

## ● 原著論文 ●

# 急性期病院で看取られる終末期患者の エンドオブライフケアにおける課題の検討

入澤仁美\*<sup>1,2</sup>, 小林弘幸\*<sup>2</sup>, 櫻井順子\*<sup>3</sup>, 唐澤沙織\*<sup>2</sup>, 川崎志保理\*<sup>2</sup>

## 抄録

日本では都市化や核家族化に伴って在宅死が減少し、今や病院死の割合は約80%にものぼり、急性期病院でも終末期患者のケアの充実が課題となっている。急性期病院である順天堂医院の看護記録には、終末期の患者特有の苦痛を表す表現として、「身の置き所がない」という表現がしばしば使われている。本稿では、J大学付属病院で看取られた患者の、臨死期の電子カルテの内容を確認し、「身の置き所がない」というアセスメントがされた経緯をまず考察し、考察の結果、看護師は患者に発現している終末期患者に特有の苦痛が、進行中の治療では十分に症状緩和ができていないという判断をした場合に、「苦痛の原因を早急に特定し治療の幅を広げる必要がある」ことを含有した表現として、「身の置き所がない様子」という表現を使用していた。このような場面において必要な緩和ケアの在り方について、倫理的観点から考える。

**Key words** : 終末期医療, 看護記録, 緩和ケア, ジレンマ

臨床倫理, 9:5-19, 2021

## I. Introduction

### 1. Influence by hospital death having increased

Japan is now about to experience the emergence of a super-aged society which is unprecedented in the world. According to Statistics 2018 of Japan by the Ministry of Internal Affairs and Communications Statistics Bureau, the population ratio of elderly citizens, which was 5% in 1950, had increased to 23% by 2010, it is predicted to be 30.0% by 2025 and 32.8% by 2035<sup>1)</sup>. Further, the total death toll is estimated to increase from 1.2 million in 2010 to 1.66 million in around 2040, and the number of deaths from cancer is also expected to increase. According to the research by Ministry of Health, Labour and Welfare, the main cause of death in 2016 (population 100 thousand pairs) was cancer at 298.3, heart disease at 158.4, pneumonia at 95.4, stroke at 87.4, and senility falls at 74.2. Looking at the annual trend, the number of persons who die by cancer has continued to rise continuously, making it the highest in ranking of death factor since 1976<sup>2)</sup>.

As the number of cancer patients increases, the social problem of the place of medical treatment and the place of death will intensify. According to statistics for 1947, home death accounted for 90.8% of the total, but after the Second World War, the number of hospitals increased, along with the devel-

受付日: 2020.5.27 / 受理日: 2020.8.21

\*1 兵庫医科大学先端医学研究所(細胞・遺伝子治療部門)

\*2 順天堂大学大学院医学研究科病院管理学

\*3 順天堂大学医療看護学部

opment of medicine and medical care, such that the place of death changed from home to hospital. In 1950, home death accounted for 82%, followed by a steady decrease. After 1976, hospital death exceeded home death, and home death decreased to 12.7% in 2015. Since the number of municipalities promoting home medical care has increased, in 2016, home death increased 0.3 points to 13%, but the proportion of deaths in hospitals was still around 80%<sup>3)</sup>.

In recent years, home death has become less usual for Japanese people, due to a fact that home death has decreased and that the number of families living with the elderly has decreased as a result of the proliferation of nuclear families. As a result, the perception of death as “the result of insufficient support from the families of sick people” changed, and death was viewed as “one result that happens in the hospital.” In addition, with developments in medicine and the increase of available treatments, there are many patients and families who cannot accept their declared life expectancy, and who try to visit several hospitals in order to continue therapy so as to heal the disease. Some patients wish to receive advanced medical care even if it is expensive and involves some risk, even though the family members who visit the acute phase hospital in order to give a patient the highest level of treatment often do not want to shift to local medical institutions or home care because they desire a medical environment that can quickly deal with the symptomatic changes.

However, since the premise of acute care hospitals is that professional medical care should be applied intensively to patients who need urgent treatment due to sudden injury or acute exacerbation of the onset of chronic illness, medical staff are often unfamiliar with the appropriate care, such as palliative care and mental care that are necessary for patients who deteriorate day by day in the terminal or near-death period.

In addition, because hospitals are not “places of care”, they often continue treatment to prolong temporal life with a belief that medical personnel can sustain life, even for 1 minute or 1 second, but they cannot alleviate the pain distinctive to the end of life effectively. As there are cases in which patients in the near-death period are transferred to university hospitals or municipal hospitals, sometimes there are cases when such hospitals need to provide care in the last term, making the care of patients at their end stage a big issue.

## 2. Use of the expression “Minookidokoroganai” in nursing records

At Juntendo University Hospital, from April 2016, the electronic medical record data of a patient who died in the general ward was kept on record. As a result, when I confirmed the nursing records among patients who were observed at the general ward of Juntendo University Hospital in FY 2016 (April 2016 to March 2017), I found that a kind of pain of the terminal patients was assessed as being “Minookidokoroganai” by nurses. Originally, this word, “Minookidokoroganai” was a subjective expression that was used when he or she was unable to calm down due to some causes such as anxiety, irritation, pain, an itching sensation, defecation desire, or feel restlessness by some causes. However, at Juntendo University Hospital, nurses tend to use this expression as an objective term to express patient specific distress at the end of the term of life.

