them otherwise, regardless of the level of care they want to eliminate. A living will is an excellent tool for patient autonomy.

Another important ethical principle is justice. Should someone who is young and healthy have the same choices as someone who is on the brink of death? For instance, a younger person may choose to withdraw care if they do not wish to be in pain. An older person may ask for the same if they are in pain. Justice states that both patients have the right to ask for the same consideration.

The ethical principle of compassion is central to end of life care. No one wants to see someone suffer, and no one wants to endure suffering. Patients and families make many end of life choices including palliative care, hospice care, Do Not Resuscitate, Do Not Intubate, and more. These care decisions are often powered by a strong desire for compassionate care, comfort, and peace of mind.

Finally, honesty is another cornerstone of the ethical principles for end of life care. When pursuing advanced directives, you need to be honest about what your patient may experience. When withdrawing care, you need to be honest about what your patient will experience. You may have to be honest as to whether there is a full chance of recovery. In the end, honesty is one of the most important parts of helping a patient and a family navigate the rough waters of end of life care. If you are not honest with them, you will severely hamper their rights to make decisions and make an ethical misstep of your own. [29]

Arguments against End of Life Care Issues

Some ethical principles argue against certain end of life care practices. End of life measures may be seen to interfere with the sanctity of life, and some patients may even regard a living will as breaking with this ethic. Most religions and cultures uphold some sort of withdrawal of care, especially when “true” death has occurred. Education about the use of the directive is imperative, but the patient also has the right to autonomy. Sanctity of life, though, is an important ethical principle for both patient and caregiver alike.

Some cultures look at passive versus active dying. In our society, passive dying is the more accepted practice. Examples of passive dying would include end of life choices such as hospice care, palliative care, and withdrawal of care. Assisted suicide, on the other hand, would be an example of active dying- it hurries along the process of death- making it a more controversial practice and one that is legal in only a handful of states.

Another potentially insidious problem is the potential for abuse of power. It may be easier and less expensive to put someone who is on state assistance on hospice than to take heroic measures to save them. In similar cases, some families may even feel that the cost of care is not worth the short time their loved one may have left. This is a slippery slope and is a very real ethical dilemma for the caregiver working in end of life care. The goal is always to make decisions that are in the best interest of the patient. A team approach will help in achieving this goal.

Non-maleficence is a large part of medical ethics. Do no harm is the motto for the medical profession and must be balanced with beneficence- to do good. When withdrawing care, it can feel like doing harm. Medical professionals are trained to do everything they can to save a life. If they are told to stop, it is like throwing a switch that turns off everything they have been trained to do. This pull between non-maleficence and beneficence is a challenge for all healthcare professionals when dealing with end of life.

Finally, humans are fallible. They make mistakes. They do not always agree and they do not know all of the answers. This is one of the more difficult aspects of end of life care. The simple fact is that end of life care often brings uncertainty. When there is an end of life decision that cannot be resolved and is accompanied by persistent conflict, disagreement, or uncertainty, it is a good idea to consult your ethics committee. An ethics committee can offer recommendations and help find agreement and resolution.

Dying with Dignity and Physician Assisted Suicide

Definitions

Physician assisted suicide is an ethical dilemma for the entire medical field and society as a whole. There are arguments to be made for both sides of the issue but the reality is that the practice is not legal in most states. Some definitions are in order for both clinicians and laypeople to understand just what “assisted suicide” is and what it is not.

First, let us review what assisted suicide is not. Hospice is a practice which focuses on caring for those with a terminal illness. It focuses on making the patient comfortable and pain free rather than attempting a cure. The patient is allowed to die naturally in a pain free environment. Similarly, withdrawing care is another form of end of life care. When withdrawing care, usually one of two criteria is met: the patient is brain dead or there is no hope for the patient to recover from their injuries. In many cases, both criteria are met, and the care is withdrawn. This means that all the machines are shut off, the ventilator and feeding tube are pulled, life sustaining medications are stopped, and the patient is allowed to pass away. These practices are not considered suicide because nothing active is done to hasten the patient’s death.

