Medical Humanities, Ethics and Legal Considerations in Palliative Care: Toward a Good Clinical Practice in End of Life

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Abstract: Palliative care is end of life care for the critical patients. Decision making for palliative care is so difficult because its depends on several aspects such as medical humanities, ethical and legality. Medical humanities aspects included a humanistic approach, cultural, religious and spirituality must be considered. Whereas ethics- legal aspects include ethical and legal consideration in decision making to end of life . This article discusses about decision making to palliative care in terminally illness of patient and hopeless.

1 INTRODUCTION

Treatment of patients nearing the end of life requires considerable attention from health professionals, especially doctors and nurses. The spiritual and humanistic support of professionals is especially meaningful for the patient enduring his life (Wheatley et al ., 2015). Doctors and nurses as professionals who have an ethics code of proffesion have a duty to respect the patient's autonomy rights in the hope of the patient at the end of their life. Doctors are on duty to support the patient's full expectations and nurses serve as patient advisors at the end of their life (Wilson et al., 2013). The increasing number of hospitalized patients approaching the end of life in recent years desperately needs a special so-called palliative care. Based on a study conducted by Van Tricht et al ., 80% of 2420 patients underwent restrictive measures and the termination of therapeutic assistance is caused by the patient's condition that is very old, a disease that has reached the terminal stage, having limitation from organ function previously, chronic diseases, and medical disorders with severe and acute condition .

The terminal stage of an illness is a medical condition characterized by there is no hope for patient to recover (hopeless). The terminal medical condition is a progressive process towards death through some stage in the form of a decline in physical function, psychological, social, and spiritual for the patient. Types of diseases that often entered the terminal stage of which is cancer, infection, heart disease, lung disease and nerve disease (Van Tricht et al., 2011) .

Based on the Decree of the Minister of Health of the Republic of Indonesia Number: 812/Menkes/SK/VII/2007 about Policy in Palliative Care, in Indonesian not more hospitals that already gives services palliative care, it is still limited in the five provincial capitals, namely Jakarta, Yogyakarta, Surabaya, Denpasar , and Makassar. The limited number of hospitals that provide palliative care because of the large needs of patients, the lack of doctors and nurses are able to provide an palliative care and also facilities infrastructures are still limited. Seeing this condition required hospitalization -home other hospitals have facilities and adequate resources for the implementation of palliative care. In Aceh until now there is no services to palliative care spesifically, Dr.Zainoel Abidin hospital in Banda Aceh has the potential to develop palliative care given these hospitals because the hospital have sufficient resources, sufficient equipment and hospital conditions were Islamic shariah supports palliative care based on Islamic services for patients. In its implementation palliative care requires consideration of the medical humanities, ethics and legal so that the activity can be a good clinical practice in the case of end-of-life care.

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According to the World Health Organization (WHO) , palliative care is an approach to improving the quality of life of patients and families facing disease-related illness- related problems , through the prevention and recovery of disease by early identification and a perfect assessment for the treatment of pain and problems others, both physical, psychosocial, and spiritual (WHO, 2018). The main purpose palliative care is improving the quality of life of the patient, not to cure his illness. Therefore, both doctors and nurses must understand the procedures for improving the quality of life desired by the patient. But keep in mind that palliative care no intented to accelerating or delaying death (Rasjidi, 2010).

2 PALLIATIVE CARE

Based on Decree of the Ministry of Health of the Republic of Indonesia Number: 812 / Menkes/SK/VII/2007 on Palliative Care Policy, palliative care conducted by a team consisting of a variety of disciplines integrated, among other health professionals (such as doctors, nurses, psychologists, physiotherapists, nutritionists), social workers, religious leaders, families, and volunteers who have participated in education/training palliative care and has obtained a certificate of competence from the Ministry of Health of the Republic of Indonesia . Successful palliative care depend on effective co-operation and interdisciplinary approaches between physicians, nurses, social workers, religious leaders, volunteers, and other service members who meet the needs of the patient. Collaboration between members of the palliative care team with the patient's family is considered a primary need that mutually supports the smooth conduct of palliative care (Muhith & Suyoto, 2016). The purpose and benefits of palliative care include: (Downing et al., 2010; Nur wijaya, 2010; Rasjidi, 2010).

