

GROUP 3 PRESENTATION ON THE TOPIC QUALITY OF LIFE

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DEPARTMENT: NURSING
SCIENCE

MATRIC NUMBER: 17/
MHS02/068

COURSE: ETHICS AND MEDICAL
PHILOSOPHY

COURSE CODE: PHI 210

DATE: 23/04/2020

TO BE SUBMITTED TO DR.
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1. **OVERVIEW**

Quality of life has so many different meanings as we will see as we move on, but most medical ethical philosophers stated the different between quality of life and sanctity of life in which they said quality of life may be defined as a multidimensional constructs that include performance and enjoyment of social roles, physical health, intellectual functioning, emotional state and

life satisfaction while by the term sanctity, they mean that human life represents the highest value that preserved.

Most people; no matter the level and frequency of pain they experience, they irrationally choose it over death. Some have a very low pain threshold while others can handle it to some extent. Christians view this differently; they see pain as something that is temporal and inevitable for the testing of their faith and also a virtue. No matter the kind of pain they face, they will choose it over death hundreds of times. It goes same for the non- religious. Some people experience very severe and extreme amounts of pain as a result of their illness yet, they prefer and choose to remain alive and conscious than die and forgo the pain. Terminally ill patients are trapped in this dilemma as well. The use of life support or

extension is not new anymore. For example patients who suffers from a stage four breast cancer and does not have any hope of living as preparing for death is the only alternative, still want to be placed on hospice care despite the hopelessness. They are fully aware of the kind of pain they will face and how they will end up dying in the nearest future yet, they want to go through it and endure the pain because they want to live as much as they can.

2. DEFINITION

MEANING: When defined as a state of satisfaction, quality of life expresses a value judgment: The experience of living as a whole or in some aspect, is judged to be good or bad, better or worse. In recent years, efforts have been made to develop measures of quality of life that can be used to give some empirical basis to this

valid judgment and to evaluate outcome of clinical interventions. **DEFINITION:** Quality of life maybe defined as a multidimensional construct that includes performance and enjoyment of social roles, physical health, intellectual functioning, emotional state, and life satisfaction or wellbeing.

3. DIVERGENT EVALUATION OF QUALITY OF LIFE

The evaluation of quality of life is so subjective; observers will rate certain forms of living quite differently. This diversity gives rise to several common major problems in clinical ethics:

1. Lack of understanding about the patient's own values
2. Divergence between physicians assessment of their patient's quality of life and the assessment made by patients themselves
3. Bias and discrimination that

negatively affect the physician's dedication to the patient's welfare

4. The introduction of social worth criteria into quality of life judgments.

Studies have shown physician's consistently rate their patient's quality of life lower than to the patient themselves. Also in another study, physician and patients were asked independently to evaluate living with certain chronic conditions. Physician judged life with these conditions to be less tolerable than did the patients who suffered them. Physician based their assessments primarily on disease conditions, whereas patients took into account nonmedical factors, such as interpersonal relationships, finances and social conditions. Also, studies have shown that clinician's quality of life assessments strongly influence clinical decisions such as those

about resuscitation or forgoing life support.

4. ENHANCEMENT MEDICINE OF QUALITY OF LIFE

Medicines have two different capabilities, there's enhancement and treatment, enhancement augments the already normal psychological, physical and physiological characteristic beyond the normal range and it isn't initiated because of an obvious psychological, physical or physiological deficit but rather it satisfies the desire of individuals whereas, treatment is the reverse (initiated because of an obvious and medically proven deficit). There is a thin line in the distinction between treatment and enhancement medicines because they are both medically proven and they improve the quality of life. But enhancement medicines satisfies individual desires: cosmetic surgery for

individual who desire a more attractive appearance, growth hormone for individuals who are short and so on. Therefore ethical questions have been raised and it's seen as unfair to others who do not use these enhancement medicines or cannot afford them even if they desire them.

Though enhancement medicines is now a part of medical practice, practitioner should be aware that most enhancement medicines are on the fringe of ethical goals of medicine and may cause negative and personal consequences.

