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Review of Legal Ethics in Applying Palliative Care to Improving the Quality of Life of Patients

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Abstract.
Palliative care is a treatment for patients who have incurable diseases by optimizing the patient's quality of life and reducing pain and other symptoms by paying attention to psychological and spiritual aspects. Previous studies have assessed the importance of implementing palliative care in Indonesia because of the high prevalence of incurable diseases such as cancer, heart failure, and other diseases such as HIV/AIDS. Palliative care is a form of medical care and patient comfort that controls the intensity of a disease or slows its progress, whether or not there is hope of recovery. Palliative care does not aim to provide a cure or reverse disease progression. It is an important part of caring for terminal patients, which can be done simply, although their main priority is quality of life and not recovery of the patient from the illness. Most patients come for treatment with a diagnosis of disease in an advanced stage. In such conditions, the patient tends to choose a short but happy life rather than a long life with many limitations. For patients, the only realistic treatment options are pain barriers and palliative care. So palliative care is an effective way to improve the quality of life of patients.

Keywords: legal ethics, palliative care, patient

1. INTRODUCTION

In this era of globalization, it is increasingly demanding quality improvement for each individual, so quality improvement is an absolute thing that must be done, so as not to be left behind with the times. Likewise in the field of health services, service improvement must be based on professional values. Professional nursing services must be based on intellectual values, moral commitment to oneself, responsibility to society, autonomy, and control. Therefore, health workers are expected to be able to make an optimal contribution in accordance with the knowledge, technology and aesthetics of patient care.

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The increasing number of patients with incurable diseases both in adults and children such as cancer, degenerative diseases, other chronic diseases, and even HIV/AIDS require palliative care, in addition to promotive, preventive, curative, and rehabilitative services.[1] However, currently, health services in Indonesia have not touched the needs of patients with this incurable disease, especially at an advanced stage where the priority of services is not only healing but also treatment in order to achieve the best quality of life for patients and their families. At an advanced stage, patients with chronic diseases not only experience various physical problems such as pain and complaints other than pain, but also experience psychosocial and spiritual disturbances that affect the quality of life of patients and their families[2]c. So, the needs of patients at an advanced stage of a disease are not only the fulfillment or treatment of physical symptoms, but also the importance of supporting psychological, social, and spiritual needs which are carried out with an interdisciplinary approach known as palliative care.

Palliative care is an important part of caring for terminal patients which can be done simply, often the main priority is quality of life and not recovery from the patient's illness. Most patients come for treatment with a diagnosis of disease in an advanced stage.[3] This can be seen in terms of the patient's condition, they tend to choose a short but happy life rather than a long life but with many limitations. For patients who choose treatment in a realistic way, therapy is only a pain barrier and palliative care physically and spiritually for the patient.

Society considers palliative care only for patients in terminal or chronic conditions who will soon die. However, the new concept of palliative care emphasizes the importance of integrating earlier palliative care so that physical, psychosocial and spiritual problems can be handled properly.[4] Palliative care in health services is holistic and integrated by involving various professions with the basic philosophy that every patient has the right to get the best care until the end of his life. Then palliative care provided by these patients is regulated in the Regulation of the Minister of Health Number 812 of 2007.

In order to improve the quality of life of patients and their families from problems associated with life-threatening diseases, various chronic disorders, or in terminal illnesses.[1] Palliative care focuses on multidimensional aspects, namely physical, psychological, social, spiritual, cultural, interpersonal, and components of care. One of the important aspects of palliative care is love, caring, sincerity, and gratitude. So important is this aspect, that it exceeds the importance of pain management which absolutely must be done in palliative care. He also stated, for cancer patients who cannot be cured anymore, palliative care is basically an effort to prepare for a quality start to a new life (afterlife).

The act of palliative care in therapy for patients is based on the view of society that patient care continues to be attempted without considering autonomy and ethics in medical services.[5] So that it often creates ethical dilemmas that are often found in health service practices that can be personal or professional. This dilemma becomes difficult to solve when it requires choosing the right decision between two or more ethical principles. As professionals, the palliative care team is sometimes difficult because the decisions that will be taken by both have good and bad. When dealing with ethical dilemmas there are also emotional impacts such as anger, frustration, and fear during the rational decision-making process that must be faced, this requires the ability for good interaction and communication from the palliative care team. In palliative care, volunteers are part of the team who are also involved in interactions related to patient complaints or suffering and are the spearhead, especially in services at patient homes.