1. Reduce or eliminate other disturbing pain and complaints.
2. Make the patient understand that the process of life and death is normal.
3. Integrates the psychological and spiritual aspects of patient care.
4. Provide support to allow the patient to live as actively as possible up to the death.
5. Provide support to help families overcome the illness of the patient and in preparing for death.
6. Use a team approach to find out the needs of the patient and his family, including death counseling if necessary.
7. Improve the quality of life and slow the course of the disease.
8. Monitor underlying disease and together provide other therapies intended to prolong life, such as chemotherapy, radiation or antiretroviral therapy (ART), and include finding out the patient's need to better understand and manage clinical complications.
9. Respect the patient's trust and social values and culture.
10. Balancing to benefit of the investigation and treatment of the danger that may occur and thus ensures the quality of living.
11. Caring for patient autonomy rights and patient choice.

2.1 Medical Humanities

The medical humanities have some insight in the medical literature, sometimes overlapping with medical ethics. the medical humanities seriously develop together aspects of the humanist, scientist, medical and others, who believe that the doctors will put a touch of humanity to the practice of medicine, despite getting increase of medical science and technology (Alabi et al., 2008). The fundamentals of the medical humanities are inclusively defined as a collection of the humanities sciences of literature, philosophy, history, arts, music, cinema, theater, law, economics, politics, theology and anthropology, culture, religious and spiritual aspects (Gillon, 2000). According to Shapiro et al (2009), the medical humanities is a mole, concepts, and content of one or more of the humanities disciplines to examine disease, pain, hope, healing, treatment relations and other aspects of medical and health care practices.

2.2 Spirituality and Patient Religiousity

Patient wants to be always cared for and treated as a complete in biological, psychological, social, and cultural human being, not enough just to see him as a "sufferer" only. The desire of patients treated as whole human point include biological dimensions (physical), mental and emotional (psychological), social, cultural and spiritual (Alabi et al ., 2008). For many patients, spirituality is an important part of his recovery. There is some scientific evidence that many serious diseases can be cured and care with the approach of the patients spirituality and religious beliefs its. Religiousity/spirituality includes a widespread practice that predicts the success of resistance to physical illness (Koenig et al ., 2004). A Study by Koenig et al (2004), the results indicate that patients with a good religious predicted faster recovery from depression, particularly in patients with impaired physical function. In a meta-analysis study of more than 850 respondents who examined the relationship between religiosity and some aspects of mental health, the majority of respondents indicated that one's experience had better mental health and able to handled stress if they were religious. Another analysis of 350 respondents was found that religious people were physically healthier, healthier in style and needed less health care (D'Sauza, 2007).

Some examples of humanistic values that rely on religious and spiritual values can be done on palliative care. The palliative patient is a very weak person because he is being tested with the disease by ALLAH Subhaanahu Wa Ta'aalaa. Patients need a moral boost and reassurance that they can pass all his exam, realize that the disease is only temporary and there is a limit and hope for a good recovery (Ondigo, 2010). Doctors and nurses can provide moral support to patients and their families by stating a few sentences of entertainment for example, that the illness was actually intended to reinforce belief and can take away sin (Haneef, 2006).

In palliative care there should also be a sense of optimism in the patient. If the patient has despaired from healing, the doctor and nurse should always give her optimistic feelings and positive expectations to her patient, bringing her the good news and desire to heal. It is necessary to convey to the patient that the believer should not despair of the trials of ALLAH, ALLAH has revealed the distress of Prophet Ayyub 'Alaihissalam, restoring the vision of Prophet Ya'kub' Alaihissalam. ALLAH the Almighty reveals all distress and disaster, restores health, and replaces from sickness to health, from weak to strong (Ramadan, 2004) . Attitude to the patient with the pain of the patient is also needed in palliative care. In Islamic perspective, patients do not feel alone, emphatic to feelings of the people who surrounded him, and the prayers that flow has eased the pain of them and calamities that befall them, it is truly a peak of charm humans and peak sublime feeling to the human's needed by the patient (Haneef, 2006 ; Malik, 2013).