While this expression refers to some kind of signs of sudden change, a third party may not be able to judge whether the cause is attributed to mental distress, physical suffering, with sudden changes or

not, from a description only. On the other hand, the correspondence that physicians and nurses should take depends on the cause. Therefore, I will attempt to clarify what medical staff should do when they see a patient undergoing such an experience, that can be judged in many ways.

## II. Method

### 1. Survey target

I targeted the electronic charts of 441 patients who were admitted to the general ward of Juntendo University Hospital in FY 2016.

### 2. Procedure of Research

The presence or absence of the word, “Minookidokoroganai” in the nursing records within a week prior to the date of death, and if such a description was found, by further checking the description in the records of a second week previous, to determine the first time when the word “Minookidokoroganai” was used. Then I confirmed the process of care and treatment, and whether or not the palliative care team had intervened, as well as the interactions between the patient, the family, and the medical staff. Then, by comparing the before and after reports which were left in the electronic medical record, a third party examined whether or not the assessment of “Minookidokoroganai” by a nurse indicated a consistent interpretation of the cause.

### 3. Purpose of the study

By searching for the bias of the assessment of patients evaluated as “Minookidokoroganai”, we consider what kind of care was chosen for patients for whom the cause of the assessment could not be identified, from the viewpoint of medical safety, in order to improve the quality of medical care.

### 4. Ethical considerations

This research does not correspond to the ethical guidelines of “Research targeting people” because I checked only the electronic medical record data of the deceased patients. But considering the privacy of the bereaved family, the patient’s name has been withheld. When recording conversation contents from the medical record, data was extracted in such a way that the individual’s nomination and address were not specified.

In addition, I recorded the speech of those who participated in the event of “Medical Café Le Moi” and checked the content. This was approved by an ethical review at Hyogo College of Medicine in November 2017.

## III. Survey results

### 1. Results obtained by checking medical records(quantitative data)

The results of confirming the nursing records are shown in Table 1 below. “Stated cases” is the number of cases where the nurse recorded “Minookidokoroganai” in the nursing record. “Cancer cases” is

Table 1 Results obtained by checking medical records

2016.4-2017.3	4	5	6	7	8	9	10	11	12	1	2	3	total
Dead cases	31	41	31	40	47	33	41	40	35	43	30	29	441
Stated cases	5	5	2	6	6	2	4	2	4	7	6	6	55
Cancer cases	5	4	1	5	5	2	4	1	2	6	6	4	45
Palliative care	4	5	2	4	5	2	3	2	2	5	5	5	44
Sedation	2	0	0	0	1	1	2	1	1	0	2	2	12

the number of patients suffering from cancer among the patients who were assessed as “Minookidokoroganai”. The number of “Palliative care” is the number of patients who were given a treatment using opioids to relieve symptoms or who were supported by the palliative care team, among the patients who were assessed as “Minookidokoroganai”. The number of “Sedation” is the amount of sedation that is administered using drugs such as Dormicum among patients who have been assessed as “Minookidokoroganai”, intentionally lowering the level of consciousness in order to alleviate patient-specific-distress prior to death.

## 2. Results of a third party's ability to identify the basis of the assessment

There were 55 cases (12.5% of the total) that were assessed as “Minookidokoroganai” in the nursing records, with the first-time assessment having been made within 2 weeks prior to the date of death. It was found that the assessment of “Minookidokoroganai” is an assessment which increased for patients who are going to approach death with various pain. Of the 55 cases assessed as “Minookidokoroganai”, 21 cases were able to have the cause narrowed down to one, including 5 cases of pain, 14 cases of respiratory distress, and 2 cases of delirium. There are cases where the assessment “Minookidokoroganai” has been made several times, but in the case where the third party was also able to narrow down the cause to one, the conditions had been resolved by the treatment and care of doctors and nurses. For 18 cases of the remaining 43 cases, although there was a possibility that multiple factors may have influenced the onset of “Minookidokoroganai”, it was possible to improve the condition of “Minookidokoroganai” while checking both the patient's verbal and non-verbal response by nurses. On the other hand, patients in the near-death period have difficulty communicating and often cause various complications. In several of the 18 cases, the cause of the “Minookidokoroganai” condition was unable to be identified, and with the consensus of the family, the patient was sedated with Dormicum to alleviate pain by lowering consciousness level as the patient approached death. One characteristic of a case in which the cause could not be identified is that the symptom assumed from the causative disease, and the complaint and the state of the patient, are clearly different from each other; or when patient can not express their opinions through physical expression, such as “hand grabbing” and “facial frowning”.

Through this analysis, nurses at Juntendo University Hospital stated the patient's condition as much detail as possible in the nursing records, and they judged that physical pain that could not be expressed with words peculiar to end-of-life patients, which include respiratory discomfort with pre-death wheezing and mandibular breathing, extreme tiredness caused by the aggravation from head to foot while in a such state, edema caused by inability to discharge urine, general malaise, brain metastasis, organ fail-

ure, or terminal delirium, among other conditions, are emerging and ongoing therapy has not relax the symptom, they then use the expression, “Minookidokoroganai”, meaning that “it is necessary to promptly specify the cause of pain and broaden the range of treatment”.