5. COMPROMISED QUALITY OF LIFE AND LIFE SUSTAINING INTERVENTION

Quality of life can be compromised in various ways and it is important to identify these ways as well as the relationship between quality of life evaluation and the use of life sustaining treatment in order to be able to

answer the questions often raised at times when patients are seriously ill and receiving intensive life sustaining treatment. There are three different ways in which compromised quality of life appears in clinical ethics and they are:

1. Restricted quality of life
2. Severely diminished quality of life and
3. Profoundly diminished quality of life

RESTRICTED QUALITY OF LIFE: It describes a situation in which a person suffers from severe deficits of physical or mental health. Their ability to perform one or more common human activities is restricted and this causes the person with the deficit or an observer to form an opinion about the worth of a life restricted in that manner. Opinions of the person living the life may differ from that of the observer. It is one

of the goals of medicine to support and enhance restricted quality of life. For example, Ms. Cope, a diabetic patient who has multiple medical problems considers her life, although restricted to be valuable and worthwhile, whereas some observers may judge otherwise.

SEVERELY DIMINISHED QUALITY OF LIFE: It describes a form of life in which a person's general physical condition has seriously and irreversibly deteriorated, whose range of function is greatly limited, whose ability to communicate with others is minimal and who may be suffering discomfort and pain. They often need life-sustaining interventions. The ethical question is whether the fact that the patient has a severely diminished quality of life makes it ethically permissible to discontinue life-supporting interventions. An example is the

case of Mrs. A.W., a 34-year-old woman, married with three children, and has had a history of scleroderma and ischemic ulcerations of fingers and toes. She is admitted to the hospital for treatment of renal failure. The big toe of her right foot and several fingers of her left hand became gangrenous. Several days later she consents to amputation of the right foot and the thumb and first finger of her left hand. After surgery, she is alternately obtunded and confused. She develops pneumonia and is placed on a respirator. The remaining fingers of her left hand become gangrenous, and more extensive amputation is required. Her renal condition worsens, and it is now necessary to consider initiating dialysis. The attending physician says, "How could anyone want to live a life of such terrible quality?" He asks himself whether dialysis should be

withheld and whether the respirator should be discontinued.

In this case, the severe physical deficits and problems of rehabilitation faced by her evoke in the observer an assessment that "No one would want to live that way." This, of course, cannot be verified by Mrs. A.W. at this time. She has a progressive disease with its associated problems. Many of these problems are susceptible to effective medical treatment and rehabilitation. In addition, she herself has consented to the initial amputations, suggesting her willingness to live with these deficits. Finally, her vital personality before her surgery suggested to the staff that she had the ability to cope with rehabilitation and the difficulties of subsequent life. Even though, at the time of her hospitalization, she seems to some observers to

have severely diminished quality of life, Mrs. A.W. should be viewed as a person with restricted quality of life.

In a case like this, it is ethically obligatory to continue to treat Mrs. A.W. Significant medical goals can still be attained and, although her current preferences cannot be ascertained, it can be presumed that she favors continued treatment. Many persons do live successfully and happily with such severe restrictions.

PROFOUNDLY DIMINISHED QUALITY OF LIFE: It is an appropriate objective description of the situation in which patient suffers extreme physical debilitation together with apparently complete and irreversible loss of sensor and intellectual activity. This judgment cannot result from personal evaluation, because any person in this situation lacks the ability to

perceive, understand, and evaluate his or her state. For instance, a patient in a vegetative state has no ability to determine his line of care or the actions to be taken.

6. PAIN RELIEF FOR TERMINALLY ILL PATIENT

Definition: A terminal illness is defined as a life limiting disease with an irreversible decline and an expected survival of months or less. One of the main concerns in these patients is pain which is a cardinal indicator of their quality of life. Unrelieved pain continues to be an important public health issue worldwide, despite the recommendations for adequate pain control in the World Health Organization (WHO) guidelines.

TOOL

The tools to grade pain severity is the Brief Pain Inventory Short Form (BPI-SF). The Pain

Management Indeed (PMI) is a well validated tool for assessing the adequacy of pain control. The BPI-SF measures the presence, the location and the severity of pain. The pain severity was determined as none, mild, moderate, or severe with scores of 0, 1, 2, and 3 respectively. 0 which means no pain and 10 being the worst pain imagined, 1-4 is mild, 5 - 6 is moderate, 7 - 10 is severe pain. The analgesic drug therapy score was determined for each patient according to the most patent are used, based on the WHO ladder of no pain with; 0- no analgesic drug, 1- non - opioid, 2- weak opioid, and 3- strong opioid.