2. METHODOLOGY/ MATERIALS

This writing uses a normative juridical method, which is an approach based on basic legal materials by examining theories, concepts, legal principles, and laws and regulations related to this research. With respect to legal ethics in palliative care for patients who have chronic diseases with a palliative care approach, this is one of the efforts to improve the quality of life of patients, the authors focus on the nature of normative research, which will be supported by empirical research to obtain more accurate or valid data.

3. RESULTS AND DISCUSSIONS

The main actors in health volunteers are ordinary people who directly and indirectly also provide services related to patient assistance in accordance with established corridors or norms, ethics and ethics. Ethics in nursing is a guideline for nurses in providing nursing care so that all actions they take still pay attention to the good of the client.[6] The ethics of implementing palliative care also contain elements of sacrifice, dedication, devotion, and the relationship between the nurse and the client, doctor, nurse colleague, self, client's family, and visitors.[7]

Use of ethics in the principles of noble values as a commitment to patients and families in order to fulfill the right to obtain information and be involved in medical decision-making. The medical principles that are agreed upon and need to be known in palliative care are Autonomy (respecting the patient's rights), Non-Malficience (not harming the patient), Beneficience (doing the best for the patient), Justice (being fair to all patients).

1. Autonomy (autonomy)

   The principle of Autonomy is based on the belief that we are able to think logically and make our own decisions. Adults are considered competent and have the power to make and have decisions or choices that must be respected by others. The principle of Autonomy is a form of caring for someone, or seen as an agreement that is not forced and acts rationally. Autonomy is the right of independence and freedom for patients to claim their own rights. Therefore, with the existence of Autonomy ethics in palliative care, patients must respect the right of patients to make decisions about their own care.

2. Non-Maleficience (no harm)

   Palliative services do not cause physical or psychological harm or injury to the patient. The principle of not harming or Non-maleficence with the principle of “don’t harm” in the sense that we are obliged when we take an action so as not to harm other people. This principle seems to be the same as one of the principles of Hippocrates which means that the most important thing is not to harm. Patients in carrying out palliative care.

3. Beneficience (doing good)

   Beneficence means doing everything well on the basis of the patient’s interests and providing benefits for the patient. Sometimes, in healthcare situations, there is a conflict between this principle and Autonomy. So that in the ethical principles of palliative care, this must be done by providing benefits to patients by paying attention to the comfort, independence, and welfare of patients and families, and according to their beliefs and beliefs.

4. Justice

   The principle of justice is needed to achieve equality and justice for other people who uphold moral, legal, and humanitarian principles. This value is reflected in professional practice when the palliative care team works for the right treatment according to law, practice standards, and right beliefs to obtain quality health care.

   Actions in carrying out ethics towards palliative care for patients in order to improve their quality of life must use the consent of the patient and/or family must be stated in an “informed consent” and must be signed by the patient and family and health workers before any action is taken or not carried out. So that in this case, legal ethical principles must also be needed in palliative care services for patients with chronic or terminal illnesses. The legal ethical principles that need to be upheld in providing palliative care to patients are Veracity (honesty to patients and families), Fidelity (always keeping promises to patients and families), and Confidentiality (ability to keep patient secrets).

5. Veracity (honest to patients and families)

   This principle means delivery with honesty and truth with good and polite language and speech, not giving the impression of being patronizing. This value is needed by healthcare providers to convey the truth to every patient and to ensure that the patient really understands. This principle relates to one's ability, to tell the truth.

   So that information must be accurate, comprehensive, and objective to provide understanding and acceptance of information, and tell the patient the truth about everything related to his condition while undergoing treatment.

   But as a volunteer, there are still limitations and it is not recommended to tell the truth in matters related to the doctor's field such as conveying a diagnosis and course of illness, follow-up treatment, and action. So if you are not competent to answer patient and family questions, you should honestly say that you should first consult with the medical team (doctors and nurses). Truth is the foundation for building a trusting relationship.

6. Confidentiality (Confidentiality)

   The rule in this confidentiality principle is that information about patients must be kept private. What is contained in the patient's health record document may only be read in the context of patient treatment. No one can obtain this information unless the patient has consent with proof of consent. Discussions about patients outside the service area, and conveying it to friends or family about patients with other health workers must be prevented. Maintained communication is information provided by the care team to patients with trust and confidence that the information will not be leaked.

7. Fidelity (always keeping promises to patients and families)

   This principle is closely related to fidelity which means that responsibility is certain for every action and can be used to judge others. Accountability in keeping promises to patients and families is a definite standard by which the actions of a volunteer can be judged in ambiguous or unqualified situations. We morally start a good thing by looking at the situation to determine what to do, based on what consequences will be experienced by the people involved if the action is carried out.