## 3. Presence of dilemma in patients and families

When it is recognized that the patient is in a state of “Minookidokoroganai”, palliative care needs to be reexamined in order to broaden the range of treatment. Palliative care, as used here, is defined as follows: “Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual<sup>4)</sup>”, including support for both the mental care of the family and the patient's own death acceptance. However, only 80% of the patients undergoing the assessment of “Minookidokoroganai” had been given opioid-based pain care or had received intervention by a palliative care team, including family care, since if any patient expressed the experience of pain, if it was home care, palliative care was supposed to have been done. Therefore, in order to confirm the background behind why palliative care was not given, I reconfirmed the nursing records and the minutes of the team-conference.

In this regard, while palliative care is an indispensable treatment for patients who are about to die, it was confirmed that patients and families rejected it simply upon hearing the word “palliative care”. Speaking of “palliative care” in Japan, the reality is that many people still think that it is “pain control” and “supportive care for cancer patients”. Patients and families who selected Juntendo University Hospital as the place of treatment at the end of the term of life tend to expect to be treated if they are hospitalized, so if doctors inform them about the “palliative care policy”, they may feel that they are being abandoned by a hospital, without being treated. Also, as for confirmation of the intention of DNR (instruction to refuse resuscitation treatment) that is a part of the procedure at the time of hospitalization, they sometimes feel that the hospital is rejecting their wish to look for the possibility of treatment, at least as much as possible.

In such a case, even if the patient himself is so weak that he can not express his intention, the family insists on continued treatment with anticancer drugs, believing that if he were to be given such treatment, he would become healthier again. However, as medical persons also treat according to the needs of their own families, they may miss the timing of appropriate palliative care intervention. Patients and patient families who make such remarks tend to misunderstand the term “palliative care” as “care after treatment methods are gone”.

On the other hand, patients and families may be reluctant to intervene in palliative care because of the fear of opioids being drugs, and because of intrinsic anxiety. In fact, when a medical doctor proposes a palliative care using morphine to a patient's family, there are families who make remarks such as “Do not use morphine, I think you can still treat him”. There are many negative remarks about morphine in the records, such as, “we want to communicate with the patient, so please do not use it”, “It is poisonous”, “His or Her life will be shortened if you use drugs” and other such remarks.

In fact, there was a case in which the patient couldn't receive pain control as his family did not

approve the use of opioids. Medical persons recommend that the family allow flushing with Oxifast in order to alleviate the pain of the patient at the end of lung cancer, but his family answered, "There is a possibility that consciousness will be lost, so do not use it", so the nurse informed that he might tend to be somnolent but there was a high possibility that he was currently suffering from pain from abdominal fullness, and flushing with Oxifast would reduce his pain. However, his family would not approve, saying that they saw a little more hope. After that, the patient frowned with saying, "painful, painful", and although it is possible to reply occasionally, it becomes impossible to speak. Then the nurse recommended flushing with Oxifast to the family again, but they only say, "We do not think it is needed as he do not even have a consciousness". The following day, even though the patient was growling, and the nurse continued to persuade his family by explaining that there was a possibility that flushing with Oxifast may ease his pain, the family could not accept the patient's state of death. Consequently, medical persons could not flush with Oxifast until the patient died 2 days later.

In another case, while palliative care teams have begun using morphine to alleviate the pain and respiratory distress of lung cancer patients in the late stage, his family recognized that using morphine was a prerequisite treatment for transfusion, so they asked doctors to transfuse the following day as they felt that the patient would have desired it even on the day before his death.

In the other case, a patient with whom general condition was deteriorating due to the worsening of mesothelioma and his family were reluctant to have palliative care using morphine, but when he was in a state of anguish just before death, he suffered from various pain and his wife finally asked his doctor to sedate him. His death was approached by lowering his consciousness level by administering Dormicum.

Another case is that the patient's pain suddenly worsened two days before the day of death, and the patient himself informed a nurse that he could not put up with the pain in his back and could not wait for another hour until the next painkillers. He also assessed that his pain level was about NRS 9, however a nurse responded with only Loxonin as a pain treatment. He could not sleep and went back and forth between his bed and the lobby during that night. The next day as well he made a strong appeal. Although the patient had not proposed a way to treat his pain, Loxonin alone cannot alleviate the pain of end-stage liver cancer. Considering that the patient had a feeling of abdominal bloating and the urinary flow was poor even after catheter insertion, doctors should check the condition of ascites of a patient with a portable echo or request the palliative care team to intervene in order to ease his pain.

On the other hand, when a palliative care team nurse suggested the use of morphine for a patient who had pain from abdominal fullness, the patient asked her whether the side effects such as serious nausea, as seen in the TV dramas, would emerge or not, so she explained about the side effects carefully and then he answered, "I would like to use it, even if I become a little sleepy, I'd like you to use it right away." In this case, the importance of the knowledge about palliative care is well demonstrated.