PREVALNENCE OF END OF THE PAIN.

Pain at the end of life is most often equated with the medical consequence of significant illness such as cancer, late HIV disease,

but it occurs not simply because of the underlying diagnosis, but rather as a consequence of the underlying pathology.

CARE SETTING AT THE END OF LIFE.

The availability of resources, and the level of expertise of the care provides influence pain management at the end of life. People have the opportunity to receive pain management services at the end of life but only 35% utilize their benefit with a median length of stay of about 3 weeks.

PAIN ASSESSMENT IN ADVANCED DISEASE.

Pain should be assessed utilizing a thorough pain assessment including location, duration, onset, characteristic, severity, alleviating/ relieving factors and associated mechanisms should direct appropriate treatment. It is

not appropriate for someone else to know the quality of pain another person feels. But they can assist with the patient assessment when they cannot give self-report. But if a patient is unable to be assessed due to cognitive impairment, type clinicians should ask themselves if they would be in pain in this situation. If the answer is YES or of the condition is known to cause pain, it is best to assume that pain is present and should be treated accordingly.

PHARMACOTHERAPY FOR PAIN IN ADVANCED DISEASE AND AT THE END OF LIFE.

Adjuvant analgesics are routinely used in pain management for many types of pain. The commonly used agents like antidepressant, and anticonvulsants are generally not available as intravenous preparation and thus potentially

limit their use at the end of life. Opioids are the principal class of analgesics used at the end of life because of their potency concomitant, mild sedative and antiemetic properties and ability to be administered by multiple routes. Opioids therapy fortunately provides adequate pain relief for greater than three quarters of patients with cancer pain. Examples of Opioids used in end-of-life setting except meperidine includes a) Morphine b) Fentanyl c) Hydromorphone d) Methadone e) Oxycodone. Meperidine is not included due to the accumulation of its metabolite normeperidine which is not reversed by naloxone and produces neurotoxicity.

ROUTE OF ADMINISTRATION.

For those able to swallow and for whom pain can be controlled the preferred routes for administration of Opioids are oral,

buccal and sublingual. Therefore opioid administration may become necessary through rotation to transdermal, rectal, vaginal, and intravenous and neuroaxial when a disease progress and pain increases.

7. MEDICALLY ASSISTED DYING

Some patients conclude that the quality of their life is so diminished that life is no longer worth living. People who come to this conclusion are usually terminally ill, having unrelieved pain or suffering or consider themselves a burden on others and are usually under the care of a physician. It may occur to them to ask their physician to help them die quickly and painlessly.

EUTHANASIA

Euthanasia means "good health". Medically, it implies that the doctor assure that his patient dies as peacefully and

comfortably as possible. Direct killing was unacceptable. Later the term was used to describe "mercy killing" which means killing a sufferer to relieve pain, either by a physician or a compassionate party. Distinctions were made between voluntary, non-voluntary and involuntary euthanasia.

- Voluntary euthanasia described situations in which the patient consciously and deliberately requested death.

- Non-voluntary euthanasia described situations in which the patient makes no request with no capacity of making the decision.

- Involuntary euthanasia described situations in which patients were killed against their wishes.

Involuntary has been condemned by commentators, voluntary is controversial, but has been defended by commentators, non-voluntary has been criticized by

most commentators.

Today, voluntary euthanasia is highly debated and considered illegal taking of human life in American law, and in all ethics statements of medical organizations, it is considered unethical behavior.

PHYSICIAN ASSISTED DYING

The physician's role in traditional discussions was generally administration of lethal drug, usually by injection. In more recent debates, the role is legalization of physician's prescription of a drug that the patient may take to bring death.

Example; A patient is dying from cancer and suffering is intense.

The patient requests the physician to prescribe medication to end his/her life, to give him/her instructions on appropriate dosage and administration and to be present when he/she takes the medication to end his/her life.

ETHICAL ARGUMENTS

1. The dedication of medical profession to the welfare of the patient and promotion of health might be seriously undermined in the eyes of the public and the patient by participation of physicians in the death of the very ill, even of this who request it.