2.3 Patient Condition

Each patient has a unique with the symptoms and diagnosis of the disease are different, but none of the patients had a condition exactly the same as other patients. This uniqueness should be considered in planning palliative care for each patient (Rasjidi, 2010). This attitude includes sensitivity and empathy to the patient. Need consideration all aspects of the suffering of patients, not only health problems but also psychological and social. The approach should be holistic and integral (Wheatley et al ., 2015) . There are patients with palliative care always give special attention, especially in patients with advanced disease because the condition will tend to decline over time (Rasjidi, 2010) . the factors non-medical such as ethnicity, race, religion, and other cultural factors can affect the suffering of patients, therefore these factors must be considered in palliative care planning (Alabi et al ., 2008) .

Palliative care must in accordance with stage right and the patient's prognosis, because inappropriate treatment, whether more or less, will only add to the suffering of the patient. Giving an extremely care (over medicalization) can excessive risk to provide false hope to patients who could care it becomes useless (Alabi et al., 2008). This is related to ethical issues that will be discussed later. Treatment is given only because the doctor feels the need to do something even if it is useless is unethical (Rasjidi, 2010) .

2.4 Ethical Considerations

Patient criteria to be given palliative care based on ethical considerations can be based on principles base of ethics according to Beauchamp and Childress theories and by using clinical ethical theory from Jonsen, Siegler and Winslade (Beauchamp and Childress, 2013; Jonsen et al., 2010; Kusmaryanto , 2012).

Decision-making by using ethical approach to treatment of paliatif both by Beauchamp and Childress theories and by using clinical ethical theory from Jonsen, Siegler and Winslade (Beauchamp and Childress, 2013, Jonsen et al ., 2010) can be seen in table 1.

Table 1: Decision-making for palliative care.

Assessment of Patient Condition	Basic Principles of Ethics	Clinical Ethics	Recommendation
Patients with terminal stage (terminal state) and there is no hope of recovery	Beneficence (-) Non-maleficence (-) Justice (+) Autonomy (+)	Medical indications (-) Patient preferences (+) Quality of life declines Contextual features (+)	to be given palliative care
Patients who are given optimal therapy but in vain (futile treatment)	Beneficence (-) Non-maleficence (-) Justice (+) Autonomy (+)	Medical indications (-) Patient preferences (-) Quality of life declines Contextual features (+)	to be given palliative care

According to the theory of Beauchamp and Childress, medicine adheres to four basic moral principles (principles base of ethics-the same term) ,ie autonomy, beneficence, non-maleficence and justice. Autonomy means any medical action must obtain the consent of the patient (or his immediate family, in the case of his / her consent), beneficence means any medical action should be directed to the patient's good, non-maleficence means any medical action should not exacerbate the patient's condition, and justice means that attitude or medical action should be fair - especially in terms of distributive-justice (O'Rourke, 2000; Beauchamp and Childress, 2013). Moral dilemma is still possible if the moral principle of autonomy is confronted with other moral principles or if the principle of beneficence is confronted with non-maleficence , for example if the patient's wish (autonomy) is contrary to the principle of beneficence or non-maleficence , and if something measures contain beneficence and nonmaleficence simultaneously as in rule of double effect (Beauchamp and Childress, 2013 ; Kusmaryanto, 2012).

Beneficence is concerned with always providing the best for the patient (providing benefits), while non-maleficence is intended to prevent illness in the patient (preventing harm). Beneficence aims that all patients should be treated (general principles) if they are beneficial, but if the patient's treatment is virtually useless it is not the goal of beneficence. Likewise, if therapy is continued with the consequences of not providing benefits to patients and their families then this is also contrary to the principle of non-maleficence (McLimunn, 2006). Indications of palliative care are social, psychological and spiritual care that are no longer purely medical. When a patient has been established by the treating physician that the patient has entered the terminal phase of his illness or therapy has been in futile and medically no longer can be taken any action then the ethical choice is which is the most dominant based on the primafacie principle (Beauchamp and Childress, 2013) . According to the clinical ethical theory of Jonsen, Siegler and Winslade, there are four quadrants that can be considered, namely medical indication, patient prefference, quality of life and contextual features (Jonsen et al ., 2010) so that this theory is often called as four box method .

