

**NURSING ETHICAL GUIDELINE IN CARING OF
TERMINAL CANCER PATIENTS**



**A THESIS SUBMITTED IN PARTIAL FULFILLMENT
OF THE REQUIREMENTS FOR
THE DEGREE OF MASTER OF SCIENCE (PUBLIC HEALTH)
MAJOR IN MEDICAL AND PUBLIC HEALTH LAW
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Thesis
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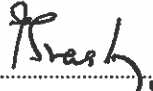

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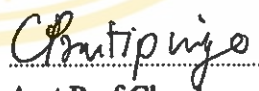

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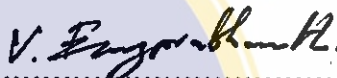
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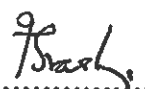

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NURSING ETHICAL GUIDELINE IN CARING OF TERMINAL CANCER PATIENTS

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ABSTRACT

The objective of this study was to set up nursing ethical guidelines for caring for terminal cancer patients using the EDFR (Ethnographic Delphi Futures Research). The sample group consisted of a total of 32 experts in caring for terminal cancer patients, experts in medical law and public health, and experts in moral problems concerning care of terminal cancer patients.

Basic ethical principles of health care such as the respect for person, beneficence, non-maleficence, and justice or fairness were used as guidelines for caring for terminal cancer patients in 6 key areas 1) Proper pain handling.; 2) Veracity/truth telling where relatives desired to withhold information from patients.; 3) Carrying out treatments at proceeding believed not to in patients in treat.; 4) Prolonged life.; 5) Stopping treatments.; 6) Preparing the advance directives by evaluating the conditions of patients and relatives such as level of awareness, understanding in disease diagnosis and prediction, coordinating patients and relatives to discuss with treatment team for joint planning, respecting the patients decision and recording the treatment on the written basis.

This study offered a suggestion that these constructed guidelines should be tested to find out possible applications in Thailand's context.

KEY WORDS: GUIDELINES / TERMINAL CANCER PATIENTS / NURSING ETHICS

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แนวปฏิบัติในการดูแลผู้ป่วยมะเร็งระยะสุดท้ายให้สอดคล้องกับจริยธรรมการพยาบาล
(NURSING ETHICAL GUIDELINE IN CARING OF TERMINAL CANCER
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บทคัดย่อ

การศึกษานี้มีวัตถุประสงค์เพื่อสร้างแนวปฏิบัติในการดูแลผู้ป่วยมะเร็งระยะสุดท้ายให้สอดคล้องกับจริยธรรมการพยาบาล โดยใช้เทคนิค EDFR (Ethnographic Delphi Futures Research) กลุ่มตัวอย่างจำนวน 32 คน คือ ผู้เชี่ยวชาญด้านการดูแลผู้ป่วยมะเร็งระยะสุดท้าย ผู้เชี่ยวชาญด้านกฎหมายการแพทย์และสาธารณสุข และผู้เชี่ยวชาญด้านปัญหาจริยธรรมในการดูแลผู้ป่วยมะเร็งระยะสุดท้าย

จากการนำหลักจริยธรรมพื้นฐานของบริการสุขภาพ ได้แก่ การเคารพในความเป็นบุคคล การทำในสิ่งที่ดีและเป็นประโยชน์ การไม่ทำอันตราย และความยุติธรรมหรือความเสมอภาค มาเป็นแนวทางจัดทำแนวปฏิบัติในการดูแลผู้ป่วยมะเร็งระยะสุดท้ายใน 6 ประเด็นสำคัญ คือ 1) การจัดการความปวดที่เหมาะสม 2) การบอกความจริงกรณีญาติต้องการปิดบังผู้ป่วย 3) การปฏิเสธการรักษาที่ก่อให้เกิดความทุกข์ทรมาน และไม่เกิดประโยชน์ 4) การใช้เครื่องมือเพื่อยืดชีวิต 5) การยุติการรักษา 6) การทำหนังสือแสดงเจตจำนง ให้ใช้วิธีประเมินสภาพผู้ป่วยและญาติระดับความรู้สึกตัว ความเข้าใจข้อมูลการวินิจฉัยโรค และการพยากรณ์โรค ประสานให้ผู้ป่วยและญาติได้พูดคุยกับทีมผู้ดูแลรักษาเพื่อวางแผนร่วมกัน โดยต้องเคารพการตัดสินใจของผู้ป่วยและ บันทึกลงเป็นลายลักษณ์อักษร

จากการวิจัยครั้งนี้มีข้อเสนอแนะว่า ควรนำแนวปฏิบัติที่สร้างขึ้นนี้ไปทดลองใช้ และศึกษาความเป็นไปได้ในการนำไปใช้ในบริบทของประเทศไทยต่อไป

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CHAPTER 1

INTRODUCTION

Background and significance of the problem

Cancer is a chronic disease that is a health problem of citizens around the world since it causes losses and torture. Most cancer patients going to the hospital for treatments were found they were at the last stage of disease in which it has been widely spreading and it was difficult to be cured. Most patients came to see the doctor for the right treatment when cancer has spread so much and they became ill seriously; hence, the treatment did not give any good results and patients passed away eventually, which led to the high rate of death. But, according to medical technology progress used in health caring, patients had longer life. Changes of public health system, economics and politics, complication of health problems, and expansion of nurses' roles resulted to moral problems of related parties, especially nurses who closely cared of patients than other personnel in the health team (Prakong Intrasonbat, 1994:36; Mutchupa Vongweera; 1997:49; Siwalee Sirilai; 1999:10-11). The tendency of situations that were moral problems in this nursing practice would be more difficult and complicated. Therefore, the nursing ethical guidelines on caring of terminal cancer patients were so essential and important, which helped nurses facing moral problems in caring of cancer patients efficiently.

Terminal cancer patients had fragile life and they had to count days they were still alive because their life might come to an end at any minute (Pinit Ratanakul, 2002:12). Thus, nurses caring of patients at this stage had to achieve qualifications that were different from general nurses. The important qualification was ethics, which made nurses stay aside patients without disgust or leave them stay alone when they had the last breath. Ethics reminded nurses to treat patients, who had dignity, with love and kindness. Ethical nurses would take every effort to minimize patients' distress or, if possible, to wipe out all or did not add more misery to them whether by

words or actions. Ethics concerned what should be done and what to be done was the most useful for related parties. To help the terminal cancer patients die peacefully was an action full of ethical and religious value since it showed out love and kindness that were the most important ethics appraised and promoted by all religions. In practice, moral problems have been frequently found and severe gradually. This situation was inevitably avoided by nurses caring of terminal cancer patients. As nurses always confronted moral problems without any attention and care by related parties; nurses felt exhausted, discouraged and tried to avoid it (Aranya Chovalit, 2002:43). According to literature review, moral problems regularly faced by nurses caring of terminal cancer patients included pain handling, veracity, allocated treatments, medical equipment to sustain life, stopping treatments, and advance directives (Siwalee Sirilai, 1992: 33-35; Tassanee Thongprateep and Vipada Kunavikantikul, 2002:127-137; Farida Ibrahim, 1999:139-141; Wanwisa Sangprasert, 2003:184-189).

Terminal cancer patients should have opportunities of talking with nurses and relatives to let them know about their thinking, feelings, and problems after learning their coming death. Hence, nurses should have communicative skills since they had to coordinate with all related parties or caring agencies. However, perspectives about caring as well as thoughts about death and death handling have changed greatly; for example, increasing death in hospitals, refusal of life rescue, life willing, etc. Therefore, caring plans for patients had to be discussed clearly, which should be flexible and adjustable as appropriate and was recorded carefully for future transfer. The most important matters were the contact between the treatment providers and patients and family, acceptance of behavior, understanding of feelings, careful wording, and giving opportunities to patients and family to do what they required based on spiritual belief (Phra Phaisarn Visalo, 2004:2-11), which could allow patients and family to overcome such crisis and patients would die peacefully or called “good death”. During this crisis, many changes would be reversibly made; for example, a patient decided not to bear the respiratory apparatus at the first time, but when the disease was more severe causing the patient felt more difficult in breathing, the patient or relatives might ask such equipment from the doctor due to fear and worrisome, or, sometimes, the patient might require it while his/her family not, etc. Therefore, the evaluation and follow-up had to be done periodically. These problems

made nurses caring of patients or patients' family feel no confidence or agitated in caring of patients, especially at the last period of patients' life. If nurses emphasized on their work more than patients' needs, this might result to the ignorance of patients' mental, emotional and spiritual needs.

Moreover, caring of terminal cancer patients involved other problems since it dealt with ethics and laws. For instance, life-sustaining procedure by permanently connecting the patient body with many medical equipment deteriorated human prestige or dehumanization, or the patient's refusal of treatment subject to life-sustaining procedure made the rescue procedure for a nearly-dead patient maintain his/her actual humanization (Vitoon Ungprapan, 2001:2). Treatment of terminal cancer patients, so, dealt not only medical considerations but legal issues until the Right to Die Laws was issued in the United States such as California, Oregon, and Texas, etc. In Thailand, this matter has been mentioned as well. Giving a right to a person to die peacefully with human prestige at the end of life was the right to access into the natural condition when it was time to leave this world and it was the original fairness that humans had; it should not the right to handle the life before the appropriate time (Sawaeng Boonchaloemvipas, 2004:142). The legal issue to be considered further dealt with the person(s) who had intention to exercise such right. If this was theoretically answered, it should be the patients who exercised such right, but, in practice, the nearly dead patients were unable to express their intention because most of them were unconscious and any decision about medical treatments had to be made by the doctor or relatives. This issue might cause many problems since the relatives might not acknowledge a fact that patients were nearly dead; so the relatives always hoped that their beloved ones would become well and go back home, or if relatives knew this fact, they required the full treatment in return for gratefulness. The more there were relatives in a family, the harder the decision could be made (San Hatteerat, 2001:22-24). This could be seen that if the decision were made in contrary with the fact, the good wish would conversely add the misery to patients who would die unmercifully. This problem led to the concept on advance directives; patients' directives could be expressed in advance. Several countries issued laws to support this matter. For Thailand, this issue was prescribed in Section 10 of the National Health Bill:

“A person has a right to prepare the advance directive indicating not to receive health services only for sustaining the last period of life.

Any action pursuant to Paragraph One of the advance directive shall be subject to the criteria and procedures as prescribed in the Ministerial Regulation.

Public health professionals have a duty to perform in accordance with the person’s intent as described in Paragraph One. Actions as per such intent shall not be deemed the mistake of public health professionals who shall be relieved from all faults.”

Setting up a right to die peacefully with human dignity at the last breath was to select the death, by nature, without being intervened by equipment or technologies until patients were in the condition of “impossibly recovering but not dying”. The statement on “human dignity” was stipulated in the Constitution and Section 10 of the National Health Bill, but it was not much concerned by the government so nothing was in progress.

Now, there were more attempts to study knowledge components concerning this matter for medical personnel, but such knowledge has not been widely spread, especially the terminal cancer patients because most people in the Thai society did not like to talk about death since they felt that death was the bad omen or fear to be avoided as far as possible. Talking about death seemed that we cursed patients to die quicker. But, death could not be avoided. Caring of patients who were confronting death, so, was the complicated circumstance since every related party whether the health team, patient, or patient’s family all desired to select the most appropriate treatment methods that gave the best benefit to both patient and family. However, since humans had different values, beliefs, experience, and points of view about life and death (Aranya Chaovalit, 2002:48); thus, caring of terminal cancer patients inevitably caused moral problems. Constructing the knowledge base and conducting researches regarding these matters that fit to the Thai society should be studied to have guidelines so that nurses would be able to understand concepts on changes in each period and factors affecting patients and family; as a result, nurses were able to have care in consistence with actual needs, which might be revised as appropriate until patients and family felt that they had value, had less embarrassment, were able to talk or leave what was in their mind, and confronted the death with brave and calm

heart, consciousness, and confidence. In the meantime, nurses would not have any embarrassment in facing patients' problems and have more confidence in their caring. Therefore, the researcher selected the Ethnographic Delphi Futures Research: EDFR as the study method that was suitable and reliable because the guidelines were set up by experts with knowledge and experience in caring of terminal cancer patients. In addition, the study results could be applied as guidelines in conformity with each hospital's treatment policy.