2. Medical ethics has traditionally emphasized the savings and preservation of life has repudiated the direct taking of life. The Hippocrates oath says 'I will not administer a deadly poison to any one when asked to do so nor suggest such a course'. These ancient prohibition seems directly aimed and medical workers-assisted dying.

Contemporary organized medicine reaffirms this tradition.

3. Request of swift death are often made in circumstances of extreme distress, which may be alleviated by skillful pain management and other positive

interventions such as those employed in hospice care, similarly, such request may manifest a treatable depression

4. They involve of a medical worker as a prescribed and not an administrator of lethal intervention should be equally objectionable.

8. CARE OF THE DYING PATIENT

Dying patients are patients that are very close to death, and exhibit many signs and symptoms of near-death. For instance, actively dying patients are often times unresponsive, and their blood pressure often drops significantly.

Comfort care is an essential part of medical care at the end of life. It is care that helps or soothes a person who is dying. The goals are to prevent or relieve suffering as much as possible

and to in some people want to be surrounded by family and friends; others want to be alone while some, oft do not even get to choose. But, avoiding suffering, having your end-of-life wishes followed, and being treated with respect while dying are common hopes.

Ideally, people who are dying need care in four areas—physical comfort, mental and emotional needs, spiritual issues, and practical tasks. Also, their families need support as well. Although everyone dies, each loss is personally felt by those close to the one who has died.

End of-life care is the term used to describe the support and medical care given during the time surrounding death. Such care does not happen only in the moments before breathing ceases and the heart stops beating. Older people often live with one or more chronic illnesses

and need a lot of care for days, weeks, and even months before death.

Ways of caring for a dying patient includes the following:

1) Providing physical comfort:

There are ways to make a person who is dying more comfortable.

Discomfort can come from a variety of problems. For each, there are things you or a healthcare provider can do, depending on the cause. For example, a dying person can be uncomfortable because of:

I) Pain

II) Breathing problems

III) Skin irritation

IIII) Digestive problems

V) Temperature sensitivity

VI) Fatigue

It is our duty as a health care professional to ensure that our patient is not affected or is relieved by the above mentioned so as to provide maximum physical comfort to the patient.

Pain killers or opioids should be administered to the patient when he or she is in pain to relieve pain as pain cannot be easily cured but relieved. This should be done effectively because pain can cause the patient to have mood swings or depressed.

The patient may experience breathing problems such as dyspnea (shortness of breath) or death rattle (very noisy breathing) which is common during the end life cycle of a patient. The doctor or nurse should assist in raising the head of the bed, opening a window, using a humidifier, or having a fan circulating air in the room. Sometimes, morphine or other pain medications can help relieve the sense of breathlessness.

Skin problems can be very uncomfortable. With age, skin naturally becomes drier and more fragile, so it is important to take

extra care with an older person's skin. Gently applying alcohol-free lotion can relieve dry skin and be soothing. Also, pressure sore complication may arise from constant sitting or lying down position without movement. The patient should be turned from side to back and to the other side every few hours may help prevent bed sores. Try putting a foam pad under an area like a heel or elbow to raise it off the bed and reduce pressure. Ask if a special mattress or chair cushion might also help. Keeping the skin clean and moisturized is always important.

Digestive problems. Nausea, vomiting, constipation, and loss of appetite are common issues at the end of life. Medicines that can control nausea or vomiting or relieve constipation, should be administered to the patient to help reduce the symptoms.

Temperature sensitivity.

People who are dying may not be able to tell you that they are too hot or too cold, so watch for clues. For example, someone who is too warm might repeatedly try to remove a blanket. You can take off the blanket and try a cool cloth on his or her head. If a person is hunching his or her shoulders, pulling the covers up, or even shivering—those could be signs of cold. Make sure there is no draft, raise the heat, and add another blanket. Avoid electric blankets because they can get too hot.

Fatigue. It is common for people nearing the end of life to feel tired and have little or no energy. Keep activities simple. For example, a bedside commode can be used instead of walking to the bathroom. A shower stool can save a person's energy, as can switching to sponging off in bed.

2) Managing mental and

emotional needs: Someone who is alert near the end of life might understandably feel depressed or anxious. It is important to treat emotional pain and suffering.