2.5 Informed Consent

In the palliative care, the patients must understand the meaning, purpose and benefits as well as the implementation of palliative care through intensive and continously communication between palliative care team with the patient and his family. If a medical treatment is necessary, an informed consent is required. Implementation of informed consent has two dimensions, both ethical and legal. Ethically, informed consent is the implementation of autonomy rights of patients and legally also provided for in the law and regulation in Indonesia (Kusmaryanto, 2012; Republic of Indonesia, 2008) . In Indonesia generally every acts of medicine, medical treatment or medical intervention must be requires an informed consent (Beauchamp and Childress, 2013), including to palliative care (Republic of Indonesia, 2008) . Legally, both who is receiving information and giving consent done by the patient himself when he was still competent, but if the patient is not competent may be delegated to her family.

2.6 Advanced Directive

Before doing a palliative care, doctors and nurses, with the whole team should strive to get a message or a statement of the patient (advanced directive) when the patient is still competent about what you can or should do or should not do with him when will anything happens, for example a comma condition (Republic of Indonesia, 2008) . While there is no rule about the right to die, there are rules for adult patients to refuse medical treatment that could result in his death. There are several requirements that must be met to receive an advanced directive will be: at the time of making an advanced directive patient must be competent, when refusing a patient's actions should be voluntary without coercion and pressure, advanced directive can contain any explicit what action may or not do, or it may be only delegate a person as represent him make decisions when the patient is incompetent (Jordens et al., 2005). Advanced directive statement should be made in writing and entered into the medical record that will serve as the main guide for the palliative care team. In emergency condition, for the best interests of patients, palliative care team can perform medical actions if necessery, and information can be given on the first occasion (Republic of Indonesia, 2008).

2.7 Do Not Resuscitate

Decisions about the commission or omission of Cardiopulmonary resuscitation (CPR) in patients with life-threatening illnesses to be made in the regulations related hospital palliative care (Wheatley et al., 2015). Decision to Do not resuscitation (DNR) can be made by the competent patient after discussion with the palliative care team. Information about DNR, it has been conveyed to patients while entering or starting palliative care. Competent patients have the right to DNR, which an adequate information has been given and they have understood. The decision can be made by using form of written messages (advanced directive) or other form in the patient's informed consent before the loss of competence. The patients family is basically not be made the decision to DNR, except it has been booked in written advanced directive. The ethical principles applied to the DNR also refer to Beaucamp and Childress's theories of four basic principles of autonomy, beneficence, non-maleficence and justice. If the patient has been in terminal stages and resuscitative measures will neither known or improve the quality of life based on scientific evidence at the time, the palliative care team can make a decision not to resuscitate based on clinical guidelines in this field (Beauchamp and Childress, 2013; Jonsen et al ., 2010; Republic of Indonesia, 2008) .

2.8 Withholding and Withdrawing Life Support

Basically palliative care in intensive care installation following the general provisions as described above. In the face of terminal stage of deseases, the palliative care team should follow the guidelines determining to brainstem death and termination or limitation equipment life - supporting (McLimunn, 2006). Consideration of bioethics that must be considered in determining the action withholding life support and withdrawing life support is when, where and the condition of how the doctor convey it to the patient's family. Firstly the physician must respect the dignity of the patient (patient's autonomy) in this condition the patient or his family must have autonomy to receive relevant information about the disease (Levin & Sprung, 2005). The physician should determine whether the patient, family or relative is aware of the last health condition of the patient (Aeckermann, 2000). The most important thing in determining when action withholding life support and withdrawing life support is when a medical action has changed from ordinary treatment to extraordinary (Malik, 2013).

The terms withholding life support and withdrawing life support is not the same meaning. In simple terms withholding life support means no longer doing resuscitation. In contrast to withdrawing life support, once discontinued withdrawal therapy the ventilator and inotropic should be discontinued, heavy sedation usually arises and death will soon occur (Levin & Sprung, 2005; Malik, 2013). Decision-making to withholding and withdrawing life support in critical care patients should be done cautiously. It is necessary to consider the medical, bioethics and medico-legal aspects. The basic principle of decision-making lies in patients who are medically present in circumstances that are not could healed effect diseases (terminal state) and/or medical treatment already vain (Futile). Both of these principles become the basis of bioethics through the basic principles of ethics and also become the basis of law that can be accounted professionally (Kusmaryanto, 2012; Republic of Indonesia, 2008).

