

# The Honourable Role of Nurse in Accompanying Patient's Dying Process

Krisna Yetti Malawat Rr.Tutik Sri Hariyati\* Rona Cahyantari Merduaty  
Faculty of Nursing, Universitas Indonesia, Johan Bahder, UI Depok, West Java, Indonesia, 16424

## Abstract

End of life is meant as a frightening thing, thus it makes an ignorance. Another frightening moment is the pain that attaches throughout the illness. Death has also been interpreted as a lonely feeling which is done by own self and separation with the beloved one. This study used Method of Actual Problem, it is a philosophy reflective study about handling patient with chronic disease phenomenon which is predicted will going to the end of life. In this study, problems in the hospital are directly exposed, then it is synthesized to solve a fundamental problem. Analysis and synthesis of medical intervention to end of life patient to be expected can solve the problem. Ethics which is embraced by nursing profession must be received by the patient. It means that nursing profession's existence takes more control to the problem at the end of life patient. Nursing care can help the dying process of the patient become as peaceful as possible

**Keywords:** end of life, dying process, peaceful, nursing care, role of nursing.

## 1. Introduction

In early 2018, the writer met a patient who experienced terminal illness and admitted to one of a public hospital in Jakarta Indonesia. Around 6 PM, Patient "X", 78<sup>th</sup> years old, with decreased digestive and liver function (chronic). The patient's family information, the patient no defecation for about 2 weeks and feeling pain at home. One year ago the patient was convicted with Hepatoma. The abdomen looks bloated and hard. The patient has difficulty breathing. Blood Pressure 70mmhg, pulse 70x per minute, temperature 39 Celsius and breath 32x per minute. Weight 40 kilograms and height 165 cm. During the emergency, the patient vomits and looks weak. The families have a hope for the patient to recover and be healthy again. The family looks confused and approved for laparotomy surgery. During surgery, a symptom of atrial fibrillation emerged then 3 hours postoperatively, the patient died in the intensive care room.

Many questions have arisen. Then, how appropriate care and nursing services should be given to the patient? Is the patient in need of surgery? Will setting of death (place) better? According to the observation which conducted in a hospital, patients and families had not understood yet how to react to this advance care. In addition, there is no agreement in approachment to face patient's end of life. Then, there are some families which understand that critical or terminal illness can be relieved, while healthcare provider suggested family to admit the patient into surgery. At the moment, the family didn't have a choice, thus they fully accepted healthcare provider's recommendation. Unfortunately, shortly after that, the patient died. That assistance which aims to prolong patient's life can be meant as a useless effort. As a nurse, I have a question; "What are nurse role in the cases?"

Indonesia's condition regarding patient's blindness and powerless in facing a policy which is taken by a healthcare provider. This condition only can be improved if nurses realize and empowered to change intervention for the patient in their end of life. Hence, this thought lies in axiology area. Continuum thought about how to express nurse's thinking capability, emotion, psychomotor, and how to respond a dying in terminal illness patient in Indonesia, is a contribution to Indonesia nurses existence. All of this thoughts are the incarnation of ethical care and moral obligation for an area which becomes nurse's responsibility (Swanson & Koch, 2010; Watson, 2012).

Based on description regarding terminal illness patient whose die have been predicted and healthcare provider incapability to respond patient and family, thus research question has formulated: "**What are Honourable Role of Nurse In Accompanying Patient's Dying Process?**"

## 2. Method of The Research

This study used Method of Actual Problem which developed by Bakker and Zubair (1990, pg. 107), it is a philosophy reflective study about handling patient with chronic disease phenomenon which is predicted will going to the end of life. Problem is a conflict as a result of medical technology advance which contributes to the unmet of patient's rights by the healthcare provider or the ignorance of patient and family existence.

In this study, problems in the hospital are directly exposed, then it is synthesized to solve a fundamental problem. Analysis and synthesis of medical intervention to end of life patient to be expected can solve the problem, thus appropriate and ethic solution can be attained for this situation. In the end, a whole Philosophy Conception achieved (Bakker & Zubair, 1990, pg.108). Internal coherency is among all research objects, which are the relation between sick people who face the end of life, ethics which embraced by the nursing profession.