Research Question

What were characteristics of nursing ethical guidelines on caring of terminal cancer patients?

Research Objectives

To propose nursing ethical guidelines on caring of terminal cancer patients in accordance with experts' viewpoints.

Scope of research

This study was conducted by the EDFR technique in 3 groups of experts: experts in caring of terminal cancer patients; experts in medical laws and public health; and experts in ethical problems concerning caring of terminal cancer patients to find out the nursing ethical guidelines on caring of terminal cancer patients.

Defitions of research

Moral problem referred to a situation requiring the ethical consideration about what should or should not be done, by which ethics was the reason for explanation (McConnell, 997:26).

Nursing referred to a profession of treating service recipients based on the knowledge about caring of and helping service recipients on health problems, surrounding arrangements, as well as giving assistance to physicians in the treatment.

Terminal cancer patients referred to cancer patients diagnosed by the physician that cancer was the cause of disease spreading, which could not be remedied absolutely. Also, according to the existing information, it was likely that such cancer patients would be alive not longer than 6 months.

Expert referred to a person with knowledge and experience about ethics in caring of terminal cancer patients, which could be divided into 3 groups as follows:

Group 1: expert in caring of terminal cancer patients referred to a person with experience in caring of terminal cancer patients. He/she earned the bachelor degree or up and was willing to attend the research by signing in the informed consent.

Group 2: expert in medical laws and public health referred to a physician or nurse or academic or instructor who earned the master degree or up in fields of medical laws and public health or an academic instructing medical laws and public health, who was willing to attend the research by signing in the informed consent.

Group 3: expert in ethical problems concerning caring of terminal cancer patients referred to an academic or instructor who had the academic work regarding moral problems concerning caring of terminal cancer patients, earned the bachelor degree or up and was willing to attend the research by signing in the informed consent.

Basic ethical principles of health care referred to principles used as guidelines on nursing ethical practice (Beauchamp & Childress, 1994:120-429). These principles included:

Respect for person referred to the respect for independence of selecting or setting up one's actions;

Beneficence referred to the prevention of bad luck or danger to be affecting other persons, and the promotion of good actions;

Non-maleficence referred to not taking bad luck or danger to other persons; and

Justice/fairness referred to fairness and equality should be obtained by everyone.

Nursing ethical concept referred to the provisions or behavioral/practical guidelines on nurses, which have been already decided that they were right and appropriate for patients (Fry, 2002:37-42) including:

Patient advocacy referred to doing a duty of protecting basic human rights.

Accountability/responsibility referred to the assistance given to each patient so that he/she obtained quality health care while his/her needs were also served.

Cooperation referred to the involvement with other persons to achieve the quality of caring patients.

Caring referred to the behavior showing supports such as not ignoring patients, respecting patients, sympathizing, and giving informality with patients.

Caring guidelines for terminal cancer patients in conformity with nursing ethics referred to the content prepared as guidelines on roles and duties of nurses in caring of terminal cancer patients to meet the set goals.

CHAPTER 2

LITERATURE REVIEW

This study concerned the nursing ethical guidelines on caring of terminal cancer patients. The researcher has studied related documents and research to support the research concepts as listed below:

1. Nursing ethical principles
2. Concepts on caring of terminal cancer patients
3. Concepts on nursing moral problems in caring of terminal cancer patients
4. Related research

1. Nursing Ethical Principles

Professional nursing was the profession containing the relationship between human life and nursing. Nursing was the ethical magnificence relating to caring of individuals' health based on the art of hospitality and ethical principles. Persons working in this profession had to touch persons who had illness, pain from diseases, and distress caused by loss of life almost all the time. Therefore, professional nursing aimed at nursing excellence, which meant that nursing had to satisfy and favor service recipients under the willingness of service providers. The way to nursing excellence depended on ethics of nursing providers. Ethics, thus, helped stimulate nurses to have morality and to have ethical behavior to patients whether by physical, oral, and mental manners (Apiwan Khaewwannarat, 2004:3).

According to Dictionary of the Royal Thai Academy B.E. 2525 (The Royal Thai Academy, 2002:216), ethics was defined as morals for operation, morality, and moral doctrine.

Several authors presented definitions and ethical concepts that were valuable and beneficial for nursing operation as follows:

Sivalee Sirilai (1992:32) stated that there were two meanings for ethics. The first one referred to good behavior for benefit and happiness of oneself and society, which

was based on the religious doctrine, cultural and traditional moral principles, laws as well as ethics of professions. The second one referred to the consideration about what should or should not be done when facing a situation and decision should be done.

Mutchupa Vongveera (1997:6) stated that ethics was rules of behavior to be performed by humans based on morality, philosophy, culture, laws, or custom to promote the qualifications naturally existing in humans for the benefit of humans and society.

Somkid Isarawat (1994: 38) stated that ethics referred to good actions by physical, oral, and mental manners that were useful for oneself, others and society.

From statements mentioned above, it could be said that ethics referred to obligations or operation guidelines decided what should be done and right. In the professional nursing, ethics was greatly used for nursing operation in almost nursing procedures.

Key basic ethical principles of health care referred to principles used as guidelines on ethical nursing operation consisting of (Beauchamp & Childress, 1994: 120-429; Veatch & Fry, 1997:29-115):

1. Respect for person – This ethical principle believed that living in a society had to be based on respect with each other and respect for autonomy that a person was oneself, had autonomy to select or dictate his/her own actions according to human rights, had autonomy to make decisions, and dictating his/her own behavior. The philosopher presenting this concept was Kant, who had a belief that an individual was reasonable and capable of making decision by oneself. Therefore, this principle supported a patient's decision to take actions according to his/her own value and belief, to have rights to make decisions independently and free of enforcement, which should be accepted by the health team whether the team would agree with it or not. Chally & Loriz, 1998:18) stated that a person's autonomy meant that a person had a right to perform based on personal value and belief whereas nurses had ethical duties to respect for patients, accept their value, and support them to make decisions as per their self-value. In case of conflicts between value of patients and value of nurses or professional value, patients should be respected in terms of autonomy to select the treatment methods by themselves. The above statement was consistent with the concept of Vitoon Eungprabhanth (1995:168) that every human had an ethical duty to

respect for others' autonomy. Therefore, in order to respect patients' decision to select their path according to belief, morality, and religious faith, health service professionals had a duty to honestly provide all information to patients for patients' decision about health services they actually desired. Each patient's history was the personal secret; nurses had the duty to keep it confidential. The autonomy of professionals had to be in the frame of standard operation and services provided to patients had to be based patients' benefit first.

2. Beneficence – The concept of this ethical principle was that one should prevent bad luck or danger affecting other persons. One should wipe out the evil. One should have good actions or promote good things. One's actions should convey kindness, good wishes, and hospitality to mankind as well as actions benefiting other persons. Nurses' roles based on this principle included disease prevention, health promotion, health recovery, pain and torture ease. However, it was usually found that the principle of good and beneficial actions might be contrary to the principle of respect for autonomy; health personnel made decisions for patients by believing that such decisions were suitable and useful for patients, which should be acceptable and followed. However, although the objective of this method focused on patients' interest, health personnel's views about health treatment might be contrary to those of patients who had no right of choice when they have not been involved in decision-making. Jameton (Jameton, 1987: 29) divided such paternalism into 2 types: strong paternalist by which decision was made for one who was able make a decision by himself/herself, and weak paternalist by which decision was made for one who was unable to make a decision by himself/herself. Nowadays, roles of health care have changed; the focus was on giving correct and sufficient information so that patients would be able to choose the most appropriate ways by themselves. Care emphasizing on patients' independent decision was an operation based on the principle of good actions and interest and the principle of autonomy (Thelan et al., 1998:21-22).

3. Non maleficence – this ethical principle prescribed that one should not take bad luck or danger to other persons. This principle was based on a concept that everyone in the society had a duty not to harm others, whether physically or mentally. Nurses also had the commitment not harm patients both directly and indirectly or not to take patients to any risks. But, in practice, the principle of non-maleficence had to

be considered with the principle of beneficence. For example, a decision in the conflict situation between life sustaining and stop treatment, which could not be decided based on either ethical principle, but all related principles to get the most appropriate decision while non maleficence principle should be used as the key guidelines on decision-making (Thelan et al., 1998:22).

Moreover, in practice, it might be found that some nursing activities did not harm patients directly or make them in danger while nurses did not violate this principle. For example, in case of giving chemotherapy to patients, nurses have learnt that chemotherapy gave side effects to patients; so this case was contrary to this ethical principle or not. For this issue, McCormic (1973 cited in Aranya Chaovalit, 2002:79) proposed a principle to help decide such action or the principle of double effect. This principle identified 4 conditions. If such action consisted of all 4 conditions, it shall be deemed that such action was right whether it led to advantages or disadvantages. Those conditions were 1) That action was not bad or wrong.; 2) Actor intended to have advantages only.; 3) Disadvantages should not means leading to advantages, that is, advantages would be achieved by results of actions not disadvantages.; 4) Advantages resulted by that action should have more proportion or weight than disadvantages to be arising out.

4. Justice/Fairness – The meaning of this ethical principle was that everyone should be treated fairly and equitably. Ellis & Harley (Ellis & Harley, 1995:204) explained fairness/justice in 3 characteristics: fairness in term of equity, which referred to equivalent opportunities and freedom to access into provided health services; fairness in what should be got, which referred to the receipt of health services in accordance with fundamental rights as it deemed necessary or suitable for each person; and fairness in term of interest distribution, which referred to the appropriate distribution of health services, resources, and burden in the society because taking actions to enhance fairness in the society was quite difficult especially the fairness-based allocation of limited health resources. Nurses were able to use the principle of fairness instead by respecting patients' decision and alternatives to receive the medical treatment because patients would be treated fairly as ones taking part in self-caring.

For ethics as the guidelines on professional nursing, they enhanced professional values since they have been set up and developed from ethical philosophy and basic concepts to be used as guidelines for confronting moral problems. Ethics of professional nursing and announcement of patient' rights were detailed below:

Code of Ethics

Nursing was the treatment directly done to person, family, community, and society. Nursing was a kind of services significant for people's life and being; thus, professionals had to be highly responsible, reliable, and specialized in work performance, and had ethics. Therefore, code of ethics was set up as the performance guidelines. The code of ethics in each profession consisted of declaration, oath, commitment, and setting of rights, duties, and responsibilities as well as operation of that profession to be used as professional decision and to maintain professional standard. Main points joined by each profession were the realization in human value and prestige of service users and fair and equitable service. For The Nurses Association of Thailand, it set up Thailand's nursing code of ethics, which was first announced on 26 October 1985. However, due to technological progress and awareness in human rights, self-reliance, and public needs of higher standard quality of life, nursing code of ethics was revised and replaced by Nursing Code of Ethics B.E. 2546 (A.D. 2003) containing the following contents (The Nurses Association of Thailand, 2005:3-13):

1. Nurses shall be responsible for general people who desire nursing and health services;
2. Nurses shall carry on their profession with kindness and respect for the value of life, good health, and happiness of mankind;
3. Nurses shall have professional reaction with service users, colleagues, and general people under the respect of individuals' prestige and human rights;
4. Nurses shall hold the principle of justice and fairness in human society;
5. Nurses shall perform the profession with a focus on nursing excellence;
6. Nurses shall prevent the danger to health and life of service users;
7. Nurses shall be responsible for treatment until the public is reliable to nurses and professional nursing;

8. Nurses shall have cooperation to make progress with the professional nursing;
and

9. Nurses shall be responsible for themselves like for others.

In Thailand, health organizations, which were directly involved with patients, namely The Medical Council, Nursing Council of Thailand, The Pharmacy Council, The Dental Council, and The Therapeutics Committee, foresaw the benefit of compiling fundamental rights of patients as well as traditional operation relevant to Thai ways of life. Hence, they issued the announcement of rights of patients on 16 April 1998 aiming at enhancing good understanding and reducing conflicts that would lead to the trust as the basis of good treatment. The key contents of such announcement were as follows (Nursing Council of Thailand, 1998:32):

1. Every patient has fundamental rights to receive health services as stipulated in the Constitution.

2. A patient has rights to receive services from health professionals without any discrimination due to different status, race, nationality, religion and society, political faith, sex, age, and characteristics of illness.