#### 4. Results derived from survey

Due to reduced ADL (daily living behavior), a patient who is about to die will need assistance for excretion; and restrictions on bathing and even oral care will result in dignity becoming vulnerable, resulting in mental distress and pain. Also, when suffering from severe pain, the patient feels death and it can also be assumed that the patient is falling into panic due to the sense of anxiety that he may die as

he is. Medical persons need to support pain relief for such patients, allowing them to spend every day as they like<sup>5)</sup>. Even one claim, "painful", includes not only the pain coming from invasion and metastasis but also the pain that is derived from anxiety, fear and loneliness, such as the patients' claim, "the nurse accompanies me by talking about pain" and "I can not keep calm when I stay alone, but if a nurse comes to give pain relief, I can sleep safely". There was a case where a patient who had difficulty getting to sleep even though she seemed not to have increased pain at the time of death detained a nurse saying, "do not go". When the nurse touched her back for about five minutes, her facial expressions calmed down and she was able to fall asleep. There was another case where the patient complained of mental suffering to the nurse and he said that he wished her just to stay in his room because he did not want to put on even an electrocardiogram and an oxygen mask and if he was alone he would cry out a loud voice.

Regarding the pain that is assessed as "Minookidokoroganai" by nurses, even if they take advantage of the expertise of nurses at the acute care hospital, the cause of the pain should be considered as "total pain", which encompasses four aspects of terminal pain—physical, psychological, social, and spiritual, which are related to and influence each other. Even if the suffering on all sides is not manifested in a superficial complaint of the patient, we should understand that the patient is suffering internally from pain and distress in various aspects.

In order to broaden the range of patients' treatment in such situations, medical staff have to assess the true cause of the patient's "distress" that appeals, and multiple occupational staff, such as the doctor in charge, palliative care staff, nurses in charge, counselors, science therapists and patient families must work unitedly and correctly assess the condition of the patient in concordance in order to cure both psychological and physical pain at the same time. And in order to be able to effectively collaborate with each other, it is necessary to share information about the patient and patients' opinions about the medical treatment. Additionally, the management system that enable doctors in charge to collaborate with the doctors of the other departments and to exchange opinions about the change and satisfaction of the patient after engagement must be collaborative.

Further, patients under crisis situations have difficulty making decisions, even when families witnessing a sudden change in their patients also suffer upset and confusion, even if they are asked for surrogate decisions about treatment. Also, in the confusion, family members may not be able to speak clearly about their intentions, or they may not be able to make a choice that reflects patients' top priority. Therefore, in the treatment and care of a patient in the near-death period, an ethical dilemma tends to occur between a patient, a family member and a medical professional, or a patient and a sense of family and medical staff.

#### 5. End-of-life medical issues ascertained from interviews with medical staff and patients

##### 1) Nurses' roll in terminal care

At Juntendo University Hospital, a special function hospital, reports on the death cases of all hospitalized patients have been submitted to the Medical Safety Management Division, with about 60% of the reported cases being cancer patients. Even if medical staff explain that a condition is serious but does not require aggressive treatment, offering strong expectation and hopes, there are cases where

treatment is carried out under adequate IC (informed consent). Some staff report to the Medical Safety Management Division and consult about whether their medical attitude will develop into a lawsuit or not. Patients who choose the hospital regard palliative care as “terminal defeat”, so some family members feel that this hospital does not offer any medical treatment to the patients after their death. Therefore, even in the field of medical safety, there is a major problem in connection with the patient at the end of the term, and “care”.

At Juntendo University Hospital, where the average length of hospital stay is 11 days, the bed occupancy rate is 98% and the nursing necessity exceeds 30% on average, it is difficult to keep attending to one patient for a long time while one nurse is in charge of multiple patients. Nevertheless, in these conditions, it is the nurse who has been involved with hospitalized patients and their families for the longest time, who is physically and mentally close to both. Therefore, it is important for the nurse who provides patient centered terminal care in order to keep patients' QOL (Quality of Life) to understand that patients and their families are individually unique, that is, the fact is that “death” cannot be avoided, and encourage them to think about how to spend the remaining time, and to prepare. In order to respect the hope of patients and families, nurses sometimes have to consult doctors and review the nursing environment. The ability to observe non-verbal expressions of the hope of patients and families is needed for nurses.

## 2) Present condition of the palliative care team

The palliative care team at Juntendo University Hospital was established in January 2003 prior to the “Basic Plan for Promotion of Cancer Countermeasures” in July 2007, after which palliative care diagnosis by a full-time medical team began. The palliative care team consists of a palliative care physician, a pain clinic doctor, a mental clinic doctor, cancer specialist nurses, a clinical psychologist, pharmacists, medical social workers, physiotherapists, who hold a joint conference on a regular basis with relevant departments, the doctor and the nurse in charge with consulting about care. At the time of team intervention, patients and families will be interviewed, and intervention will be done after signing a consent form. Then, palliative care medical treatment will be added for cases where relaxation or team intervention occurs<sup>6)</sup>.

The palliative care team at Juntendo University Hospital is involved in the treatment in the form of consultation from the first to the last. For proposals relating to treatment given by the team, only the proposal content which has been examined and adopted by the department in charge will be provided to the patient. In addition, when a request comes to the palliative care team, the purpose of the request is stated. Basically, the palliative care team will consult the contents according to the purpose. However, even if the doctor in charge sees palliative care as supportive therapy, it might not provide for the mental support of patients and families. Also, when the palliative care team intervened and made a proposal, it was adopted into treatment by only about 50% of patients.