Further, it would be found which more dominant aspects that control this research problem, also the aspect which follows the dominant one, or either aspect became dominant or follower. It means that either does nursing profession's existence taking more control to the problem at the end of life patient or another aspect as well so that a new whole horizon of nursing intervention has developed to the patient in end of life.

### **3. Discussion: A Philosophy Reflective Study about Handling Patient with End of Life**

#### **3.1. The Meaning of End of Life**

Generally, end of life is meant as a frightening thing, thus it makes an ignorance. Another frightening moment is pain which attaches throughout the illness. Death has also been interpreted as a lonely feeling which is done by own self and separation with the beloved one. Since human has a life goal and meaning, it causes they tend to avoid a death. Thus, a frightening frequently found when facing the death (Moore & Williamson, 2003).

There is a reason why death become a frightening thing (Hidayat, 2005), it is because too much love to leave a joyful of the world. This joyful is an instrumental facility (Hidayat, 2005, page 125). This instrument can be improved for reducing the sadness by leaving the testament. Yet, the most frightening reason is knowing nothing about what might happen after death. In contrast with early discussion, Hidayat (2005) delivers that dying is not the end of life but a transition line to enter a more beautiful life.

#### **3.2. End of Life Art**

Imhof (1994) suggested someone who will die should be supported spiritually and be accompanied at the moments of their end of life. Participation of chaplain is needed because religious support will transform a frightening to be optimism (Hidayat, 2009). The death art is also discussed by Al-Ghazali who lived in 1059-1111 century in his book titled *Remembrance of Death and the Afterlife*. Moreover, Shihab (2007), mentioned that death as a journey to The Creator. Thus, both of Imhof (2004) and another Islamic scholar stated that chaplain is needed to be a part of dying process, especially in the hospital, hence in the future, they should be a part of the healthcare team. On the other hand, the healthcare provider is also needed to plan dying process journey of a patient.

Loewy with a background as a doctor and his wife who is a nurse. Loewy explained that planning of dying as a musical orchestra. In their book, *The Ethics of Terminal Care: Orchestrating the End of Life* (2002) described how to face a peaceful death at the end of life. Task sharing among orchestra player which is planned will play a melodious harmony that can plan a death become less suffered to face.

#### **3.3. Reaction to Threatening Life Illness**

Elisabeth Kubler-Ross is psychiatric who focus to care to patients that predicted will be died. In 1969, Kubler-Ross reported that her finding the patient with terminal disease experience in her book *On Death and Dying*, that explained the patient reaction to face death and how the environment can help a patient to go through well dying. Those environments include healthcare provider, patient family, religious scholars, and social worker.

Furthermore, in 1977, Kubler-Ross built a place for the patient with the terminal illness so that they can attain a peaceful death. This place was named Shanti Nilaya, means *Home of Peace*. Since 1955, Kubler-Ross experienced recurrent stroke attack which made her paralyzed. In *On Death And Dying* is discussed 5 stages on patient undergo end of life. Those stages include 1). Denial and isolation, 2). Anger, 3). Bargaining, 4). Depression, 5). Accept. Most of the patients (around 200 respondents) who were interviewed by Kubler-Ross deny their condition by stated: "*it is not me who experience this disease*". Denial is an effort to balance the feeling of loss. That situation literally helps the patients to unite their thought to seek the real condition of what happens to their self.

Then, in anger situation, patient tend to be more clear regarding their situation. That situation which is experienced by patient makes she/he always does not well respond to the environment, for example, "*why my bed cover didn't change yet today? Why the tea that served not sweet? I don't want to be taken care of by Nurse A*". Kinds of denial forms are anger way about the situation that experienced. After passing denial and anger phase, the patient tries to bargain their illness condition. They hope to God, for example, "*If I can, I wait for my child graduates first*".