Encouraging conversations about feelings might help. A dying person may also have some specific fears and concerns. He or she may fear the unknown or worry about those left behind.

Some people are afraid of being alone at the very end. This feeling can be made worse by the understandable reactions of family, friends, and even the medical team. The nurse should indulge in the following:

I) The simple act of physical contact: holding hands, a touch, or a gentle massage—can make a person feel connected to those he or she loves

II) Try to set a comforting mood. Remember that listening and being present can make a difference.

III) Some medical experts have said that when death is very near, music at a low volume and soft lighting are soothing. In fact, near the end of life, music therapy might improve mood, help with relaxation, and lessen pain.

Listening to music might also evoke memories those present can share.

3) Spiritual needs at the end of life : People nearing the end of life may have spiritual needs as important as their physical concerns. Spiritual needs include:
I) finding meaning in one's life and ending disagreements with others, if possible. The dying person might find peace by resolving unsettled issues with friends or family. Visits from a social worker or a counselor may also help.

II) Many people find solace in their faith. Others may struggle with their faith or spiritual beliefs. Praying, talking with someone

from one's religious community (such as a minister, priest, rabbi, or imam), reading religious texts, or listening to religious music may bring comfort.

III) Sharing memories of good times is another way some people find peace near death. This can be comforting for everyone.

Some doctors think it is possible that even if a patient is unconscious, he or she might still be able to hear. It is probably never too late to say how you feel or to talk about fond memories.

9. TREATMENT OF ATTEMPTED OR SUICIDES

The ethical basis for suicide prevention is the well authenticated psychological thesis that the suicide attempt is often a "cry for help" rather than an unambivalent decision to end one's life. The suicide attempt

may not be an act of autonomy but rather an act resulting from impaired capacity because of a mental or physical disease or emotional conflict.

Suicide attempts are often undertaken in psychopathological conditions, such as depression, that are treatable under social conditions that are transient, such as disappointed love or financial loss. Physicians have an ethical obligation to recognize the suicidal inclinations of patients whom they encounter in their practice and to make efforts to assist them personally or by referral to a trained suicide counsellor or a psychiatrist.

SUICIDE AND REFUSAL OF TREATMENT

It is sometimes asked whether refusal of treatment by a patient, especially a patient who is

terminally ill is equivalent to suicide. Significant ethical differences exist between suicide and the refusal of medical care.

The differences include;

1. In the refusal of care, death is caused by the progress of lethal disease, which is not treated. But in suicide, the immediate cause of death is a self – inflicted lethal act. In refusing lifesaving care, the patient's refusal authorizes the physician to refrain from therapy and the fatal condition itself, is the cause of death.

2. In refusal of care, persons do not take their lives but instead they do not permit another to help them survive. Persons who abhor the thought of suicide may say, "I do not want to kill myself, I only want to be allowed to die on my own terms and to control the time and manner of my dying".

Even though suicide and refusal of treatment both result in death, the moral setting differs

completely in intention, circumstances, motives and desires. Many judicial and legal statutes now distinguish between legitimate refusal of care and suicide. Hence, involuntary psychiatric treatment may be given to persons considered "a danger to themselves" by possible suicide.

10. PEDIATRIC NOTES ON QUALITY OF LIFE

Quality of life judgments about children differ from those made about adults in two important ways. First, adults often can express preferences about future states of life and health. Second, when an adult is incapable of expressing preferences, the history of that person's preferences and style of life often allow others to estimate how that person would value and adapt to

future situations.

In pediatrics, the life whose quality is being assessed is almost entirely in the future. Also, just as in adult care, pediatricians tend to assess quality of life as lower than either parents or the affected children.

Medical interventions that are generally effective in alleviating physical disability are ethically mandatory when the only supposed contraindication is developmental disabilities in range characteristics of Down syndrome. More complicated medical conditions such as cardiac deformity, maybe genuine contraindications to treatment.

11. CONCLUSION

Quality of life is one of the most controversial construction in bioethics. In general, quality of life is considered as freedom from emotional and physical

discomfort. This view is inconsistent with the basic principle of medical ethics, that life is a 'bonum onticum' that has a value on its own. In an ethical perspective of quality of life should be considered an important means to preserve a person's dignity that is the ability to pursue his/her own unique mission.