Among the patients subject to intervention by the palliative care team at Juntendo University Hospital, the number of patients admitted to palliative care treatment is 400 to 500 per year. Now, palliative care team is in the state of very heavy over loaded because they provide mental care to the other patients; and on Saturday, they hold a salon where cancer patients and families can talk to each other

and offer patient association activities. Considering the activities of the palliative care team beyond now, it is necessary to consider the expansion of the team.

## 3) Voices from the citizens

One day, Seven cancer patients, families, and bereaved families in “Medical Cafe Le Moi” held in Nishinomiya City, Hyogo Prefecture in March 2017. On that occasion, I examined whether they knew the definition of “palliative care” and confirmed whether they wished for palliative care when they entered the terminal stage of cancer. None of the participants knew the definition, and all of them think that palliative care is a terminal treatment with Morphine in order to control patients' pain. One of them, who had parotid gland cancer, insisted that she did not want palliative care because it involved drugs. And then, I informed her about the definition of palliative care by WHO (World Health Organization), she changed her mind because she then realized that mental support is essential for terminal patients.

On the other hand, a pancreatic cancer patient said that she had heard that Japan hospice has a limited number of hospices and that it is difficult to be admitted when necessary. She seemed to be anxious about the future because she thought palliative care was only practiced in hospices. Another woman who has experienced stage 4b malignant lymphoma said that when she had been a patient, she did not know palliative care included mental support and family care, so if one patient in the same room seemed to be nervous, the others in the same room encouraged her, and they did not realize that they could consult medical persons easily. She told that she felt that patients at the serious stage tended to cope with the anxiety about death and mental pain by themselves and with each other because they felt that they should not bother others as they may be dead in several months. In addition, she told us an episode about a particular nurse. She was hospitalized the next day after being diagnosed with Stage 4b cancer, and chemotherapy was scheduled to start from the following day. On the morning of the day that chemotherapy began, the deputy chief nurse visited her room and talked for about an hour to make her positive for treatment. She said, “I thought that if I had not met that nurse, I would have started treatment without understanding myself.”

It seems that many people are not well informed about palliative care, and that they regard it as being scary. They often begin to start treatment without thinking about the illness and the value of their remaining life time. If they get more information about the clinical conditions and clinical treatments, they may not feel a vague anxiety about terminal cancer or their own death. Therefore, disclosure of correct medical knowledge for citizens is important in order to promote self-determination about how they live and how they choose their recuperation places.

Also in Japan, even though the term “mental care” is frequently used, when it comes to the word “spiritual care”, it often connotes a negative image in that religion is involved and can not be trusted. Regarding this point, we should tell them that anyone can feel spiritual pain at the end stage of life.

## IV. Consideration

### 1. On the suffering of patients at the time of death

No matter how much medical technology advances, there is no treatment that can ultimately prevent

death, and everyone will die. It is a highly individual matter as to how to eliminate the suffering of patients in the near-death period and provide assistance for patients and families to have the death they wanted. Because patients at the time of death feel not only direct pain such as symptomatic pain or dyspnea, but also “total pain” caused by various factors, such as mental suffering from anxiety about relationships with family and friends, social distress from economic conditions and spiritual distress from why he or she contracted such a disease, or what his or her own life’s meaning was.

In such situations, a collaborative approach involving the multi-occupation such as physicians in charge, palliative care staff, nurses in charge, counselors, physiotherapists and patients’ families should collaborate to determine the true consequences of such background “suffering”. In order to ease patients’ total pain, we simultaneously offer psychological support and the treatment of physical distress by correctly assessing the condition of the patient.

## 2. Issues of terminal care in acute care hospitals

The hospital is not a place to support patients during the near-death period. However, in view of the current situation in which approximately 80% of Japanese deaths are now hospital deaths, we have no choice but to think about “giving better care in hospitals”. Nurses’ assessment of nursing records plays an important role in assessing the patient’s condition of suffering, because medical persons often reexamine their treatment plan and try to identify and cure the cause of the patient’s affliction at the terminal stage when they find a doubt in the nursing record created by the nurse.

In an acute care hospital, nurses oversee the patient on a 24-hour basis, but since intensive care of patients in the acute phase requiring urgent examinations and surgery will be prioritized in the state immediately after illness or injury has occurred, it may be more time consuming to provide patient care in the acute phase than to relieve pain and anxiety in end-of-life patients. Therefore, it is currently difficult for end-of-life patients and their families to decide how to spend their leisure time until their arrival. In addition to this, the feelings of patients and families during the terminal period, especially in the late terminal or the death period, frequently fluctuate as the symptoms get worse, and there is a tendency that selection of the treatment policy and place of recuperation will not be decided due to discrepancies in opinion on treatment among families or the opinions of relatives who suddenly appear. In such a medical environment in acute care hospitals, in order to carry out appropriate care for terminal patients with total pain, and realize satisfactory patient and family satisfaction, it is essential for nurses to enhance the skill of health communication: listen to the causes of distress of patients and their families, and explain symptoms and treatment in an easy-to-understand manner.