3. A patient asking for health services should gain sufficient and clear information from health professionals so that he/she shall be able to make a decision on agreeing or disagreeing to be treated by health professionals except in the necessary or emergency case.

4. A patient at the risk of life has a right to obtain the emergency help from health professionals immediately as necessary regardless of that patient's request for help.

5. A patient has right to know the first name and last name as well as type of health professional providing health services to him/her.

6. A patient has right to ask for comments from other health professionals who do not provide him/her health services. The patient also has right to change health service providers and health service houses.

7. A patient has right that his/her own information is strictly concealed by health professionals except any permission by the patient or their duties prescribed by laws.

8. A patient has right to obtain full information for the decision on participating or withdrawing from being tested in any research conducted by health professionals.

9. A patient has right to obtain the information about his/her own medical treatment noted in medical records upon demands, but such information must not violate the personal rights of others.

10. Father, mother, or duly representative may exercise rights on behalf of patient who is younger than 18 years old or is physically or mentally disabled and is incapable of exercising such rights by himself/herself.

In the past, it was found that the first nurse of professional nursing was Florence Nightingale, an English lady. She perceived that human illness was what to be cared, attended, and helped with each other. She sacrificed her own happiness to ease pain and illness of miserable persons by her moral and ethical nursing without concerns about profits or returns resulted by her actions. Consequently, professional nursing was not a profession undertaken for monies, work positions or work progress, but for human care and life while those professional nurses had kindness, mercy and good wishes to make others happy pleasant all the time. Nurses have always sustained the ethical actions done by Florence Nightingale. Ethics and professional nursing, so, were actually essential for patients and service recipients. There were many concepts on professional nursing, but only 4 concepts would be proposed here (Fry, 2002:37):

1. Patient advocacy – Nurses had a duty to provide help to patients in important situations (Fry, 2002:38). In the eye of the law, it shall be deemed that nurses perform a duty of protecting fundamental human rights (Annas, 1974 cited by Fry, 2002:38); for example, a patient had unsolvable problem, did not understand or did not pay attention in his/her own rights as health service user, did not know how to expect for care to be given by health service system, did not know who could give some help in problem solutions, did not obtain some convenience caused by complicated rules and regulations in health service agencies, and obtain unsafe or unqualified service. These problems should be watched out by nurses always. Duties of nurses as patient advocates were listed below (Farida Ibrahim, 1995:247-248):

1. To educate patients about health problems so that they were able to find out appropriate alternatives.
2. To inform patients of their rights so that they were able to use such rights upon demands completely.

3. To supply resources suitable for patients and give them opportunities to use as appropriate.

4. To communicate among patients, family, physicians, and health team for relevant understanding.

5. To educate the personnel so that they realize in their work responsibilities and promptness to serve patients' needs.

In addition, performing duties on behalf of patients mirrored the relationship between nurses and patients. Fry (Fry, 2002:38) proposed models of performing duties on behalf of patients as the guidelines on ethical decision:

- Rights protection model: nurses should perform under the scope of health service system by informing patients of their receivable rights, and nurses should be confident that patients understand their own rights, and prevent the violation of patients' rights.

- Value based decision model: nurses should help patients discover their needs, interest, and alternatives that were in conformity with their own value and belief. Nurses only informed of advantages and disadvantages of each alternative and allow patients to make decisions by themselves.

- Respect for person model: in performing duties on behalf of patients, what should be first considered by nurses was human values, personalization, and alternatives of patients. In case that patients were incapable of making decisions, nurses should protect patients' interest by following patients' demand as previously told to relatives or others having power to make decisions on behalf of patients. In the event that no one was able to inform of patients' demand, nurses would select the best for patients.

2. Accountability/Responsibility – This was an important ethical concept on nursing operation concerning the relationship between nurses and patients according to ethical accountability as prescribed in the Code of Ethics by identifying nurses' accountability for caring patients in respect of health promotion, disease prevention, recovery, and care for less pain (ICN, 2000 cited by Fry, 2002:39), and by showing nurses' responsibilities for themselves, patients, profession, agencies, and society (Fry, 2002:39; Potter & Perry, 1997:322-323). Ethical accountabilities of nurses included helping patients to obtain the quality care and performing professional

nursing. Nurses not only held the potential in helping patients, they were capable of easing displeasure and pressure, and selecting the best ways to respond patients' needs (Mutchupa Vongveera, 1997:44). The accountabilities in professional nursing helped maintain the standard of health care, which could be used as a mechanism for evaluating the professional self-development. In addition, as taking roles on behalf of patients, accountabilities helped set up ethical concepts and were used as the guidelines for solving moral problems (Fry, 2002:39).

3. Cooperation – This was an ethical concept emphasizing on the cooperation between nurses and colleagues both inside and outside the profession in order to meet the main goals, that is, quality care, which was a concept on promoting nurses to work with others under joint objectives, promise keeping, good reaction, and sacrificing self-interest to maintain sustainable relationships in the profession. Therefore, cooperation was the significant power pushing professional personnel to work together under good quality (Fry, 2002:41). For Thailand's professional nursing, the concept on cooperation with others was set forth in the Code of Ethics in activities that were useful for the whole society, both inside and outside the health regime in the local, national, and international levels (The Nurses Association of Thailand, 2005: 11).

4. Caring – This concept dealt with the value-based relationship between nurses and patients. The behavior showing mercy or caring indicated roles and duties of nurses in caring patients because it showed out the commitment of nurses in protecting human prestige for patients and health caring (Fry, 2002:42). There were 4 models on caring: 1) Being there for the patient model.; 2) Respecting the patient model.; 3) Feeling with patient model.; 4) Closeness with the patient model (Forrest, 1989 cited by Fry, 2002:42). Therefore, mercy or caring was an ethical duty holding by nurses to show out their supports (Mutchupa Vongveera, 1997:46).

Nursing was a profession developed from people's moral sense and realization in human rights in order to serve the social needs to maintain health and happiness of all mankind for all physical, mental, social, and spiritual parts, which were performed with high responsibilities based on intelligence, expertise, and morality.

The Professional Nursing and Midwifery Act B.E. 2528 (A.D. 1985) (Nursing Council of Thailand, 1999:2) prescribed that nursing referred to actions done to

humans in relation to caring and helping in case of illness, condition recovery, disease prevention, and health promotion as well as assisting physicians in medical treatments based on scientific principles and nursing science.

Ratana Thongsawas (1991:15) stated that nursing referred to the profession was the knowledge-based profession or solution procedures by the scientific ways on a concept that human was the composition of body, mind, spirit, and environment. Understanding in the principle of caring, thus, was the most important composition of nursing.

Farida Ibrahim (1999:127) gave the definition of nursing as helping persons solve health problems, whether physical health, mind-society, or spirit as well as caring of both persons and environment so that they lived peacefully and adjusted, whether persons or environment, suitably.

In conclusion, nursing referred to a profession acting towards service recipients based on knowledge about caring and helping service recipients about health problems, arrangements of environment as well as helping physicians in medical treatments. Therefore, the professional nursing required both good nursing and ethics. From the above definitions, professional nursing should refer to obligations or guidelines of operation to service recipients based on 4 fundamental elements of nursing code of ethics; namely, respect for person, beneficence, non maleficence, and justice or fairness. These four elements would be used as the guidelines on caring and helping service recipients solve health problems and arrange the environment, and helping physicians in medical treatments and judge what should or should not be done.

The professional nursing was a duty giving high impact to service recipients; service recipients relied on nurses, both body and mind, when they became weak or ill. Nurses could give the close care to make patients overcome the crisis until they were able to fight against diseases, have spirit to maintain self-prestige and pride, and have better and happier recovery. The success in these roles required strong supports by morality and ethics of nurses. From the aforesaid reasons, every nurse should realize and take emphasize on morality and ethics. In practice, if nurses had some ethical deficiencies, whether personal matters or working behavior, they would be widely commented by the public. Professional organizations, therefore, stepped in to

take care and lay down the criteria for all nurse members, that is, “nursing code of ethics”, which shall be deemed as rules and regulations to be complied by all professional members. In addition, such code of ethics prescribed obligations in relation to penalties for anyone violating the code of ethics.

In daily working, nurses, inevitably, faced problems relating to ethics. Thus, in any operation, nurses should have careful consideration and comprehensive understanding in each situation as Davis & Aroskar (Davis & Aroskar, 1991:1-2) stated that to enhance good results for all parties, nurses had to consider or check out the situation, patient and family, laws or philosophy of living, custom and tradition, and principles of ethics. Moreover, nursing leaders have tried to build up nursing ethical models as the guidelines on caring of patients in order to insist that, in nursing operation for the public health, nurses have performed their work under ethics, mercy and caring without any danger to patients, and their nursing quality was guaranteed.

2. Concepts on Caring of Terminal Cancer Patients

“Cancer” was the horrible word for general people; it made patients who acknowledged that their illness was caused by this disease had severe tension, and frightened anyone diagnosed as the cancer patients. Furthermore, if the physicians told patients that they were at the final stage of cancer, patients would feel that death was coming since this disease was so severe and it was impossible to be totally cured. However, according to scientific progress and medical technology, many equipments have been invented to rescue or sustain life such as respiratory apparatus, cardiac pacemaker, as well as drugs to sustain patients’ life although they were in the unconscious condition. Such technologies took roles to sustain patients’ life unnaturally and to be alive without any feelings or perception, and no one knew how long this condition would continue. Such illness could not be cured and most patients were terminal cancer patients whose death was delayed by advance technologies. Such type of patients was likely to be increasing (Supaporn Daodee, 1994:1).

Narin Voravut (2003:1) stated that cancer was the genetic disease whose tumorigenesis was the multistep carcinogenesis. It was caused by many factors starting from genetic changes, body immune system, environment as well as

carcinogen and some infections. When the genetic changes arouse out in body cells, whether grounded by natal abnormality or environment, it led to the biochemical changes, and cell shape and qualifications were turned to be the premalignant cell and the malignant transformation finally. Then, the metastasis occurred; it gradually destroyed tissues of body organs and also caused the metabolic changes and physical complication until patients had symptoms and clinical feature, and died eventually.

Seymour (1993, Paiboon Suthiwan, translator, 1997:186-189) said that cancer could be divided into 4 levels to specify the extent of cellular changes. The specific features used to divide the levels of cancer included the characteristics of cells, the characteristics of nucleus, and the number of mitotic division of cells. The least severe cancer was ranked in Stage I, showing that the malignant tumor was still at the same position. For cancer ranked in Stage II, the malignant tumor became bigger, and in Stage III, the metastasis spread out to nearby lymph glands. For the most severe stage of cancer, the metastasis spread out widely from the original malignant tumor. The severe cancer could be spreading out in 4 ways: 1) Absorbing into surrounding cells.; 2) Passing through lymph glands.; 3) Intervening into the blood stream.; 4) Growing the serous cavities of the body. The cancer severity was staged under the same standard by using TNM Staging System from International Union Against Cancer (UICC) and American Joint Committee on Cancer (AJCC) by T referred to the primary tumor, N referred to regional lymph node, and M referred to metastasis. Each stage was also subdivided into 1-4 according to worse disease foretelling. Knowing the patterns of metastasis was important for treatment planning.

Definitions of terminally ill patients were various as some examples below:

San Hutteerat (2001:2-3) defined terminally ill patients as the seriously ill patients and/or hopeless patients with the following 3 definitions:

1. Seriously ill patients – Patients whose body organs necessary for living were being attacked seriously, especially central nervous system (brain and spinal cord), blood pressure system, and respiratory system.

2. Hopeless patients – Patients with physical and/or mental illness who had no chance to be out of pain and to spend their remaining life for their self-interest or others' interest. They were hopeless patients in the eye of modern medicine, but in

view of patients and relatives, they still had some hope. Or in views of traditional medicine or other kinds, such patients might not be hopeless ones.

3. Terminally ill patients – Patients with symptoms as signals that they would be alive no so long such as cancer patients in the metastasis stage.