The concept of physician assisted suicide is frequently misunderstood. In this scenario, the doctor gives the patient the means to end their life, and they use them. [31] Euthanasia is completely different, and it is probably what most people think about when they hear the term physician assisted suicide. It means that the doctor themselves deliver the medication that causes death to occur.

Statistics

Of course, most Americans are split on how they feel about physician assisted suicide, which is the practice of a physician supplying the medication to a patient for the purpose of ending their life. According to the Pew Research Center, 62 percent of Americans believe that people have the right to end their own lives if they are in intractable pain. [32] Only 56 percent believe that a person has a right if they have an incurable disease, and even fewer, 38 percent, believe that someone should commit suicide because life has become a burden. [33] Physician assisted suicide remains almost completely divided down the center in the opinion of Americans. [34]

Cultural Viewpoints

Although the vast majority of religions condemn any form of suicide, the percentages of the Pew survey do not necessarily bear that out. About 61 percent of white mainline Protestants are in favor of legislation of physician assisted suicide, and 55 percent of Catholics feel the same way.

[35] It comes as no surprise that two thirds of adults with no religious affiliation believe the laws should allow for this type of suicide. [36] The survey goes on to state, “However, by a margin of about two-to-one or more, black Protestants, white evangelical Protestants and Hispanic Catholics disapprove of laws that allow doctor-assisted suicide.” [37]

Checklist

When doctors are considering assisting in suicide, they may encounter strong ethical and emotional forces inside of them. In fact, all of the healthcare team involved may feel the same way. If the patient asks for this type of treatment, there is a six step checklist that can be followed to ensure that the patient knows what they are asking for before any decisions are made.

The first step is to clarify the request. Be sure that you know what the patient is asking for. They may be making an offhand comment or possibly not know what they are speaking of. In many cases, a statement like this may call for some counseling or therapy to screen for depression or some other form of mental illness before proceeding with any further step. [38]

The second step is to determine the root causes of the suffering. This can be anything from physical pain to spiritual. You can address these issues with the patient to attempt to allay what they are experiencing. For instance, if pain management is not adequate, then certainly it can be increased. If there are spiritual concerns, then perhaps talking with an elder of their faith would help them to work through some of the pain they are feeling. Please note that they can suffer on many levels, and it takes a skilled and patient caregiver to tease out the specific pain that is causing the patient to ask for such a radical action. [39] There may be practical concerns as well.

Step three is to affirm your commitment to helping the patient. No matter what they are going through assure them that you will be with them to help them through their suffering. It is an affirmation to the commitment that you will be there until the end. If you are not sure that this is ethically for you, assure the patient that you will help them with their suffering in any way that you can, including finding resources for what they need. The legal ramifications behind this decision are not supported in most states, and you will need to talk to the patient about that. [40]

The fourth step is to aggressively address all root causes of why the patient asked for this radical end to their lives. Explore physical pain, depression, anxiety, loss of control, fear of pain, and spiritual crises, and then treat them all as aggressively as possible. Do not assume that clergy is always helpful, and do not assume that you can handle this completely by yourself. Reach out to other doctors, nurses, social workers, case managers, and specialists as needed. It is important to

do a complete evaluation of the patient to find out exactly what is causing them to feel the need to die immediately. [41]

In the fifth step, you advise the patient of the legal alternatives to easing their suffering. As mentioned before, physician assisted suicide is against the law in many places. However, counseling, pain management through the use of narcotics, and hospice are all possibilities that are open to a patient who is ready to die. Many patients are unaware that healthcare providers are not legally allowed to assist in suicide. It is also important, then, to ensure that the patient does not attempt to take their life on their own. [42]

Finally, the sixth step comprises seeking counsel. Support can be sought from peers, chaplains, nurses, social workers, ethics committees, and so on. Support from others will be very important here. [43]

AMA Code of Medical Ethics regarding End of Life Care

The American Medical Association has its own code of ethics regarding how physicians ought to approach end of life care. Instead of an ethical guideline, the code offers opinions or stances, and the individual physician determines how to proceed.