## 3. Response to ethical dilemmas over palliative care

Patients in a crisis of death are in a difficult condition to express their intentions even by inference, and their families who see sudden changes of patients also experience confusion, and even if they are asked for surrogate decision on treatment, family members may not be able to express their intentions accurately, or they may not be able to make a choice that ensures the patients’ top priority. Therefore, in the treatment and care of a patient in a near-death period, ethical dilemmas tend to occur between a patient, a family member and a medical professional. Since the awareness of advance directive

in Japan is low<sup>7)</sup>, it can be difficult to confirm the patient’s own intentions. Therefore, the medical person often has difficulty dealing with many situations. Even if the patients express their own will by themselves, the intention of the patients also changes according to the situation at each occasion. In the event that a manifestation of intention can not be indicated due to a decline in the consciousness of a patient who has reached the terminal stage, doctors and nurses often obtain information from families and friends in order to draw out the patient’s intentions. In addition to this, confusion among medical personnel make it difficult to make appropriate judgments in a situation where the patient suffers intensely, making it difficult to provide the treatment desired by the patient<sup>8)</sup>.

While we recognize the necessity of hospice and palliative care in modern medicine, it is only the pursuit of diagnosis, treatment, cure and prolongation of examination points that is developing. In addition, the medical system of modern hospitals is specialized and subdivided, meaning that patients receive a series of examinations for different symptoms when they consult a medical institution, after which the examination results are comprehensively diagnosed and treatment is begun. End-of-life patients are also included in such a medical flow, and since many doctors concentrate on examination and treatment, relief for symptoms afflicting patients is regarded as “symptomatic treatment”, and interests and concerns are low in the current medical situation. Under these circumstances, WHO called for the global promotion of palliative care for patients and families who were unable to be cured even with modern medicine, in 1990. WHO defined the palliative care as follows “palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” in 2002<sup>4)</sup> indicating that palliative care is also applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications. This represents a change in the guidelines for palliative care, in that palliative care should intervene not only at the stage of the terminal period but also at the stage of entering the terminal stage in order to relieve pain immediately in parallel with the treatment of the disease. In 2003, the European Ministerial Committee also adopted the “Recommendation 24 of the European Ministerial Committee on Palliative Care to Member States” which states that palliative care is to be provided not only to some cancer patients, but also to all patients in the end stage of life should be positioned as an important part of the health insurance system in each country. “Moreover, the origins of palliative care lie in the areas of religious care and nursing, rather than medicine<sup>9)</sup>, and palliative care draws heavily on a broad spectrum of disciplines, knowledge, skill, experience and creative thought<sup>10)</sup>”.

In light of this trend, all patients who feel distress-unique pains should have access to palliative care. According to a study of hospice terminal cancer patients conducted by Yodogawa Christ Hospital, the appearance of pain is conspicuous when the survival period is more than one month, and from the survival period of about one month, general malaise, anorexia, constipation, insomnia and other symptoms appear with increasing frequency. Confusion began to increase as the survival time approached 2 weeks, together with increased disability for self-mobilization. At the stage of only a few days, before death, wheezing begins, and disorders of water intake, conversation, and response increase rapidly.

Among patients and families, when making decisions on palliative care, a dilemma arises from the conflict between Morals and Ethics. Morals define personal character, while ethics dictate the working of a social system<sup>11)</sup>.

From the perspective of Ethics, patients' families understand that "it is necessary to relieve symptoms so as not to suffer from the patient", "I do not want patients to suffer unnecessarily", "palliative care is a socially recognized treatment" in their mind, on the other hand, as Morals of individuals, conflicting emotions emerge, such as, "morphine is scary", "you should not use it to the patient as well", "If a doctor uses morphine once, a patient may not be able to take treatment anymore", "a patient will be unable to communicate during palliative care" or "a patient must be unwilling to use narcotics". In order to alleviate such a dilemma, it is important for medical personnel to provide correct knowledge of palliative care to patients and patients' families, and to suggest palliative care intervention at an appropriate time while looking at the patient's condition.

It is said that ethical principles in medical treatment are harmless, benefits for patients, respect for autonomy, and fairness<sup>12)</sup>. Family members often do not give a consent to palliative care during a near-death period even when patients cannot express their intention any more. But if the family does not agree, it will not be possible to carry out necessary care to alleviate patients' suffering in the near-death period. Patients and their families who need to make decisions will make choices about treatments while being worried, anxious, and confused as to what should be used as a standard of judgment. And when patients and their families make decisions, it is necessary to explain the symptoms and the side effects of treatments sufficiently and ensure that they understand it. When choosing a treatment, the intent of the patient should be respected most, but sometimes the treatment advances without the patient's full understanding. Therefore, it is necessary for medical staff to not only support patients and patients' families in decision-making situations but also to understand the process of their decision-making in order to circumvent regret about their decision. The opportunity for genuine consultation and collaboration is of great benefit for the patient. These benefits have been an integral part of the practice of medicine for a long time, but the concept of who has the final say when there is conflict may still present difficulties. In palliative care, the final decision-maker is the patient, and the patient uses many pieces of information, many sources of support, and their own values as a guide<sup>10)</sup>.

Even if the patients themselves do not recognize the pain as a problem to be addressed, the medical staff must support and encourage them to accept actively pain relief, while paying attention to the fact that the majority of patients at the terminal stage have pain. Specifically, medical persons should explain that it is important to deal with pain at an early stage leading to efficient pain relief, since the progress of the disease state and pain are not necessarily proportional, and there is a possibility of improving ADL by relieving pain while speaking in plain language to both patients and their families. Palliative care in acute care hospitals should also provide whole person care<sup>13)</sup>.