Wandee Phokakul (2000:2) defined a hopeless patient as the illness impossibly to be cured by any medical treatments. Caring methods, thus, were not aimed at remedying until they turned to normal, but allowing him/her to have good quality of life and prestige and to spend his/her remaining time as worthily as possible.

Pornlert Chadkhaew (2003:289-290) defined a terminally ill patient as the following 3 groups of patients:

1. Imminent-death patients such as seriously ill patients who could not return to normal, and it was expected that they would pass away in next hours or days, and it was no sign of recovery.
2. Lethal-condition patients such as seriously ill patients who could not be cured, and it was expected that they would die by 3-6 months.
3. Severe, irreversible-condition patients such as seriously brain-ill patients who were unconscious or comatose, but they were still alive for several months.

Chanchai Sitthipan (2005:1) defined terminally ill patients as physically ill patients who could not be cured totally. In addition, according to existing data, it was expected that patients would be alive no longer than 6 months.

Supaporn Daodee (1994:29) stated that caring of terminally ill patients would be the palliative care. The characteristics of terminally ill patients could be summarized below:

1. Terminally ill patients required a great extent of mental and spiritual palliation due to pain and torture caused by cancer at the final stage. As a result of discouragement and despair to live on, caring of such patients dealt with responding their mental and spiritual needs, but physical caring had to continue; otherwise patients would have more torture. The terminally ill patients, so, required the integrated care covering physical, mental, social, and spiritual parts.
2. Terminally ill patients required more caring than curing. They might not stay in the hospital for any remedies since they were irreversible, so they required some care instead. Caring of terminally ill patients did not concern caring of disease, but

taking care of patients as persons whose human prestige should be respected until their last breath.

3. Terminally ill patients did not live alone, but they had the family and members in the health team dealing and acknowledging patients' feelings. Therefore, nurses had to take care of patients' family and colleagues in the health team as well.

In conclusion, a terminal cancer patient referred to the cancer patient medically diagnosed that cancer was the ground of disease that could not be cured. According to existing data, it was expected that cancer patients could be alive longer than 6 months.

Subject to definitions of terminal cancer patients, every patient has been threatened by death, but the reactions of each were different depending on individuals' specific characteristics. In accordance with researches regarding death conducted by scientists, it was more understood about the impact to body when death arrived, which could be predicted by doctors. However, what threatened patients' mind was difficult to be understood. Hence, everyone understood that death meant losses; most people preferred to avoid it or not deal with it. But, in fact, death was inevitable for everyone although he/she desired it or not.

Facing Death by Terminal Cancer Patients

Facing death by terminal cancer patients was the situation where patients were learning that their death was coming, which led to the reactive behavior, either accepting or denying it. Kubler Ross (1969:289) divided the reactions to death by terminal cancer patients into 5 stages; each stage might not occur step by step, but reversibly:

Stage 1: Stage of denial and isolation – Once patients knew that they were going to die, they would feel frightened, fell in a faint, and choked since they have never prepared themselves for such news before. After feeling frightened, patients would deny and not accept this fact.

Stage 2: Stage of anger – When patients were able to accept the fact, they would be sad and angry; admonished others, felt irritated and annoyed, had inconsistent moods, were worried, sleepless, had no appetite, might be foul tempered, and did not cooperate in any treatment.

Stage 3: Stage of bargaining – Patients began to accept and negotiate for hope, desired to rely on the holy objects they trusted.

Stage 4: Stage of depression – Patients had depression and much sadness, did not talk to anyone, have less food, desired to stay alone silently, looked forlornly, and were sleepless.

Stage 5: Stage of acceptance – Patients accepted, were resigned to their fate, accepted the medical treatment and were ready for solutions, did not negotiate for any hope. At this stage, patients felt exhausted, weak, and desired to have a rest.

Later, Buckman (1993 cited by Copp, 1998:384) proposed and divided patterns of reaction and emotions of terminally ill patients into 3 stages: initial stage, chronic stage, and final stage. Each stage focused on all emotions and reactions expressed by persons when they learnt that their life was facing death. Buckman also proposed that the expression was the result of stimulus. He did not mention 5-stage reactions described by Kubler Ross such as fear of nearly dead condition, guilt, hope, despair, and adjustment by humorous thinking, which Buckman said that they could be found in clinical feature. Moreover, there was another death facing pattern proposed by Pattison (1977 cited by Copp, 1998:385) who mentioned about the living dying interval. He indicated that a person would have reactions and expression lapping and dealing with the worrisome. Such living period starting from the time of acknowledgement of death to the time of death could be divided into 3 stages: critical stage, chronic stage, and final stage.

According to concepts on death facing and patients' emotions at the last stage that were full of sadness and lamenting, we have learnt that patients' mental status and needs were variable and different for each. Caring to response patients' needs should emphasize on the individual care base. The terminal cancer patients actually desired much mental palliation (Puangrat Boonyanurak, 1998:5) and the palliative care should come into place (Smith & Bohnet, 1983 cited in Rossaporn Prathumwan, 1991: 20). Therefore, terminal cancer patients should be cared to have the quality of life and happiness; nurses should give some help and palliation to serve physical, mental, spiritual, and social needs of patients (Pickett, 1993:104).

Lack (1977:160-166) mentioned about the palliative care of terminal cancer patients as follows:

1. Total care focusing on the individual patients as persons with physical, socio-mental, and spiritual needs.

2. Control of actions possibly giving impact, both physical and mental, to patients.

3. Control of pain. Pain of terminal cancer patients involved not only the physical pain, but also other kinds of pain such as mental pain, economic, interpersonal relationship, etc. The principles of control were as follows:

- Continuous pain control – Nurses needed not to give medicine once patients felt painful because it would add up pain and worrisome to patients; they feared that pain would return, and distress came from thinking about pain; so pain became more severe.

- Patients should wake up to stay with their family and friends – Nurses should not give medicine to patients when they were sleeping.

- Patients should live like normal people with the least pain.

- Patients should be comfortable and free for moving; so nurses may give the oral medication or insert the suppository into the rectum.

4. Palliation of patients' mind, emotions, and spirit by not ignoring them, listening to them, and give them some assistance.

5. Care of patients' family that was in the state of sadness due to losses. The palliation should be done before and after the patients' death.

Most people did not want to die. But when the death came, everyone wanted to die peacefully without any pain or torment (Tassanee Thongprateep, 2004:42). However, due to technology progress, now, death could be prolonged; patients might die lonely among high-tech equipments. At present, when patients' rights were announced, the final-stage patients or nearly dead ones gained such rights as well. Bear (1994:428) noted rights of nearly dead patients and their needs during the last period of life as listed below:

- Right to be cured as humans until they die.
- Right to maintain a full hope.
- Right to be cared by persons helping patients maintain some hope.
- Right to express emotions or feelings about the coming death.
- Right to be involved in any decision about self-caring.

- Right to expect treatments from doctors and nurses continuously although the objective of treatment was turned from remedies to comfort.
- Right to die lonely.
- Right to be painless before death.
- Right to ask questions and get factual answers.
- Right not to be deceived.
- Right to obtain some assistance from other persons to allow patients' family to accept patients' death.
- Right to die peacefully and deserve human prestige.
- Right to insist patients' self-being and not to evaluate patients' decision that might not be consistent with other beliefs.
- Right to express feelings and talk about religion(s) or spiritual experience.
- Right to expect that patients' human being would be respected by the public even after their death.
- Right to receive kind care by knowledgeable persons who comprehended needs and satisfaction of patients until they were capable of confronting the death.

We could see that terminally ill patients had health inefficiency and needed some care from nurses. Hence, nurses giving the completed care had to achieve skills, knowledge, expertise, and mindset. Earnest (1993:1073) said that nurses should have 3 kinds of responsibilities: **Responsibility to themselves** whereas nurses had to know about their own thinking and feelings to response patients' death, understand facts of life and death, discover and separate their own feelings, and participate in sadness with patients and family.; **Responsibility to patients** by giving the palliation covering physical, mental, socio-mental, and spiritual care in order to maintain functioning of controllable body organs, to control pain, release symptoms, give and take information, palliate and support in the sadness procedure.; **Responsibility to family** by always realizing that family members of patients should be cared by nurses as well since these members took part in perceiving feelings caused by patients' death.

Definitions of Guidelines

Anuwat Suppachuthikul (1997:89) defined guidelines as the contents

systematically prepared to direct operators in working and to be an appropriate instrument for decision-making in a situation.

Guidelines pursuant to Dictionary of the Royal Thai Academy B.E. 1982 (2002: 456) referred to lined practice.

Principles of Guidelines Preparation (Yuwadee Ketsompan, 1997:90-92)

The preparation of guidelines was based on the following principles: focusing on patients and results to them based on the best; such principles could be scientifically proved including principles received by experience that was acceptable by that profession; synchronizing the principles should be done by the most reliable methods to avoid any doubt in the operation; there should be suggestions attached for operators' consideration; the procedure of preparing guidelines should consist of multi-sciences and be flexible so that they could be used in many areas; the information about resources should be considered including supports in part of devices, appliances, and budgets; drafted procedures should be tested and evaluated periodically for further regular revision for being updated guidelines.

There were different forms of guidelines starting from short and simple contents showing the operation standpoints to the complicated form attached with a great extent of information or the article form by giving the information and values, which led to suggestions about conclusions on what should be done.

The variety of operation partly came from the different discretion of operators, which resulted to the different distribution and outcome. Guidelines systematically prepared to enhance appropriate actions could be used as instruments for decision-making and reduction of unnecessary difference (Anuwat Suppachutikul, 1998:89). The method of acquiring the information for the preparation of guidelines by the EDFR technique could be applied for such preparation suitably.

3. Concepts on Nursing Moral Problems in Caring of Terminal Cancer Patients

Moral problems could be explained in 2 meanings: a situation dealing with ethical issues that had to be selected while there were two or more alternatives (moral

dilemmas); and ethical-conflict situation requiring a decision for further action (Davis & Aroskar, 1991:7; Mutchupa Vongveera, 1997:49).

Sivalee Sirilai (1992:33) defined moral problems as situations or matters with the following characteristics:

1. Matters could not be terminated by the empirical fact only.
2. Matters were so complicated that it was difficult to determine clearly how facts and information would be used in judging.
3. Results arising out did not take impact the facing situation only, but also future situations.
4. Results affected all patient, caregiver, and family.

McConnell (1997:26) defined the moral problem as a situation requiring moral considerations about what should or should not be done while ethical principles were reasons of explanation.

Therefore, guidelines on caring of terminal cancer patients in conformity with nursing ethics referred to the contents prepared as the guidelines for roles and duties of professional nursing in caring of terminal cancer patients as set goals.

In daily operation, it was impossible that nurses avoided moral problems because nurses had direct responsibilities for caring of patients and represented patients (Fry, 2002:38). But, frequently, nurses did not have decision power and were unable to take part in decision-making about patient caring. In addition, Chally, 1997: 399) found out that moral problems faced by nurses concerned the violation or infringement as the fundamental rights of patients by the health team. If moral problems were ignored and solved, they would give hard impact to professional capabilities of patient caring. Also, they might be factors leading to burn out, be powerless, and resign from this profession. Moral problems in caring of terminal cancer patients were identified by several persons below:

Sivalee Sirilai (1992:33-35) stated that, generally, nursing moral problems frequently found included truth telling, giving some to patients before their death, helping attempts, or stop treatments.

Tassanee Thongprateep and Vipada Kunavikatikul (2002:127-137) stated that moral problems about caring of terminal cancer patients included rescue and non-rescue, life ending or helping patients commit suicide, euthansia, natural life ending

without any special help, allocation of limited medical equipments, caring of service users to allow them to die peacefully.

Farida Ibrahim (1999:139-141) studied and collected moral problems on caring of terminal cancer patients, which included truth telling, caring for pain and torment relieve, will, life sustaining or death.

Wanwisa Sangprasert (2003:84-189) conducted a study by interviewing terminal cancer patients, relatives of terminal cancer patients, and physicians giving medical treatments. She found out moral problems on caring of terminal cancer patients as follows: terminal cancer patients desired to know the truth, pain handling, selection of treatment forms, use of medical equipments to prolong life, stop treatments, and advance directive.