Next phase, the patient starts to feel depression. This is signed by the enormous and saddest loss. There are two steps of depression which are needed by a nurse to determine how to communicate with the patient. Reactive depression is marked by feeling sad, lonely, and hopeless about loss. Patient wonders to validate their condition. Thus, in this phase, nurse needs provide their time with the patient to explain what will be acknowledged by the patient. *Preparatory Depression*, in this phase, is found a situation where the patient reflects and introspect, patients won't disturbed by their environment, thus nurse should give a time for the patient to be alone.

Accepting phase is a winning phase when individuals accept their condition. It means they have to know their self and be friendly with their own self. Those five phases are not always undergone by patient systematically. It depends on patient's understanding of life after death. Death accepting by dying actor gives a

good result. The peaceful situation can also disturb their family (Coleman & Jinpa, 2008 pg. 58).

### 3.4. The Dying Place

The urgency of dying place discussion is because there is no conformity in nursing-health intervention in end of life of the patient. Individual who dies in the house does not get nursing care while the patient in hospital receives nursing service which tends to be more instrumental. Based on observation, more patients died at home, whereas, those patient needs a fulfillment of basic needs as the patient in hospital receives.

**Home.** In Indonesia, proper places to die are home and hospital. In principle, if dying at home be an alternative, thus it needs a conformity of nursing intervention for basic needs fulfillment. Those basic needs are oxygenation, nutrition, elimination, and thermoregulation. Beside those, spiritual care is a basic need which must be met. Those needs are suited to the patient condition so that existence of patient and family can be preserved.

Death gives a serenity feeling for the one who left, as reported by Coleman & Jinpa (2008) in their book *Meditations on living, dying, and loss*. Coleman depicted an old mother in law who is dying, had prepared an altar as a place to die. Then, Rinpoche guided a mother to pass away by singing the praise songs. Slowly, her soul gone without suffering. How can it be explained? It was something beyond the knowledge of researcher to understand. However, the researcher believes when someone wants to go (pass away), they want to be accompanied by people who proper to deliver the prayers. As this is believed, thus nurse needs to identify who is proper to accompanying patient so that separation process between soul and body are not having an obstacle.

**Nursing Home.** There is also nursing home for elderly, thus they would die at those place, it can be said they are not dying in the hospital. A nursing home is not under Health Ministry coordination. Besides that, nursing service in end of life does not regulate yet by Health Ministry and in Indonesia is still uncommon.

**Hospital.** In Indonesia, dying in hospital become the main alternative. It is caused there is no place except hospital which is completed by healthcare provider and equipment. Thus, the hospital becomes the only one resource to gain support. Nowadays, the intensive care regulation causes a family can not accompanying the patient to release the pain they feel. There is no report yet about how many patients want to be accompanying, with whom, and how their's role to release the suffering throughout the dying process. As referred to physical dimension, that hearing would be the latest ability to lose as long as the dying process going, logically for those who believe in God, definitely, they want some prayers to calm and release their suffering.

In The United of States America (LaPorte Matzo & Sherman, 2006, pg. 94) reported that in the period from 1992 until 1997, there was the increasing of number for those people who chose dying at home, vice versa for the hospital. Those trends are caused by participation from the patient and also family in making a decision. That decision includes using an advanced medical equipment and kind of support that needed by the patient.

The reason of patient to avoid a treatment at the hospital because, in their end of life, they feel isolated, separated from family. Patient and family need sociological, spiritual, and emotional support (LaPorte Matzo & Sherman, 2006). Those needs cannot be fulfilled at the hospital because hospital setting is impossible to be met. If die at home is impossible, while die at the hospital is unwanted. Avoiding a death at the hospital, especially in intensive care means avoiding a lonely death, machine voices which disturb serenity in dying process, and also avoiding a large budget. Hereby, the decision to undergo intensive care should be agreed to by the patient, wherein that decision should be taken when the patient in compos mentis state, far from terminal phase comes.