For patients in the near-death period, the medical personnel will be charged with two obligations: "Eliminating patient suffering" and "Do not let the patient die without treatment." However, in the case of sedation, the two responsibilities conflict and the dilemma emerges. The patient cannot express his intention, and the patient's family does not know whether he can speak accurately to his doctor. With lack of knowledge of the patient and family background, the medical doctor may experience confusion

regarding his choice of treatment. In such a case, an important consideration of view at such a stage is to recognize that if one intends to satisfy one's ethical value, the other value will not be satisfied. For example, by attaching a life support device, the principle of self-reliance of a patient is kept, but a patient is subjected to physical invasion and a change in appearance, and the principle of harmlessness to a patient will be violated. Therefore, medical staff seek to understand the background of the conflicting value, and the values of people related to the patient, and as a member of a medical team, medical staff judge what is the best for patients and consider the treatment and care plan while taking account of the patient and family.

#### 4. Issues relating respect of the Quality of Death of patients in the near-death period

The report of the National Congress of the Social Security System Reform that was announced in 2013 stated that for the range of "Medical treatment and cure for the whole region" commensurate with the super aged society, there also must be medical treatment to raise "quality of death (QOD)" with a view to ensuring the dignified death of human beings who are destined to die<sup>14)</sup>. The concept of QOD was transferred to the Lien Foundation of Singapore's charity organization in 2010<sup>15)</sup>. It was the beginning of the assurance that the quality of care to be given to people who are about to die is reported as a result of investigation based on materials such as basic environment, degree of penetration, and cost, among others. In the report, it was pointed out that the QOL has spread but QOD has not been spread in the same way, noting that countries incorporating palliative care in medical policy are few<sup>15)</sup>. Japan is no exception.

According to the results of the Ministry of Health, Labor and Welfare's statistics for the first time in 2014 about house death by region, the regional difference has almost tripled due to the influence of the state of home medical care in the area. By municipality, the ratio of home death tends to increase with depopulated areas with few medical institutions. The highest in the entire country was 54.8% at Kozushima village in the Izu Islands; the second was 50% at Yoron-cho in Kagoshima prefecture. Both are remote islands<sup>16)</sup>. Taking into consideration the current state of Japanese "hospital-weighted type" care in the present age where the aging society is accelerating, it is necessary to improve the medical system within hospitals in order to respect the QOD of the patient such as what kind of death they want. To that end, it is important to look not only at biological phenomena that are made data with the aim of prolonging the patients' lifespan simply by using advanced medical care, but also to observe by paying attention to the patients' view of life and death, mental satisfaction and their narrative. In addition, it is also necessary to ensure patients and families understand information that is offered by medical persons and help them form their own values. Self-responsibility is accompanied by the formation of values and decision-making about medical treatment. Patients and family members have freedom of choice according to their own sense of value, that is so-called self-making; but once they express their opinion, the consequences from that will be to take full responsibility on their own.

Therefore, instead of emphasizing just procedural justice, such as, confirmation of DNAR (Do Not Attempt Resuscitation), informed consent using written forms and acquisition of consent forms, medical personnel should explain not only the merit of treatment and the hospital environment but also the dis-

advantages, and when patients and families are confused, they should also propose and explain other options in order to ensure equality of opportunities for their decision-making. In the case of late terminal and near-death patients, since the general condition changes day by day, there is no treatment manual or fixed form of care. Therefore, medical staff should recognize that such way of thinking like, “should be involved”, “such an ideal care” and “should accept such death” sometimes cause excessive performance from Paternalism.

## V. Conclusion

It is essential for the medical staff involved in end-of-life care of the patient to strive understand the importance of the patient’s background, the existence of conflicting value and the relationship of the persons related to the patient, and to consider the treatment and care plan in terms of the benefits for patients. It is also necessary to understand the background of the patient by paying attention to the fact that patients may not understand information that medical persons take for granted.

In order to realize patient and family-oriented medical care, it is necessary to abandon pride as professionals and develop medical care in a way that involves patients and families actively. When technical provision as a profession becomes the object of treatment and is pushed on to the patient and the patient’s family unknowingly, it will be impossible to understand the background and benefit for the patient. For this reason, when other medical professions collaborate and practice team medicine, patient-centered viewpoints must be shared among them since the staff at the acute care hospital have less time to get in touch with the patient than staff at home care. The acute care hospital is not a system in which the purpose of each job category is different within the organization with the top belonging to the doctor, but rather a team medical system in which patients and families participate in the form of sharing the terminal points of terminal care.