As mentioned above, moral problems have existed so long but guidelines have not yet been concluded. Therefore, the researcher was interested in conduct a study about nursing ethical guidelines on caring of terminal cancer patients in 6 areas: 1) Pain handling.; 2) Truth telling.; 3) Allocated treatments.; 4) Use of medical equipments for prolonged life.; 5) Stopping treatments.; 6) Advance directives. These guidelines would help nurses experience moral problems fearlessly or avoid such problems.

3.1 Pain Handling

Terminal cancer patients desired to live on without any torment caused by pain; receiving suitable and adequate pain-killing drugs was essential. However, sometimes, the health team was afraid that giving a high dose of opioid would cause some side effects; compressing the respiratory system that made patients die quicker. Sometimes, the health team was afraid that patients would be addicted to drugs although, in fact, the addiction was least possible for patients having pain and no background of narcotic addiction (Kemp, 1999:107). Therefore, it was found that painful patients were not given sufficient amount of medicine to relieve their pain (Aranya Chaovalit, 2002:71). Caring of terminal cancer patients for benefits and no-harm or drawbacks to patients and family had to depend on the joint operation of multi-profession team. In addition, professional operators should be equipped with knowledge and abilities of caring of patients as well as positive attitude towards caring of this group of patients. But, in fact, the health team has not had sufficient

knowledge and abilities of caring of such patients, especially knowledge and abilities of assessing pain and pain handling. In according with a study reporting knowledge and abilities of nurses caring of painful patients (Kemp, 1999:107; Aranya Chaovalit, 2002:71), it was found that nurses achieved insufficient knowledge about giving pain-killing drugs and assessing patients' pain since they were afraid that patients would become addicted or the pain-killing drugs might compress patients' respiratory system.

A key target of caring of terminal cancer patients was to allow patients to have the quality of life by controlling their torment caused by pain. But, when the health team achieved insufficient knowledge about pain handling, especially pain assessing and pain-killing drug giving, they feared to give such drug to patients; as a result, the health team could not meet the target set for patients' quality of life.

3.2 Veracity/Truth Telling

Veracity was a basic principle of developing and maintaining trust among humans. Veracity was also a basic necessity for communicating and creating the relationship in the society that accepted persons' rights to acknowledge facts. Therefore, one had a duty of telling truth and was not deceived (Chally, 1997:400; Fry, 2002:24).

Subject to the research conducted by Wanwisa Sangprasert (2003:185), it was found that every terminal cancer patient desired to acknowledge the truth that he/she got a cancer, which resulted to his/her decision on selecting or denying medical treatments. Guidelines of truth telling for cancer patients were summarized below:

1. Truth telling should be based on a principle that every patient should acknowledge this fact except 1) Patients did not have good mental condition or had some mental problems until they were unable to receive such fact.; 2) Patients stopped their ear to anything and had negative thinking always.; 3) Patients were uneducated, did not understand or have any roles in medical treatments.; 4) Patients did not have completed consciousness.

2. Truth telling should be artistic by not dictating patients' fate. The teller had to build up his/her self-confidence so that he/she would be able to persuade relatives and patients. Truth telling should start from telling such fact to relatives and asking about characteristics of patients from those relatives to assess patients. Telling the truth to

patients should be soft and avoid serious wordings strongly attacking patients or making them have negative feelings. For some patients, the direct telling might not be suitable; thus, “cancer” should be avoided and replaced by “severe tumor” or “bad tumor”. If patients required knowing the stage of cancer, the teller should explain that tumors could be divided into 4 stages and patients were in the fourth stage; not tell them that they were at the final stage of cancer.

3. If relatives disagreed to tell truth to patients but patients did not have those said exceptions, the teller should not follow relatives’ comments, but had a confidence to make patients accept that truth undauntedly and be encouraged finally. The teller should persuade relatives to realize good points of truth telling, which exceeded bad points, and to explain general reactions when patients received the fact until they were able to accept such fact and have the encouragement to fight against the cancer.

4. The teller should tell such truth to relatives and patients frankly, and have psychological principles in providing good information to patients. Telling a lie should be avoided, but persuaded them to confront the fact, and to have hope and encouragement to build up their quality of life.

5. While telling the truth or confirming what patients were in doubt, the doctor might go to see the patients together with one of nursing team. This action prevented patients to feel that the doctor just told the truth and left them alone. If the nurse stayed with them for a while, they would feel better if someone still stayed aside to encourage them. This method gave better results than just telling and leaving. The training on encouraging cancer patients should be organized for related nurses.

6. After telling the truth to patients, they should be persuaded to see other selective ways or turning the crisis into the opportunity. The teller should mention about what each patient believed in or trust such as religion, meditation, or other alternative treatments. Suggestions should be based on individuals’ faith so that patients would feel calm.

3.3 Allocated Treatment

San Hutteerat (2001:153) mentioned about patients’ right to select that “if a patient decides not to get any medical treatments, laws still give rights to patients, except, in the past, for patients of some diseases or in dangerous cases. Therefore, if patients are unwilling to be cured or to stay in the hospital, doctors or nurses cannot

force them. Treatments have to be subject to patient s' needs and intention of remedies. It is not illegal upon patients' willingness, but, for merit and sin, they depend on the doctors' heart. If doctors do not require being cured like that but applying that method to patients may lead to conflicts or sin in doctors' mind. Decision on treatments is the right of patients and relatives. If the doctors make decisions on many matters for patients, doctors have to be responsible for their decisions as well. However, patients may sue the doctors that medical treatments are done without patients' consent, causing patients facing troubles or difficulties and others. These cases have been most found in the United States where patients and lawyers seize opportunities to sue doctors who do not give all facts to patients before asking patients to sign for approval."

Bunlu Siripanich (2000:13) mentioned about rights of patient that every person has rights according to human rights and the Constitution of the Kingdom of Thailand. Patients have many different rights; one of patients' rights is to select medical treatments by themselves. Patients have several alternatives and have rights to select any of them such as types of treatments, whether international, traditional Thai, or Chinese treatments, etc. The selection depends on patients' belief on the way giving them the best and quickest outcome while patients have the least torment and expenses.

3.4 Use of Medical Equipments for Prolonged Life

"Death prolongation" has been frequently found by nurses and physicians due to the progress of medical technologies, which also took effect to the attitude of Thai society about death. Technologies gave new choices for life while nurses got indirect impact since they had to play roles suitable and relevant to technologies in caring of terminal cancer patients. This is a moral problem discussed in the past to now. In the early period of Roman Empire, helping patients die could be done to relieve patients' torment and pain (Bodemer, 1979 cited by Haisfield, 1996:931). For the use of medical equipments to prolong life of terminal cancer patients, it should be considered whether it was suitable or not. Or if medical equipments were used, should they be removed or not, when should they be removed, and what were principles of consideration (Pinit, 1995:290). In practice, it was found that the physicians usually used the respiratory apparatus by not notifying patients or relatives since the

physicians considered that it was the emergency case concerning patients' death and life, and they had the duty of rescue as one of moral duties. But, at present, there was a viewpoint that each patient owned his/her life; so he/she should make any decision by himself/herself. Upon the principles of human rights, terminal cancer patients should have rights to select whether the medical equipments for life prolongation should be used or not, to sustain or end their life. These are moral problems in which nurses were involved as giving care to patients and relatives, following the treatment plan instructed by physicians, answering questions or giving advice or being requested to do anything for patients and relatives. Therefore, nurses should have careful consideration and discretion, and always remembered that they should persuade terminal cancer patients to accept the death and face it peacefully subject to human dignity.

3.5 Stopping Treatments

At present, advance medical technologies caused more complicated moral problems for caring of terminal cancer patients when they were used to sustain patients' life although some patients might be irreversible. This situation led to the concept on euthanasia or allowing hopeless patients to die peacefully and not to have any torment caused by diseases. If considering in another facet, health personnel, patients, and relatives all agreed that the calm death was to stop patients' torment. For patients getting severe diseases such as AIDS, cancer, etc. that patients were irreversible and caused much pain to patients, such technologies prolonged patients' death process and added them some torment. We could see that euthanasia was the moral problem of this profession; it was difficult to judge whether it was the worthwhile action or not. Euthanasia might cut patients' life short but it was done under kindness and good intention to take patients out of torment. As a result, the whole society gained some benefit by not wasting resources and manpower to care of patients who were impossibly reversible whereas those resources and manpower could be shifted for others who had more chance of recovery. It was difficult to have a conclusion whether such action was inhuman or not or euthanasia was reasonable or not. However, nurses had to find out the best guidelines by evaluating between the treatment by advance technology to prolong patients' life that caused them have further torment or the cease of treatment to allow patients die prestigiously. Nurses

had to decide which way was the best for both patients and family. Decision-making by other persons in case patients were incapable of making own decisions could lead to conflicts due to contrastive comments between the health team and patients' family or contrastive comments among patients' relatives. The key question was that who should make the decision.

3.6 Advance Directives

Thailand had not issued the Act like the United States prescribing rights of patients to make decisions by themselves or Patient Self-Determination Act (PSDA). By this Act, patients were able to express their advance directives by preparing the living will or assigning others to make decisions for them in case they were incapable of such. The treatment of health team would be consistent with patients' living will prepared while patients were still conscious or patients' assignment to others for decision-making; thus, decision-making for patients stood on this ethical principle. According to the research done by Wanwisa Sangprasert (2003:88), she proposed that there should be the written advance directives in the treatment process for terminal cancer patients including other seriously ill patients. These advance directives should be divided into 2 cases: Case 1 dealing with patients' advance directive about their own decision-making on treatments; and Case 2 dealing with patients' advance directive about assigning others for decision-making on future treatments. The announcement of patients' rights for selecting and denying treatments was insufficient since such rights were subject to the civil laws based on the principle of consent. When the litigation occurred, related laws such as the civil code and the criminal code, and others had to be interpreted. Many lawyers certainly had different viewpoints, which led to problems for every related party. Actually, such rights dealt with human rights and constitutional rights that definitely emphasized human dignity. Taking any laws should not be against the obligations set forth in the Constitution that was the supreme code of the country.

Pinit Ratanakul (1995:292) mentioned about substitutive decision-making in the Western culture that there were still different viewpoints regarding persons making the substitutive decision in case of patients' incapability of decision should be physicians or patients' family. The group judging that physicians should have the substitutive decision since physicians were always responsible for patients' death, had

knowledge and capability of curing of patients, and had the code of ethics as the operation guidelines. But, another group judged that patients' family should have substantive decision since they have known patients, had care and attention, and have learnt patients' needs more than others. However, some problems might occur if patients' relatives had some conflicts of interest with patients. Therefore, to ensure that patients would not be harmed by that substantive decision, there should be the joint decision between patients' family and physicians.

In the social viewpoints, professional nursing would be more or less worthwhile depending on the quality of nursing. Such quality came from merciful nursing services. If nurses held fundamental nursing ethics to boost the nursing quality, professional nursing would have more progress. The nursing quality needed good planning, appropriate operation, and clear evaluation. The preparation of nursing ethical guidelines on caring of terminal cancer patients was one of nursing operations to be done for every hospital since, at present, relatives preferred to take terminal cancer patients to the hospital for possible treatments. To cover the nursing operation, the nursing guidelines should be done in conformity with nursing code of ethics in caring of terminal cancer patients. Those guidelines consisted of contents systematically prepared as the operation guidelines on caring of terminal cancer patients based on 4 fundamental nursing ethical principles; namely, respect for persons, beneficence, non maleficence, and justice or fairness. It was found that nurses have not yet understood or realized in many moral problems. The reason might be no written ethical guidelines covering nursing operation, which led to conflicts or hesitation in nursing operation. The guidelines in conformity with nursing code of ethics should be prepared as the manual for caring of terminal cancer patients, which would be consistent with needs, and suitable for nursing moral problems. This study took the interview done by Wanwisa Sangprasert (2003:186-191) for 6 patients regarding 6 ethical issues: 1) Pain handling.; 2) Truth telling.; 3) Allocated treatment.; 4) Use of medical equipments for life prolongation.; 5) Stop treatments.; 6) Advance directives to be the guidelines by using the EDFR techniques to collect the comments of experts (Chumpol Poonpatracheewin, 2003:84).