Futile care is a concern that physicians must sometimes confront when providing end of life care to patients. The AMA position is that physicians must make medical decisions that are scientifically sound and medically appropriate. For the AMA, respecting autonomy does not necessarily mean pursuing a treatment merely because they have been asked. If physicians and patients are not able to agree on a plan of care after careful discussion and reassurance, physicians might consult with an ethics committee or transfer care to another physician or institution. [44]

Withdrawing treatment is another common end of life decision. The goals of the patient are an important component, and if the intervention is not furthering the patient's goals, then it can be withdrawn. Similarly, the patient is within their rights to refuse or stop any intervention, even those that may lead to death. Surrogates have this right, as well, keeping within the ethical constructs of the surrogate. The AMA states that although there may be an emotional difference between withholding and withdrawing care, there is no ethical difference. "When an intervention no longer helps to achieve the patient's goals for care or quality of life, it is ethically appropriate for physicians to withdraw it." [45]

Do not resuscitate, or DNR, orders are more common now than they were before. This means that the patient does not want to be revived should their heart stop. This may be due to a long struggle with an illness or unwillingness to sustain their life on medical support. The AMA supports the use of DNR orders as it promotes patient autonomy and self-determination. All patients have the right to refuse treatment, even if it will lead to their deaths, and a patient at risk for arrest has the right to refuse a code. If a code is in process when the information is discovered, the code should be immediately discontinued. [46] DNR orders are part of advanced directives, are signed by the physician, and are a legal document expressing these desires.

The AMA supports advance directives as an important way of promoting patient autonomy and informing healthcare workers and surrogates as to the wishes of the patient. The advance directive never takes precedent over the patient's wishes at the time, and if no directives are available, then the physician should proceed with the best clinical intervention. If directives are found later, both healthcare workers and surrogates should abide by the patient's stated wishes. [47] Hospitals are required to ask patients if they have an advanced directive or if they would like to formulate one during their stay.

Perhaps one of the most controversial parts of the AMA policy is the stance on physician assisted suicide: "Our AMA strongly opposes any bill to legalize physician-assisted suicide or euthanasia, as these practices are fundamentally inconsistent with the physician's role as healer." [48] This is rather self-explanatory and succinct, regardless of how many ethical arguments there may be for the practice by others, even those who are doctors.

Nursing Code of Ethics regarding End of Life Care

Nurses are similar to doctors in that they look to sustain life and end suffering. However, they seek to do so in a more holistic manner; they look at nutrition, family dynamics, and collaboration between all aspects of the healthcare team. Nurses are the hub through which all medical decisions pass, and this makes them vital. The American Nurse Association is the governing body of the nursing profession, and they have their own set of opinions and positions when it comes to end of life care.

The ANA's stance on end of life care is as follows:

Nurses are obliged to provide comprehensive and compassionate end-of-life care. This includes recognizing when death is near and conveying that information to families. Nurses should collaborate with other members of the health care team to ensure optimal symptom management and to provide support for the patient and family. Nurses and other health care providers have a responsibility to establish

decision-making processes that reflect physiologic realities, patient preferences, and the recognition of what, clinically, may or may not be accomplished. Establishing goals of care for this patient at this time may provide a framework for discussion about what care should be provided. This process often involves collaboration with experts in decision making, such as ethics committees or palliative care teams. [49]

As you can see, the ANA code of ethics in end of life care includes more in-depth coverage of what to do in the case of end of life eventualities. It takes into account patient preferences, but it also includes a clinical aspect, ethical questioning, and the inclusion of palliative care teams. As is common in nursing practice, the focus is on a collaborative effort between family, nurse, and healthcare team to make the best decision for the individual patient.