2.9 Aspects of Legal

In Indonesia, according to rules regarding the determination withdrawal or withholding to the therapeutic support listed by Rules of Minister of Health of the Republic of Indonesia Number 37 Year 2014 Chapter 3 Articles 14 and 15 about withdrawal or withholding life support that is on patients who are located in circumstances with the terminal state of desease (terminal illness) and medical treatment already vain (medical futility) can do termination or limitation of life support as same as by term of withdrawal or withholding life support.

In the Dr.Zainoel Abidin hospital, major provincial hospital of Aceh- Indonesia, the policy about criteria for withdrawal or withholding life support for patient with terminal stage condition set by Director of the hospital. Decision for termination or limitation of life support to patient do by medical team who handling the patient after consult with a appointed doctor by medical committee or ethical and legal committee. Planning to termination or limitation of life support (withdrawal or withholding life support) must informed and earn approval from family or representing patient.

The life support treatment that can be stopped or postponed only actions of an extra-ordinary treatment such as hospitalized in Intensive Care Unit, resuscitation cardiac pulmonary, control dysrhythmias, intubation tracheal, mechanical ventilation, drug vasoactive, parenteral nutrition, organ artificial, transplant, blood transfusion, monitoring invasive, and the provision of antibiotics and other actions set out in the standard of medical services. The life support treatment is not could stopped or postponed covers oxygen, enteral and nutrition fluid crystalloid because it ordinary treatment (Republic of Indonesia, 2014). Based on regulation of the Minister of Health of the Republic of Indonesia Number 290 year 2008 chapter 4 article 16 on approval action medical on special situation, that is action withdrawing or withholding life support on a patient must got it approval family nearest patient. Based on chapter 5 article 18 of this regulation, on denial or refusal a medical treatment and medical intervention that is could do by patient and or family nearby after they received an explanation about medical treatment to be do.

Ugliness patient condition to be worst that is ends with dead. Determination of death based on regulation of the Minister of Health of the Republic of Indonesia number 37 of 2014 can be do with use criteria of death diagnosis in clinical or conventional or diagnostic for brainstem death criteria. Based on article 8-13 of this regulation about criteria of death diagnosis both clinical or conventional as it is intended in Article 7 is based on has entirely and permanently cessation of circulation and respiration. Determination citeria of brainstem death only could do by team a doctor composed of 3 (three) competent physicians, in Aceh ussually do by anaesthesiologist, neurologist, neuro surgeon, intensivist and medico-legist as representative of medical committee and the diagnosis brainstem death may be or must made in the Intensive Care Unit and examination conducted must corresponding with procedure and requirement for determine the death diagnose of brainstem. Based on article 13, after brainstem occured, then all the life support therapy must soon stopped. The palliative care team has medical priviledge was given by the Chairman of the hospital, including when home care patients. Basically acts of a medicine must be done by medical personnel, but by consideration to patient safety, a medical treatment can be delegated to non-medical skillized personnel.

Based on the decree of Minister of Health of the Republic of Indonesia Number: 812 / Menkes / SK / VII / 2007 on palliative care policy, the scope of activities of palliative care as follows: pain management, other physical complaints, nursing care, psychological support,social support, cultural support and spiritual as well as preparation to end of life.

3 CONCLUSION

The large number of patients suffering from terminal illnesses and medical therapies has been in futile, demanding hospitals to provide a special treatment called palliative care. The goal of palliative care is to improve the quality of life of patients and families in dealing with life-threatening problems without providing extraordinary medical therapy. Prior to palliative care should first consider some aspects of the medical humanities, ethics and legal among others: spirituality and religiosity, the patient's condition, principles base of ethics, clinical ethics, informed consent, advanced directives, do not resuscitation (DNR) and withholding and withdrawing life support.

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