4. Related Research

Wilaiwan Chairatanamanokorn (1997:119-137) studied legal concepts and counselors' acceptance of allowing hopeless patients to die calmly. About 242 counselors responded the questionnaire, and the study found out that in case patients were unconscious and relatives asked physicians to remove the tube for intravenous drips and the respiratory apparatus for patients that resulted to patients' death after such actions 2 hours later, most counselors thought that physicians had the offence of willful kill. In case patients were conscious and physicians removed the tube for intravenous drips or the respiratory apparatus for patients that resulted to patients' death after such actions 5 minutes later, most counselors thought that physicians had the offence of willful kill.

Wanthiwa Watanachot (1997:60-74) conducted a study on truth telling about the nearly dead condition pursuant to the perception and operation of nurses in ICU wards. The sample group of this study was 596 nurses working in ICU wards of government hospitals. The study found out that most nurses perceived the truth telling about the nearly dead condition and most of them have operated the truth communication about nearly dead condition at the moderate to high levels. The coordination between nurses and health team was still slight. The coordination between physicians and patients in relation to the nearly dead condition had the positive relationship. In part of operation, it was found that the perception on truth telling about the nearly dead condition, age of nurse, religious practice, level of education, and training on the nearly dead condition were able to predict the working behavior towards truth telling about nearly dead condition. The study also found that nurses with different ages and working experience would have no different perception on truth telling about the nearly dead condition. But, nurses with different level of education, would have different perception on truth telling about the nearly dead condition.

Wilawan Boonmanuch (2000:150-190) studied the relationship between knowledge and awareness of rights of patients, and caring of terminally ill patients by 143 nurses of the Faculty of Medicine, Ramathibodi Hospital. It was found that the awareness of patients' right regarding the right of receiving the information and the

right of being cared with the respect for person had the positive relationship at the moderate level with caring of terminally ill patients at the significance level of 0.01. In addition, the awareness of patients' right regarding the right of receiving opportunities for decisions on treatments had the positive relationship at the low level with caring of terminally ill patients.

Supaporn Daodee (1994:88-92) studied on nurses' self-awareness and behavior towards caring of terminally ill patients under the conceptual framework of 10 caring factors proposed by Watson. This study was conducted with 149 professional nurses who had experience in caring of not less than 3 terminally ill patients, and have worked in St. Louis Hospital, Cameleon St. Mary Hospital, and San Camillo. Those nurses responded the questionnaire asking about their self-awareness and behavior towards caring of terminally ill patients. The study found that nurses having high self-awareness also had high scores of behavior towards caring of terminally ill patients.

Somporn U-dee (2002:101) conducted a study on nurses' ethical decision in caring of critical patients by means of questionnaire responded by professional nurses working in the ICU wards of 10 central hospitals and general hospitals located at the South of Thailand. It was found that, in a year, 55% of the sample group experienced the situations requiring their ethical decision or were involved in ethical decisions, from 'sometimes' to 'frequently' levels. The ethical decisions included

1) Commitment to the profession and themselves.; 2) Commitment to patients while maintaining the relationship with other personnel in the health team.; 3) Truth telling and truth concealing for patients' benefit.; 4) Allocation of limited medical resources.; 5) Life prolongation and stop treatments to sustain life. Regarding problems and obstacles found by those nurses, over 50% confronted them at the moderate to high level in relation to 1) shortage of ethical experts, 2) shortage of documents and manuals as guidelines on ethical decision, 3) shortage of power in ethical decision, 4) shortage of experience/skills in ethical decision, 5) over-loaded work and weakness, and 6) shortage of knowledge about ethical decision.

Kanda Rakchart (2000:97-122) studied ethical conflicts of nurses working the ICU wards. It was found that there were 7 ethical conflicts faced by nurses in the ICU wards: 1) desiring to provide help but it was out of nurses' authority, 2) desiring to take duties instead of patients but still desiring to maintain the relationship, 3)

prolonging life or torment, 4) who should take decisions, 5) not knowing how to tell the information to acquire advantages for all parties, 6) commitment to the profession and duty for themselves, and 7) being unwilling to follow instructions due to no authorization.

Chittima Thanyaban (2004:104) studied nurses' performance based on the principle of ethics regarding the respect for patients' rights pursuant to the perception of patients and nurses in Southern hospitals. Such nurses' performance based on the principle of ethics regarding the respect for patients' rights pursuant to the perception of patients and nurses was studied. The difference between the perception of patients and the perception of nurses was also compared. It was found that the perception of nurses and patients regarding nurses' performance based on the principle of ethics regarding the respect for patients' rights consisted of 4 parts: evaluation of patients' decision capability, information disclosure, respect for patients' independent decision, and respect for actions as per patients' independent decision were at the high level as well. When comparing the difference of average scores between the perception of patients and nurses, it was found that the average scores of nursing operation as perceived by nurses were higher than average scores as perceived by patients at the significance level in part of information disclosure ($p < 0.01$), respect for actions as per patients' independent decision ($p < .0001$), and all parts ($p < 0.05$). Regarding the evaluation of patients' decision capability and respect for patients' independent decision as perceived by patients and nurses, the average scores were not different at the significance level.

Wanwisa Sangprasert (2003:183-191) studied rights of selecting and determining medical treatments for the final-stage cancer. The study was conducted by way of in-depth interview for terminal cancer patients, relatives, and physicians: 20 persons per each group. It was found that all cancer patients desired to know the truth that they got the cancer, and to receive from physicians more explanation about treatments for the decision on required treatments. Over half of patients required moderate treatments and denied any treatment causing the torment. A half of patients required the treatment to relieve pain. About 7 of 20 patients desired to choose their own ways; going back home to die calmly there and staying closely with the family. In addition, 9 of 20 patients desired to choose other alternative treatments subject to

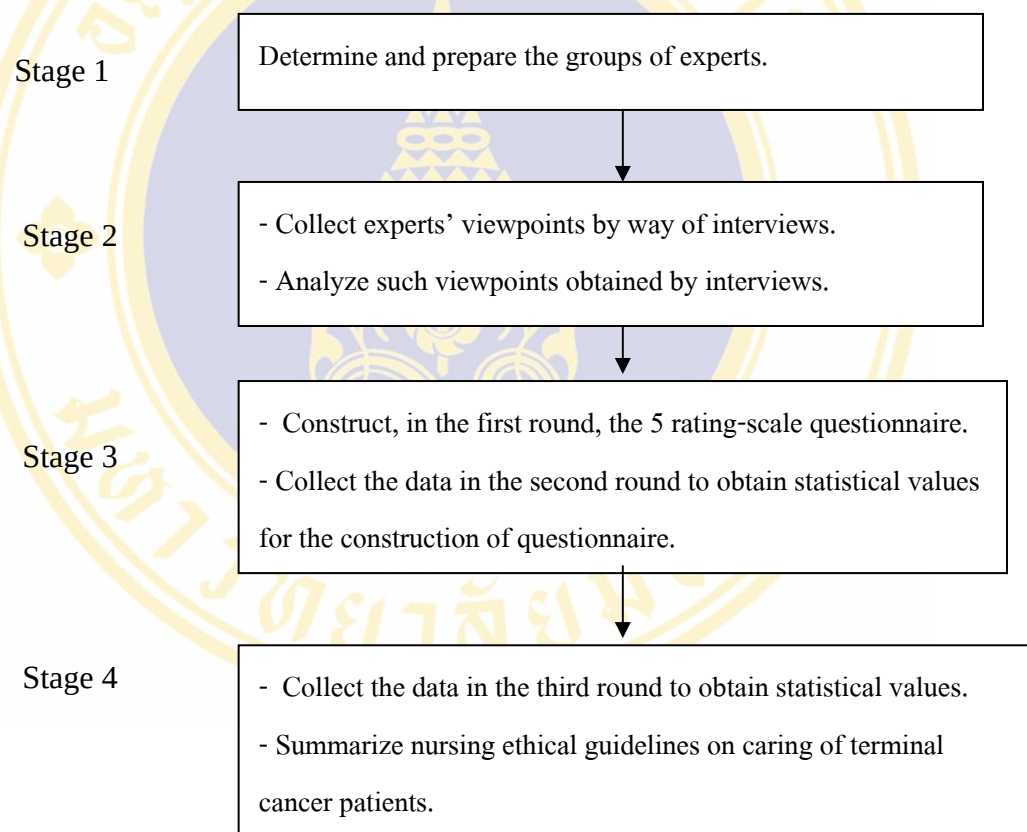
their belief and faith. Relatives and physicians were likely to accept patients' demands. For patients' advance directives, they indicated treatment types to be accepted or denied by patients. Moreover, patients were able to select a person specified in such advance directives to take part in the substantive decision on future treatments in the event that patients were unable to make decisions by themselves. All patients, relatives, and physicians accepted and agreed with the principle of advance directives.

Pursuant to the literature review, there were so few researches about nursing ethical guidelines on caring of terminal cancer patients. Therefore, creating the guidelines by collecting the comments of experts who had knowledge and experience in caring of terminal cancer patients could acquire more suitable, reliable, and clear guidelines.

CHAPTER 3

METERIALS AND METHODS

The objective of this study was to set up nursing ethical guidelines on caring of terminal cancer patients based on the Ethnographic Delphi Futures Research (EDFR). The research methodology was based on the following steps:



Expert Groups

Some experts, who the researcher has known, with knowledge and experience about moral problems in caring of terminal cancer patients, were selected. The number of experts was extended by the reference of the original group of experts. The principle of selecting experts (Van, 1974 cited in Chantra Sangsuwan, 1995:69-70) was as follows:

1. Experts in caring of terminal cancer patients – 12 experts
 - 1.1 Having experience in caring of terminal cancer patients
 - 1.2 Completing the bachelor degree and up
 - 1.3 Agreed to participate in the study by signing in a informed consent form
2. Experts in medical laws and public health – 10 experts
 - 2.1 Being the physician or nurse or academic, or teacher
 - 2.2 Completing the master degree and up in fields of medical laws and public health
 - 2.3 Being the academic who released the academic work in connection with medical laws and public health, or being the teacher who instructed in fields of medical laws and public health.
 - 2.4 Agreed to participate in the study by signing in a informed consent form
3. Experts in moral problems about caring of terminal cancer patients – 10 experts
 - 3.1 Being the academic or teacher who released the academic work regarding moral problems in caring of terminal cancer patients
 - 3.2 Completing the bachelor degree and up
 - 3.3 Agreed to participate in the study by signing in a informed consent form

Instruments of the Study

First-round Interview: It was the semi-structure and situational questionnaire extracted from the interviews of 6 terminal cancer patients done by Wanwisa Sangprasert (2003:59-172) in 6 following issues: 1) Pain handling.; 2) Truth telling.; 3) Allocated treatment.; 4) Use of medical equipments for prolonged life.; 5) Stopping treatments.; 6) Advance directives. This questionnaire was checked up by 2 thesis advisors and 1 instructor of the Faculty to gain the content relevance and language clearness, and to cover the objective of the study prior to further use.

First-round Questionnaire

This questionnaire was the 5 rating-scale one constructed by the synthesis of the first-round interview. Its content was checked up by thesis advisors and experts to gain the suitability of components and contents to be contained in nursing ethical guidelines on caring of terminal cancer patients, and to gain other suggestions.

Second-round Questionnaire

This questionnaire was distributed to experts so that answers were confirmed or changed. Other suggestions were also required.

Data Collection

The steps of data collection were as follows:

1. Requesting a letter issued by the Faculty of Public Health, major in Public Health Law Administration, to be submitted to experts.
2. Submitting the letter as mentioned in Item 1 above including the brief thesis outline to experts, and appointing the interviewing date and time as per experts' convenience.
3. Collecting the data: the first-round interview on 15 December 2005 – 3 March 2006, the first-round questionnaire on 16 March 2006 – 21 April 2006, and the second-round questionnaire on 28 April 2006 – 8 June 2006. The total dates of data collection were 175.