**Hospice.** Hospice is an approachment to improve the quality of life of individual and family who experience a problem related to life-threatening disease, by preventing and reducing the burden by doing the identification earlier and manage the pain and other problems, such as physical, psychosocial, and spiritual. Hospice care is a program or facility that gives special care to the patient who is dying. Hospice care is a program or facility which gives specific care for the patient in end of life. It can be said that hospice is a way of care based on philosophy about the end of life.

In those place, patient and family are not separated, the family can give a support which is very needed by a patient in their end of life, such as prayers chanting. As it is done by family, peaceful dying can be attained. Hospice gives a support and assistance to patient and family along 24 hours and 7 days a week (Loewy, 2002, pg. 137). Another reason that supports hospice is chosen to be a dying place because if family experiences physical burden, there are hospice staff who will substitute the role of the family. Besides a physical burden, it is possible that family can experience a psycho-socio-spiritual problem, so family definitely needs a support too. Thus, the healthcare provider can help the family to find a solution to this problem (Bruhn & Henderson, 1991).

### 3.5. Nursing Care

Nursing care is an essence of nursing service. In nursing care, the relation between nurses and patient takes place. As a clinician, the aim of nursing care is patient can feels comfort. The nurse participates to take a decision related to undergoing disease; plans who will release a separation calms the patient through digging a unexposed information such as asking apology to another person and alleviate the scared of dying process. The nurse who cares to the patient is important to entertain the patient who experiences the pain because it can isolates, ease

physical and emotional tension since the patient does not have the energy to contact to other people (Zerwekh, 2006). The existence of nurse when patient and family need it is a success. It means, by listening to patient's problem, the patient feels already share it to nurse (Laporte,2006).

In sick condition, to ease the burden, people are suggested to repent. It origins from Arab language means coming back (Shihab, 2007, h. 1). The meaning of repent is if in life journey, there are some negative deviants then it is the time to evaluate and back to the straight path. The understanding of nurse regarding this context is needed to enforce a relationship between patient and chaplain. Thus, the nurse as fast as possible can facilitate and bridge the meeting between patient and chaplain as soon as possible.

In addition, the nurse needs to assess how patient facing their illness condition. The real fact that a human passes a dying physically by own self. The people around patient should give a reinforcement. One of the things is to accommodate a patient's family to stay beside the patient. The family of the patient means a person who is expected by the patient to accompany their life.

All of this is done by a nurse through follow four stages of intervention refers to caring ethical. It starts with caring, means care to a patient who has been treated. The second step is taking care of, that means take a responsibility. After that, for the third step is caregiving, it shows by giving a nursing care. The last step is care received, the nurse evaluates a success of nursing care (Lachman, 2012).

As protector, nurse complies a patient's need that relates to another health members, for example, a nurse ensure the medicine that needed by the patient to release pain. Although the nurse does not play a role as a disease healer and remedy the physical, yet nurse ensures a received medicine correctly. As line as another health professional intervention, nurse confirms pharmacist, social worker, and spiritual worker to play their own role.

As a guide, the nurse uses knowledge, communication, and intuition which are needed together with the patient to pass a difficult journey. The nurse needs to evoke the expectation by giving a care. Nurse's power will give an ability to the patient while facing the hard moments. This need is achieved if the patient still connected to the environment, for example, remains to do some activities together around as optimum as possible. Thus, communication with around environment should be maintained. Once again, the nurse needs to assess carefully since patients' ability and need different from one person to another. By implementing those roles, the nurse always considers making family and patient remain together. Then, the aim of nursing care to provide a chance to a family by giving a quiet room and time will comply.

### **3.6 The Implementation of Nurse's Role at The End of Life**

This part discusses nurse's role in providing a nursing care in the individual's end of life. As the end of life, patient's health lies in *ceteris paribus* condition where there is not an expected recovery anymore. Though, doctor profession still provides a medical care, yet, since a recovery does not be the main goal anymore, so that nurse who will more provide an intervention. Managing and providing a nursing care directly are aimed to make the patient can passing through their end of life as peaceful as possible. These are thought and judgment to attain the peaceful end.