Like the AMA, the ANA has a strong stand on euthanasia and physician assisted suicide. The position is stated as follows:

The American Nurses Association (ANA) prohibits nurses' participation in assisted suicide and euthanasia because these acts are in direct violation of Code of Ethics for Nurses with Interpretive Statements (ANA, 2001; herein referred to as The Code), the ethical traditions and goals of the profession, and its covenant with society. Nurses have an obligation to provide humane, comprehensive, and compassionate care that respects the rights of patients but upholds the standards of the profession in the presence of chronic, debilitating illness and at end-of-life. [50]

The ANA, like the AMA, does not support this type of medical care. Instead, the nurse is encouraged to assist the patient to a peaceful, humane death with all due compassion. This is the code of the nurse, as it has been for over a century.

The ANA strongly supports the DNR, provided that the necessary directives are provided in advance. Even so, the ANA supports DNR orders when obtained by family members when the patient is unable to make the decisions themselves. Here is the official position:

Nurses must advocate for and play an active role in initiating discussions about DNR with patients, families, and members of the health care team. Provision 1.3 of the ANA Code of Ethics for Nurses (2001) states that: Nursing care is directed toward meeting the comprehensive needs of patients and their families across the continuum of care. This is particularly vital in the care of patients and families at the end of life to prevent and relieve the cascade of symptoms and suffering that are commonly associated with dying. Nurses are leaders and vigilant advocates

for the delivery of dignified and humane care. Nurses actively participate in assessing and assuring the responsible and appropriate use of interventions in order to minimize unwarranted or unwanted treatment and patient suffering (p.7). [51]

One final point of end of life care that the AMA does not mention is the specific withdrawal of nutrition and hydration. This became a large controversy with the Terry Schiavo case where nutrition was removed and the patient was allowed to die. The ANA's stance on the subject is as follows:

The American Nurses Association (ANA) believes that adults with capacity or, in the event of incapacity, their surrogates are in the best position to weigh the harms and benefits of nutrition and hydration as evaluated and discussed with them by the healthcare team. The acceptance or refusal of food and fluids, whether delivered by normal or artificial means must be respected. This belief is consistent with the ANA's expressed values and goals relative to respect for autonomy, relief of suffering and expert care at the end of life (ANA, 2001; ANA, 2010) [52]

Autonomy is the main ethical consideration in the case of withdrawal of nutrition, and the decision, according to the ANA, is the purview of the patient or surrogates. Such measures respect the patient's right to choose. Some family members worry that the patient will "starve to death," but it may be more complex than that. In fact, the patient may be perfectly comfortable without nutrition or hydration, but the decision should be theirs to make.

NASW Code of Ethics regarding End of Life Care

The National Association of Social Workers' Code of Ethics speaks to the dignity and worth of the person as a guiding principle.

Social workers respect the inherent dignity and worth of the person. Social workers treat each person in a caring and respectful fashion, mindful of individual differences and cultural and ethnic diversity. Social workers promote clients' socially responsible self-determination. Social workers seek to enhance clients' capacity and opportunity to change and to address their own needs. Social workers are cognizant of their dual responsibility to clients and to the broader society. They seek to resolve conflicts between clients' interests and the broader society's interests in a socially responsible manner consistent with the values, ethical principles, and ethical standards of the profession. [53]

Unlike the AMA and the ANA, the NASW does not take definitive positions on end of life care. Instead they offer standards that serve as a roadmap for how to proceed (NASW Standards for Social Work Practice in Palliative and End of Life Care).

End of life issues are recognized as controversial, because they reflect the varied value systems of different groups. Consequently, NASW does not take a position concerning the morality of end of life decisions, but affirms the right of the individual to determine the level of his or her care. Particular consideration should be given to special populations, such as people with mental illness, with developmental disability, individuals whose capacity or competence is questioned, children, and other groups who are vulnerable to coercion or who lack decisional capacity. [54]

With compassion and an eye toward protecting those who may be harmed, the social work role is to support the client in determining his /her own needs and care.