Data Analysis

Data analysis was done by the following stages:

1. Data collected from the first-round interview was analyzed (content analysis).
2. Data collected from the first-round and second-round 5 rating-scale questionnaires was analyzed. The experts' comments about suitability and relevance of questionnaires were also analyzed to find out the median and inter-quartile range, which were based on the following criteria of data interpretation (Helmer, 1977:29; Judd, 1977:155; Chumpol Poonpatracheewin; 2003:86):

- Median

The median calculated from the group of experts was interpreted as follows:

The median lower than 1.5 referred to the group of experts judged that that guideline contained the least possibility for caring of terminal cancer patients in conformity with nursing ethics.

The median in the range of 1.50 – 2.49 referred to the group of experts judged that guidelines contained little possibility for caring of terminal cancer patients in conformity with nursing ethics.

The median in the range of 2.50 – 3.49 referred to the group of experts judged that guidelines contained medium possibility for caring of terminal cancer patients in conformity with nursing ethics.

The median in the range of 3.50 – 4.49 referred to the group of experts judged that guidelines contained much possibility for caring of terminal cancer patients in conformity with nursing ethics.

The median higher than 4.50 referred to the group of experts judged that guidelines contained the most possibility for caring of terminal cancer patients in conformity with nursing ethics.

- Interquartile Range

The researcher calculated the interquartile range by calculating the difference between quartile 3 and quartile 1. If the interquartile range of any content was less than or equivalent to 1.50, it meant that the experts' comments towards that content was consistent. However, if the interquartile range of any content was more than 1.50, it meant that the experts' viewpoints to that content was inconsistent.

CHAPTER 4

RESULTS

The objective of this study was to set up nursing ethical guidelines on caring of terminal cancer patients based on the Ethnographic Delphi Futures Research (EDFR) in 6 following issues: 1) Pain handling.; 2) Truth telling.; 3) Allocated treatment.; 4) Use of medical equipments for prolonged life.; 5) Stop treatments.; 6) Advance directives. All comments from 32 experts were compiled. All experts consisted of 3 groups: experts in caring of terminal cancer patients, experts in medical laws and public health, and experts in moral problems about caring of terminal cancer patients. The data was analyzed and tabulated in 2 sections:

Section 1: Nursing ethical guidelines in caring of terminal cancer patients

Section 2: Analytical results from the collection of experts' viewpoints in the second and third rounds

Section 1: Nursing ethical guidelines in caring of terminal cancer patients obtained from the interviews of experts

1. Pain handling

A female patient, 36, has got the breast cancer since 1996. She has got treatments from a hospital by having the operation. After the operation, she did not get any irradiation or chemotherapy. Later, she got the breast cancer again and has been remedied by the chemotherapy method for 6 times. This patient had to admit the hospital for several times since she has worked so hard until her disease became more severe.

The patient learnt that she was the terminal cancer patient as the physician notified her and the nurse explained her the situation. What the patient needed at that time was to receive the sufficient pain-killing drugs since she was in much torment. However, nurses advised her that the pain-killing drugs had to be subject to the physician's treatment plan, which was insufficient to relieve her torment. **"It was so**

painful, but the nurse dared not to give the medicine because she had to wait for the physician's report. Sometimes, I had so much pain that I could not sleep, but the nurse had to wait and consult with the physician. I had to wait until the physician ordered and gave me the medicine. It was so painful."

The above situation was used to set up the following protocols of pain handling for terminal cancer patients in conformity with nursing ethics, which were based on experts' viewpoints.

1.1 Guidelines of proper pain handling for terminal cancer patients

1.1.1 Assessing the pain as perceived by patients as a whole, which was caused by the body pain and other grounds that were out of body condition, by applying the proper pain assessment methods.

1.1.2 Setting plans with the treatment team to set up the protocol of pain handling for terminal cancer patients. The protocol consisted of the number of regular doses and rescue doses for breakthrough. The treatment instruction should be flexible so that nurses were able to adjust the number of doses for patients.

1.1.3 Educating both patients and relatives about pain and pain handling methods apart from medicine taking such as meditation, creating a diversion, listening the favorite music, deep breathing, massage, and expressing humor, etc.

1.1.4 Arranging the environment and providing assistance in pain handling by encouraging relatives to be involved in.

1.1.5 Assessing patients' pain regularly, both in the normal condition and after the medication or caring to relieve pain, and recording such assessment as well.

1.1.6 Meeting with the treatment team periodically to adjust the treatment plan until it was suitable for each patient by considering the individual difference.

1.2 Guidelines in case patients confronted pain and torment caused by pain. When patients requested for pain handling but the treatment plan set by the physicians was not insufficient for patients. Nurses should follow the guidelines below:

1.2.1 Assessing the pain as a whole to find out grounds of pain apart from the body condition.

1.2.2 Consulting the treatment team about patients' problems. Nurses might have to consult the anesthetists or pain clinic to jointly evaluate and plan for

appropriate treatments, but the operation of medication should be clear so that nurses could operate by themselves.

1.2.3 Using other pain relief favored by patients by not having the medication such as relaxant massage, attention diversion, music, and environment arrangements, etc.

1.2.4 Caring of patients by extending them the understanding and mercy, not leaving them to stay alone, and encouraging relatives to be involved in caring of patients.

1.2.5 Following up and evaluating the treatment results regularly, and reporting such results to the treatment team for the revision of treatment plan.

1.3 Guidelines in case of the differences of patients in terms of gender, age, and occupation. Nurses should follow the guidelines below:

1.3.1 The principle of caring should be based on the same standard for every patient.

1.3.2 The principle of caring should be suitably applied for each patient since the knowledge about pain handling, gender, age, and personal background resulted to the different pain experience of each person. Therefore, the principle of nursing should be applied to fit such factors but the standard quality was maintained as well.

2. Truth telling

A male patient, 54, has got many treatments from several hospitals and the doctors gave him the different diagnosis, but each told him that he got a tumor. Later, he learnt that he got the lung cancer because it spread out to his brain. He has got 10 irradiations. This patient knew that he got the cancer so late since **his wife and friends jointly concealed this truth and asked the physician not to tell him about it.** “For something, they don’t think that I’ve known it, but, actually, I’ve known it and more than what they have known.” The patients desired that the physicians and relatives disclosed the disease, steps of treatments, even other alternatives as well as disease prediction so that they would have time to set their mind and decide to select **a way not making them torturous and die calmly.**

The above situation was used to set the protocol of truth telling for terminal cancer patients in conformity with nursing ethics according to experts' viewpoints below.

2.1 Guidelines telling truth to patients that they got the cancer. Nurses should perform as per the following steps:

2.1.1 Assessing patients and relatives' needs and promptness of perception to be the important information for the treatment team in telling the truth; for example, the patients knew or doubted that they got the cancer, the patients with the clear background that they hurt themselves when facing serious matters in life, and reactions and viewpoints of patients and relatives about truth telling. Such key information should be transferred to the treatment team.

2.1.2 Having joint meetings of all related physicians, nurses, caregivers, and specialized physicians to find out and assign the suitable person for truth telling by considering the patients' reliability to the physicians. Truth telling should be undertaken as a team with the telling techniques; patients were encouraged and given the relevant information and communication.

2.1.3 The principle of truth telling might be based on the group support, counseling, or supposing situations depending on the conditions of patients.

2.1.4 In case that the patients received the fact, but they were unable to accept it or they had strong emotional reactions, nurses had to care of and palliate them so that patients would be able to pass that situation and accept it finally.

2.1.5 Assessing patients and their family periodically after giving them the truth in order to observe their responses and to give supports for their acceptance of truth.

2.1.6 After telling the truth, nurses should give some advice to patients about practice and alternatives, as well as to palliate patients' mind.

2.2 Guidelines in case relatives did not want to let patients know that they got the cancer because relatives were afraid that patients would become worse. The relatives requested nurses not to tell such truth to patients; thus, nurses should follow the steps below:

2.2.1 Asking reasons of concealing the truth by giving relatives the opportunities of expressing their feelings, fear, and concerns.

2.2.2 Explaining about good points of telling truth, which could help patients set their life plans, handle unfinished problems, and prepare to end their life prestigiously and honorably. But, weak points might be that the patients were unable to accept their condition and became worse.

2.2.3 Setting the family participation so that both the family and treatment team had joint discussions and decisions by reminding relatives to realize that any decision should be made for patients, not for relatives, and based on patients' needs most.

2.2.4 Planning with relatives and the treatment team for telling the truth. Nurses might consult the psychologists for the assistance or appropriate planning to tell the truth to patients such as indirect telling or supposing situation, and assigning the suitable person to tell such truth.

2.3 Guidelines in case patients required the explanation about the disease progress and treatments to be given as well as the disease prediction for their decision-making on selected treatments. Nurses should coordinate with the health team in telling the truth to patients under the following steps:

2.3.1 Assessing needs of patients and relatives to receive the information.

2.3.2 Coordinating for patients and relatives for official talks to the treatment team, and giving them opportunities of discussing, questioning, consulting, and planning for treatments together. Nurses might take part in stimulating patients and relatives to ask questions.

2.3.3 Clarifying the information if in doubt by patients and relatives after talking with the treatment team.

2.4 Guidelines in case of the differences of patients and relatives in respect with gender, age, and occupation. Nurses should follow the steps below:

2.4.1 The guidelines should be adjusted and fit to each patient by recognizing the individuals' promptness and differences in respect of personal learning, information perception, interpretation, acceptance, adjustment, and strength to set up the plan, which would be suitable in terms of time, methods, level of wording, language used to explain about the disease, treatment ways, and appropriate supports.

3. Allocated treatments

A male patient, 68, has got the lung cancer. He has got 9 chemotherapies and irradiations. While staying in the hospital, he had some weakness, quick but short breaths, and gasped for breath sometimes. This patient desired that the physicians explained him clear medical treatments and treatment results; treatments should not be done subject to the physicians' demands only. The treatment methods should be explained to the patient so that he could take it for decision-making about allocated treatments. But, in fact, the physicians rarely told the adequate information. The patient said, "I would like to have a right of selecting how I will be cured. But, I don't know what I should do. In most cases, the doctors have never informed us in advance; they carry on at once. **If we were at the final stage of illness that was irreversible, we want to reject some treatments.** Inserting or bearing any equipment, I reject it" The patient also said, "If my illness is beyond any treatment, I want to go back home. It's warmer if I die there. Frankly, I want to die at home. In the worst case, I want to go back home. I want to die happily. Let me die. Staying in the hospital, I'm close to the doctors, but it is not the same as staying at home."

From the above situation, it was used to set up the guidelines of allocated treatments for terminal cancer patients in conformity with nursing ethics based on the experts' viewpoints below.

3.1 Guidelines in case the patients rejected any treatments causing the torment and uselessness. Nurses should follow the steps below:

3.1.1 Evaluating the patients' illness condition how they learnt and understood the diagnosis, treatments, treatment results, and disease prediction.

3.1.2 Evaluating that the patients had the full consciousness, not been overborne by the body torment or socio-mental and spiritual problems.

3.1.3 Recording the evaluation of patients' status and needs in the nursing daily records.

3.1.4 Consulting the treatment team for the patients' needs to find out caring methods in conformity with needs of patients.

3.1.5 Coordinating for patients and relatives for talks to the treatment team to set up the treatment ways; comparing between the expected treatment results and bad points if no treatments were done for the good understanding of patients and

relatives. As a result, all related parties would have a joint decision on treatment methods, and specify some undesirable treatments such as CPR, the respiratory apparatus if the patients were seriously ill, etc.

3.1.6 If possible, preparing patients' advance directives in the written form or in the informed consent as witnessed by patients' relatives.

3.1.7 Caring and evaluating the treatments regularly so that there were consistent with patients' intent and needs. If patients' illness conditions changed, nurses should evaluate whether patients still had the same needs or not, and informed the family and relatives of patients' needs.

3.1.8 In case that patients desired to go back home, all relatives including nearby hospitals or assistance network should be prepared; for example, contacting the home-visit unit to help both patients and family, as well as giving the emergency telephone numbers for 24-hour assistance or consult.

3.2 Guidelines in case the patients had no advance directives. Nurse should follow the steps below.

3.2.1 Surveying comments of patients and relatives to consider what extent they received the information, illness diagnosis, treatments, and disease prediction.