Until now, nursing ethics and health ethics have become interesting issues to discuss because nurses face ethical problems every day. In general, several aspects of ethical principles that are often unconsciously violated by some nurses are aspects of autonomy, nurses sometimes do not ask for approval before taking action because it is considered that patients have surrendered to health workers for their recovery.

Implementation of palliative care also requires approval of medical action or informed consent for palliative patients. This is intended for patients to understand the meaning, purpose and implementation of palliative care through intensive and continuous communication between the palliative care team and patients and their families. Based on the ethics of the patient, it is necessary to know how to implement palliative care for him. Implementation of informed consent or approval for medical action is basically carried out as stipulated in laws and regulations. The Regulation of the Minister of Health Number 812 of 2007 concerning palliative care measures also mentions the medicolegal element that must be considered in providing palliative care to patients.[8]

Although in general only medical (medical) procedures require informed consent, in palliative care it is better if every risky action is carried out with informed consent.[9] Both the recipient of the information and the giver of consent are prioritized by the patient himself if he is still competent, with witnesses from his closest family members. Sufficient time should be given to the patient to communicate with his/her closest family. If the patient is incompetent, then his next of kin will do it on behalf of the patient.

The palliative care team should try to get messages or statements from the patient when he is competent about what should or may or may not be done to him if his competence then decreases (advanced directive). Messages can contain explicitly what actions may or may not be taken, or can also only designate someone who will represent them in making decisions when they are incompetent.[10] This statement is in writing and will serve as the main guide for the palliative care team. In an emergency, it is in the best interest of the patient, the palliative care team can carry out the necessary medical procedures, and information can be provided at the earliest opportunity.

Furthermore, palliative care also requires a decision whether or not to carry out resuscitation measures that can be made by a competent patient or by the palliative care team. Information about this should already be provided by the time the patient enters or starts palliative care. A competent patient has the right not to desire resuscitation, as long as he understands the adequate information he needs to make a decision. The decision can be given in the form of a message (advanced directive) or in informed consent before he loses his competence.[11]

Basically, the immediate family cannot make a decision not to resuscitate, unless it has been ordered in a written advanced directive. However, under certain circumstances and upon certain proper and appropriate considerations, a written request by all members of the immediate family may be requested by a court order for approval. The palliative care team may make a decision not to resuscitate according to clinical guidelines in this field, ie when the patient is in a terminal stage and resuscitation measures are known not to cure or improve quality of life based on scientific evidence at the time.

Whereas in other palliative care, the condition of the patient being treated in the ICU must follow the general provisions that apply as facing the terminal stage. The palliative care team should follow guidelines for determining brain stem death and discontinuing life-support devices. So that ethics in treating patients with palliative care in accordance with the rules in palliative care guidelines[12]

This is important to do because every patient has the right to know the risks and benefits of the medical action he will be undergoing. Providing education to patients is one of the ethical principles of beneficence for patients. The application of ethical principles is important to do so as not to cause harm to patients[13]. These losses can cause injury or physical harm, emotional harm such as feelings of dissatisfaction, disability, or even death, and ultimately the goal of service in the form of patient comfort will never be realized. In addition, it will cause patient dissatisfaction which will eventually have a negative impact on the image of medical personnel and hospital revenue, patients who are dissatisfied with the services provided will not seek treatment back to that place because they feel dissatisfied with the services provided.

This ethical awareness needs to be owned by the palliative care team so that they can always consider every action that will be taken by remembering and prioritizing the interests of the patient. Likewise, the ethical awareness of the patient is also needed in order to appreciate every medical effort made by the palliative care team in an effort to relieve/liberate the suffering of the disease. Ethical awareness will function in concrete actions when making decisions on certain actions by considering the pros and cons in a responsible manner.

4. CONCLUSION AND RECOMMENDATION

Palliative care is an approach that aims to improve the patient's quality of life and families facing problems related to life-threatening illness, through prevention and elimination through early identification and orderly assessment and handling of pain and other problems, physical, psychosocial and spiritual. So that palliative care for patients with chronic or terminal illnesses can be an effort to improve the quality of life by applying legal ethics in providing services to patients, one of which is by means of ethical principles of nursing namely Autonomy, Non-Malficience, Beneficience, Justice, Veracity, Fidelity confidentiality. Then than that, with the implementation of Legal Ethics in carrying out palliative care for patients, it must be carried out in an ethical manner so that patients feel comfortable without any fear of the disease they are suffering from.

Based on the conclusions above, the recommendation that needs to be made is that providing palliative services must be carried out ethically by providing education to patients and their families. So that any information addressed to the patient and family will achieve the goal and be accepted for the decision given by the patient and family. So that in this case the patient enjoys an increase in the quality of life in his chronic disease.

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