### Reference

- 1) Ministry of Internal Affairs and Communications Statistics Bureau : statistics 2018 of Japan, I part Chapter 2 ; population and household change of the population and in the future population, (<http://www.stat.go.jp/data/nihon/zuhyou/n180200100.xls>, 2018.8.27) (2018).
- 2) Ministry of Health, Labour and Welfare : Population dynamics of our country, (<https://www.mhlw.go.jp/toukei/list/dl/81-1a2.pdf>, 2018.8.27) (2018).
- 3) Ministry of Health, Labour and Welfare : Recent trend of the home medical care, (<https://www.mhlw.go.jp/file/05-Shingikai-10801000-Iseikyoku-Soumuka/0000134262.pdf>, 2018.8.27) (2014).
- 4) Sepúlveda C, Marlin A, Yoshida T, et al. : Palliative Care : the World Health Organization’s global perspective. *Journal of Pain and Symptom Management*, 24(2) : 91-96 (2002).
- 5) Miyashita M (edit) : *Nursing Graphica Adult nursing science7 Palliative care*, 12-15, Medicus Shuppan, Co. Inc., Osaka (2014).
- 6) Okuno S : Present state of palliative care—Challenge to palliative care as comprehensive study, *Juntendo Medical Journal*, 57(6) : 570-581 (2011).
- 7) Morita T, Tsuneto S, Shima Y : Definition of sedation for symptom relief : a systematic literature review and a proposal of operational criteria. *Journal of Pain and Symptom Management*, 24(4) : 447-453 (2002).
- 8) Watanabe M, Kikui K, Ohashi N : Nursing ethical consideration on the role of nurses supporting decision making ; Analysis from narrative by phenomenological method. *Journal of Medicine, Life and Ethics, Society*, 3(2) : 62-77

(2004).

- 9) Kellehear A : The changing face of dying in Australia. *The Medical journal of Australia*, 175(10) : 508-510 (2001).
- 10) Crawford GB, Price SD : Team working : palliative care as a model of interdisciplinary practice. *The Medical journal of Australia*, 179(S6), S32-34 (2003).
- 11) Osawa M, Yoshimi S, Washida K, et al : *Encyclopedia of Contemporary Sociology*, 1328-1329, KOUBUNDOU Publishers Inc., Tokyo (2012).
- 12) Tokyo Women’s Medical University Nursing Department : End-of-life Care of Acute Hospitals and Supporting Patients with Family Minds. 42-53, Chuohoki Publishing Co., Ltd. Tokyo (2012).
- 13) Nitta K : Practice of medical care and care at home, 59, Ishiyaku Pub, Inc., Tokyo (2007).
- 14) National Assembly : Social Security system reform national assembly report ; A path to pass on sustainable social security to the future generation. (<https://www.kantei.go.jp/jp/singi/kokuminkaigi/pdf/houkokusyo.pdf>, 2018.8.27) (2013).
- 15) Economist Intelligence Unit, Lien Foundation : The quality of death ; Ranking end-of-life care across the world. ([https://www.lienfoundation.org/sites/default/files/qod\\_index\\_2.pdf](https://www.lienfoundation.org/sites/default/files/qod_index_2.pdf), 2018.8.27) (2010).
- 16) The Nihon Keizai Shimbun : Regional difference 3 times the local depth difference reflected in hand at home. ([https://www.nikkei.com/article/DGXLASDG06H7F\\_W6A700C1CR8000/](https://www.nikkei.com/article/DGXLASDG06H7F_W6A700C1CR8000/), 2018.8.27) (2016)

## A Study of the Challenges of End-of-Life Care for Terminal Patients in Acute Care Hospital

Hitomi Irizawa<sup>\*1,2</sup>, Hiroyuki Kobayashi<sup>\*2</sup>, Junko Sakurai<sup>\*3</sup>,  
Saori Karasawa<sup>\*2</sup>, Shiori Kawasaki<sup>\*2</sup>

<sup>\*1</sup>Hyogo College of Medicine Institute for Advanced Medical Sciences Laboratory of Cell and Gene Therapy

<sup>\*2</sup>Juntendo University Graduate School of Medicine Department of Hospital Administration

<sup>\*3</sup>Juntendo University Faculty of Health and Nursing

In Japan, home death has decreased due to urbanization and nuclear familization, and since 1976, the rate of hospital death continues to exceed that of home death. As the rate of hospital death has now reached approximately 80%, improvement of the care of end-of-life patients is an issue even in acute care hospitals. In the nursing records of one acute care hospital, Juntendo University Hospital, the Japanese expression “Minookidokoroganai” is often used to refer to patient-specific-distress at the end of the term of life. In this paper, we report the electronic medical record of one patient who was nursed during the final moments of life at Juntendo University Hospital, and examine the circumstances of the assessment of “Minookidokoroganai”. As a result of the examination, when the nurses judged that the distress peculiar to the terminal-end patient was not sufficiently alleviating the symptoms in the ongoing treatment, the nurses used the Japanese expression “Minookidokoroganai” meaning that the medical team should quickly diagnose the cause of the pain and expand the range of treatments. In such a context, we consider the appropriate modality in the context of Ethics.

**Key words** : end-of-life medical care, nursing record, palliative care, dilemma



ISSN 2187-6134

# 臨床倫理

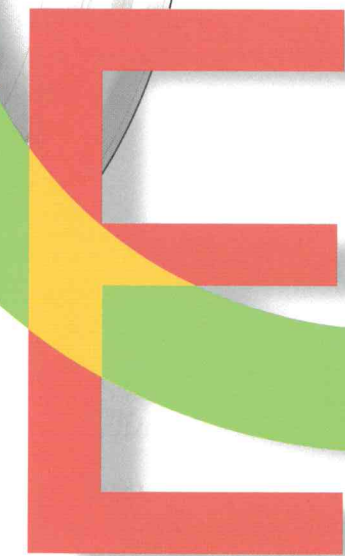
No. 9  
2021

巻頭言／素朴な疑問と臨床倫理

特集／それぞれのコロナ禍 臨床倫理の観点から



Journal of Clinical Ethics



日本臨床倫理学会