Thus, the nurse needs an understanding of process and pathway of diseases and skill from each health team member (LaPorte Matzo & Sherman, 2006). The self-submission to God is the main aim in end of life. Thus, the aim of nursing care in this phase is to provide a chance to a chaplain to accompany a separation then provide a room and time for patient and family to pass it quietly. Then, the thoughts that can support the natural death are developed.

Throughout the relation is running, thus also the advocating role of nurse does. The advocating program is aimed to maintain the existence of patient and family. Those things are obligatory for the nurse because it can preserve an existence of human as she/he wants as well. However, if those things are neglected, consequently it will break the ethical.

### **3.7 Competency Nurse on Dying Process**

Nursing care is an essential of nursing service, In dying intervention, the relation between nurses, patient, and family take place. As a professional health care, the aim of nursing care is patient feels comfortable. The nurse participates to take a decision related to undergoing disease; plans who will release a separation calms the patient by digging a unexposed information such as asking apology to another person and alleviate the scared of dying process. Nurses make up the largest part of the multidisciplinary healthcare team, aiming at addressing a wide array of dying process needs, covering the biological, psychological, social, cultural, and spiritual extents.

End of live intervention is a comprehensive approach. As a consequence, nurses need to keep up with the updates on knowledge, technology, and evidence pertinent to nursing practice (Hariyati & Safril, 2017). Credentials should be made on nurses who care for terminal patients. Credentials are implemented to maintain the competence of nurses (Hariyati, Sutoto, Irawaty, 2014, Hariyati et.al.2017). Competence in ethics, caring, comprehensive care, communication, critical thinking and collaboration with health and social systems are



desperately needed to be improved. Increased competence of nurses can be improved through continuing professional development and nurse education improvement (Hariyati et.al, 2017, Rizany, Hariyati, & Handayani, 2018). The most important thing is to continue using the heart in treating patients in the process of death.

#### 4. Conclusion

The Nurse has a noble role in accompanying patient's dying process. Nurse through follow four stages of intervention refers to caring ethical. It starts with caring about, means care to a patient who has been treated. The second step is taking care of, that means take a responsibility. After that, for the third step is caregiving, it shows through giving a nursing care. The last step is care received, the nurse evaluates a success of nursing care. The nurse has protector function that, nurse complies a patient's need that relates to another health members. Nurse's power will give an ability to the patient and family while facing the hard moments. Nurse as advocator that the advocating nurse program is aimed to maintain the existence of patient and family.

Credential should be made on nurses who care for terminal patients. It is implemented to maintain the competence of nurses. Competence in the ethics, caring, comprehensive care, communication, critical thinking and collaboration with health and social systems are desperately needed to be improved. Most important is to continue using the heart in treating patients in the process of death.

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#### Authorship

1. Krisna Yetti Malawat, DR.,SKp., M.App.Sc. (Associate Professor and Senior Researcher)<sup>1</sup>, Expert in Ethic and Philosophy Nursing at Faculty of Nursing, Universitas Indonesia, Depok 16424 Indonesia, Phone: 628129465445, email: kymmam@yahoo.com. Correspondence: Kampus Fakultas **Ilmu Keperawatan, Universitas Indonesia, Depok 16424. Indonesia**.
2. Rr. Tutik Sri Hariyati, DR.,SKp, MARS (Associate Professor and Senior Researcher)<sup>2</sup>, Expert in Hospital and Nursing Management at Faculty of Nursing. Fundamental and Basic Science Department, Faculty of Nursing, Universitas Indonesia, Depok 16424 Indonesia, Correspondence: Kampus Fakultas **Ilmu Keperawatan, Universitas Indonesia, Depok 16424. Indonesia**
3. Rona Cahyantari Merduaty, Ns. SKep. (Junior Lecturer)<sup>3</sup>. Fundamental and Basic Science Department, Faculty of Nursing, Universitas Indonesia, Depok 16424 Indonesia,. Correspondence: Kampus Fakultas **Ilmu Keperawatan, Universitas Indonesia, Depok 16424. Indonesia**.