Compassion, self-determination, and dignity are important values. “Social workers in palliative and end of life care shall demonstrate an attitude of compassion and sensitivity to clients, respecting clients’ rights to self-determination and dignity. Social workers shall be aware of their own beliefs, values, and feelings and how their personal self may influence their practice.” [55]

In addition, the social worker is an advocate. “The social worker shall advocate for the needs, decisions, and rights of clients in palliative and end of life care. The social worker shall engage in social and political action that seeks to ensure that people have equal access to resources to meet their biopsychosocial needs in palliative and end of life care.” [56]

Finally, social workers work to enhance quality of life- the nature of which, of course, is determined by the client.

Social workers are concerned with enhancing quality of life and promoting well-being for individuals, families (defined broadly), and caregivers. When confronting issues related to palliative and end of life care, social workers have a multidimensional role as clinicians, educators, researchers, advocates, and community leaders. When confronting ethical dilemmas in palliative and end of life care, social workers can draw on the principle of client self-determination in matters where clients or their proxies are faced with such issues (National Association of Social Workers, 2003). [57]

Conclusion

End of life care is not a simple subject. It is complicated by the increase in life expectancy, our cultural attitudes toward death, and the ethics that now come with this medical power we now possess. What will we do with it? Some patients do not want to endure the medical machine, and we allow them certain “rights” to escape it. Healthcare currently allows for DNR orders, advanced directives, hospice, and withdrawal of care. Some would argue that physician assisted suicide should be included in that list because it is like the others. The debate will rage on.

In the end, it should be about the will and the needs of the patient. Patient goals, as the AMA speaks of, are the most important things to consider. What are the goals for this patient or this family? What are my goals for this patient or this family? Sometimes, the only thing you can do is to help them grieve, but you can also have goals of teaching them about the condition and helping them with the transition into a new type of normal for them.

Whatever your place in the great purview of the healthcare realm, you will run across end of life issues. They are inevitable – as are the questions that surround them. Understanding the ethics surrounding end of life care is a start, but it is only a start. Now, you have to examine yourself and ask yourself if you can help patients and families through end of life care. Once you know yourself, you can provide the best care possible. And that has been the goal from the start.

Footnotes

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About the Author

Lynda Lampert

Thanks for taking an interest in my work.

I am a registered nurse, and I graduated in 2007 from Mercyhurst Northeast in northern Pennsylvania. I was quickly hired by the largest hospital in the area, and I began working on a telemetry floor. However, we took care of many other patients than simply those that needed their heart monitored. The most common type of patient we had was post open heart surgery patients, but we had a great deal of post gastric bypass, as well. In general, we took mostly surgical patients, but we also took anyone who needed telemetry. It was a great place to learn.

At some point, I needed a break, so I moved to the intensive care unit. I saw a lot of patients there — too many to name — and eventually went back to my old telemetry unit.

In 2010, I decided that I wanted to focus on my life long passion of writing, and once I could support myself, I left nursing for the world of freelance medical writing. I have written for Minority Nurse, Mighty Nurse, Allnurses.com, Livestrong, Scrubs magazine, Ausmed Blog, Neuroaid Stroke Blog, and various doctor, clinic, and hospital websites. I use my nursing knowledge to both help nurses and to educate patients. It combines both my love of nursing with my passion for writing.

I have written on back pain, stem cell research, endoscopic care for professionals, chronic pain, senior care, ACLS for professionals, patient information sheets, clinical research projects for professionals, vaccines, mental health, issues in nursing, and many other subjects.

Resources:

NASW Code of Ethics

<http://www.socialworkers.org/pubs/Code/code.asp?print=1&>

NASW Standards for Social Work Practice in Palliative and End of Life Care

<https://www.socialworkers.org/practice/standards/Palliative.asp>

ANA Code of Ethics

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AMA Code of Ethics

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Chapter 5 Opinions on Caring for Patients at the End of Life

<https://www.ama-assn.org/sites/default/files/media-browser/code-of-medical-ethics-chapter-5.pdf>