3.2.2 Taking such received information to consult the treatment team for planning and discussing about treatment alternatives and treatment results.

3.2.3 Coordinating for patients and relatives for talks to the treatment team in order to investigate needs of patients and relatives, treatment alternatives, treatment results, and treatment rejection. As a result, both patients and relatives could be involved in selecting the caring ways in conformity with patients' needs most.

3.2.4 In case of patients' unconsciousness, the close relative would decide for treatment methods. But, if patients had several relatives, all of them might have the appointments with the treatment team (family meeting) to conclude the selected treatments. All relatives should be reminded that the decision was made for patients, not relatives; thus, the decision should meet patients' thought and needs.

3.2.5 In case the patients or relatives were unable to undertake anything, the treatment team should take roles in representing the patients and relatives in the decision on treatments while nurses also performed their work as a part of treatment team.

3.2.6 While giving patients some care, their needs or those of relatives should be evaluated periodically. If the patients or relatives changed their mind or had confusion/hesitation, nurses should provide the information for their decision-making. Then, nurses forwarded such evaluation to the treatment team for the revision of treatment plan.

3.2.7 Giving some help to the patients and relatives regarding general practice and illness relief to acquire patients' comfort; arranging the environment for tranquility and privacy; and giving opportunities for religious and faith practice.

3.2.8 In case the patients had no relatives, nurses should not leave the patients die lonely, but stay with them for spiritual guidance and giving some advice on the religious practice.

3.3 Guidelines in case of the differences of patients in respect with gender, age, and occupation. Nurses should follow the steps below.

3.3.1 The guidelines should be suitably applied for each patient depending on the personal difference while the standard quality was maintained.

4. Use of medical equipments for prolonged life

A male patient, 74, got the stomach cancer and used to have an operation including a full course of chemotherapy and irradiation two years ago. While obtaining such treatments in the hospital, this patient had the difficult breathing, vomited blood, has severe stomach ache, and had too much gas; so the physician inserted the breathing tube, tube for intravenous drips, and tube for infusion apparatus. Before admitting in the hospital, this patient told his children that, "If anything happens again, do not permit the doctor to insert or put something for me. I don't want to be painful anymore. No more torment is required. I want to die peacefully; do not treat me like I'm not a human and treat me for the case study only." His children reported those needs to the doctors, but they still insisted to insert many tubes into the patient's body, and told his children that "Anyway, the treatment must continue since it's my duty."

The above situation was used to set up the protocol regarding the use of medical equipments to prolong the life of terminal cancer patients in conformity with nursing ethics based on experts' viewpoints as listed below.

4.1 Guidelines in case the patients were terminally ill and unconscious but they had advance directives by rejecting the use of medical equipment for prolonged life, and patients' relatives rejected it as well but the physicians required it. Nurses should follow the steps below.

4.1.1 Nurses should represent the patients and relatives in transferring needs of patients and relatives to the physicians to stimulate and persuade them to follow the patients' needs.

4.1.2 If the physicians insisted on the same treatments, encouraging relatives as patients' representatives to meet the physicians to inform of patients and relatives' desires while the physicians also had chance of explaining about the usefulness of each treatment so that relatives would have better understanding about each treatment way for further decision.

4.1.3 In case the relatives still denied those equipments while the physicians insisted the same undertaking; nurses should note this event in the nursing daily records.

4.1.4 Proposing those problems to the meetings to encourage the hospital management to acknowledge that those problems would be risks of the hospital. There should be the committee monitoring ethics of caring of terminal cancer patients as the guidelines on caring of other patients.

4.2 Guidelines in case the patients had advance directives on rejecting the use of medical equipment for prolonged life, but patients' relatives required it. Nurses should follow the steps below.

4.2.1 Giving opportunities to patients' relatives for comments, asking their needs and reasons of such desire, and reminding them about patients' needs by emphasizing that any decision should be subject to patients not relatives.

4.2.2 Transferring the needs of relatives to the treatment team to stimulate the physicians to pay attention in this issue.

4.2.3 Coordinating for relatives to talk to the treatment team so that they obtained both strengths and weaknesses of bearing tubes or sustaining life, persuading relatives into caring of terminal cancer patients for the prestigious death, and reminding the relatives about the consequences of not respecting for patients' directives for the new decision-making of relatives.

4.2.4 Recording relatives' comments in the nursing daily records, and respecting for relatives' decision.

4.2.5 Evaluating relatives' needs and periodically giving them the patients' illness conditions. If the relatives changed their mind, coordinating for relatives to talk to the treatment team.

4.3 Guidelines in case of the differences in respect with gender, age, and occupation. Nurses should follow the steps below.

4.3.1 The treatments should be adjusted to fit the status of patients and family. However, nurses should negotiate with patients and relatives in some issues; if the treatment costs were high, it might or might not be selected if patients were incapable of bearing the expenses incurred.

5. Stopping treatments

A female patient, 55, has got he ovary cancer. She has got treatments in a hospital by having the operation to cut off her ovary and the chemotherapy. About 8 months later, she admitted the hospital again because she could have less food, and her belly became stiff. According to the body check-up, it was found that the cancer spread out over her pelvic cavity. Her children wanted the patient to continue the treatments, but the patient requested the physician to stopping treatments, and wanted to go back home to die their with her children. However, when her children met her, they asked the physician to have the full remedies without any concerns about payments.

From the above situation, it was used to set up the guidelines regarding stopping treatments for terminal cancer patients in conformity with nursing ethics based on experts' viewpoints below.

5.1 Guidelines in case the patients desired to stop treatments and to die at home. Nurses should coordinate with the health team under the following steps:

5.1.1 Evaluating that the patients had the complete consciousness and were not influenced by the body symptoms, socio-mental and spiritual problems.

5.1.2 Evaluating that the patients acknowledged and understood, as some partial information for decision-making, the diagnosis, treatments, treatment results,

disease prediction, strengths and weaknesses of rejecting the treatments, as well as the torment to be occurring in the future.

5.1.3 Recording the evaluation of patients' illness condition and needs in the nursing daily records.

5.1.4 Coordinating for talks between patients and relatives so that relatives understood and accepted the patients' needs, including strengths and weaknesses of rejecting the treatments by informing both patients and relatives of all facts, and giving them opportunities to question and make decisions again.

5.1.5 In case the patients insisted to stop all treatments and to die at home, a joint meeting between the treatment team and the patients as well as family should be arranged to set planning and give some advice on caring of patients at home (discharge planning), especially ways of controlling the illness condition when patients were nearly dead so that the relatives would be able to confront and handle the situation while the patients had no torment and die peacefully. Nurses might advise the relatives on supporting sources or assistance network by forwarding the treatment information and patients' needs to those sources or network.

5.1.6 Undertaking all related documents in connection with patients' treatment rejection, and preparing patients for moving by realizing that patients might pass away during such moving; thus, relatives should be ready to confront such situation.

5.2 Guidelines in case the patients desired to stop treatments but relatives desired to continue the treatments. Nurses should follow the steps below.

5.2.1 Giving the relatives opportunities for comments, asking for their needs and reasons of continued treatments, and reminding them about patients' needs.

5.2.2 Transferring the needs of relatives to the treatment team, and recording such needs in the nursing daily records.

5.2.3 Coordinating for relatives for talks to the treatment team so that they obtained the information, persuading them into caring of terminal cancer patients for the prestigious death, and reminding the relatives about the patients' needs for the new decision to be made by relatives, which should be subject to patients, not relatives.

5.2.4 If the above actions were unsuccessful, nurses might ask some assistance from the psychologist by focusing on patients' needs, which were acceptable for relatives. The counseling method might be applied.

5.3 Guidelines in case of the differences of patients and relatives in respect with gender, age, and occupation. Nurses should follow the guidelines below:

5.3.1 The methods and practice should be suitably applied for relatives of each patient depending on the differences of person and situation.

6. Advance directives

A male patient, 68, has got the lung cancer, and were admitted to the ICU for 2 times. After leaving the hospital, he told his wife and children not to take him to the hospital again if his illness became severe again; he wanted to die at home, did not want to get any torment caused by treatments anymore. Later, when this patient's illness was severe, his wife and children decided to take him to admit the hospital and stayed in the ICU. When he felt better, he told nurses that **he did not want treatments with the use of any equipment for prolonged life. The nurse chief on duty recorded the patient's needs in the nursing records** before informing the nursing team and the attending physician of such needs. Later, when the patient's illness was more severe, the physician on duty instructed the nurse to insert the breathing tube and respiratory apparatus although the caring nurse informed the physician on duty of the patient's needs, and, at that time, no relatives of patient stayed there.

From the above situation, it was used to set up the guidelines of preparing the advance directive by the terminal cancer patients, and the guidelines of preparing the advance directive by the terminal cancer patients based on experts' viewpoints below.

6.1 Guidelines in case the patients told the caring nurse that they did not want any prolonged-life equipment and the nursing chief on duty recorded such needs in the nursing records. Were those nursing records deemed as the written advance directives?

In this issue, experts' viewpoints could be divided into 2 groups:

- The group opined that those nursing records should be deemed as advance directives because those records were counted as the legal evidence.

- The group opined that those nursing records should not be deemed as advance directives because, currently, there have not yet been any laws prescribing the advance directives although the nursing records could be used as the legal evidence. This issue was on argument and set forth in Section 10 of the National Health Bill, which may be legally acceptable in the future. But, for the clear evidence, the patients might prepare the informed consent instead of nursing records so that everyone in the caring team could notice it.

The guidelines of preparing the advance directives should be based on the following steps:

6.1.1 Evaluating that the patients had the full consciousness, not been overborne by the body torment or socio-mental and spiritual problems.

6.1.2 Evaluating that the patients acknowledged and understood, as some partial information for decision-making, the diagnosis, treatments, treatment results, disease prediction, strengths and weaknesses of using the prolonged-life equipment in the treatments.

6.1.3 In case the patients insisted not to get treatments by the use of prolonged-life equipment, nurses should note the evaluation of patients' illness condition and needs in the advance directive and reporting them to the treatment team.

6.1.4 Coordinating for patients and relatives for another talk to the treatment team so that they were provided, for a new decision-making, strengths and weaknesses of treatments by the use of prolonged-life equipment including the torment to be occurring in the future.

6.1.5 In case the patients still insisted the same intent, nurses should undertake all related documents by having the patients record their own needs in advance directives that should also be signed by caring physicians who certified that the patients had full and complete consciousness, and relatives as witnesses.

6.2 Guidelines in case of stop treatments with the written advance directives identified by patients for stop treatments and no prolonged-life equipment. Nurses should follow the steps below:

6.2.1 Evaluating that the patients had the full consciousness, not been overborne by the body torment or socio-mental and spiritual problems.

6.2.2 Coordinating with the physicians to give patients and relatives the information for their decision-making about inserting the breathing tube, results of inserting such tube, the torment to be occurring in the future if not bearing it, and the disease prediction.

6.2.3 In case the patients still insisted for not bearing the respiratory apparatus, the nurses should attend the joint meeting with the treatment team, patients, and relatives to note the patients' needs in the written form signed by the patients (patients' signature might not be required if the patients showed their needs in the hand-writing, except signing to prevent any problems with relatives after the patients' death). The record of patients' needs should comprise some witnesses who guaranteed that the patients have full and complete consciousness. Those witnesses should be direct-blood relatives or caring physicians.

6.2.4 Notifying the physicians or related persons or relatives for the joint caring plan. Although the patients insisted that they did not want the breathing tube or other prolonged-life equipment, other treatments could be done to relieve patients' torment; for example, giving the oxygen by other ways. However, any treatments should mainly concern the patients' needs and not cause any torment.

6.2.5 Although the patients had advance directives, when their illness became worse, nurses should talk to patients and relatives again whether they still had the same intent or wanted to change their mind. The treatments should be revised as per needs of patients and relatives.

6.3 Guidelines in case the physicians desired to use the prolonged-life equipment although the patients had advance directives that they did not want it. Nurses should follow the steps below:

6.3.1 Nurses should represent the patients and relatives in transferring needs of patients and relatives to the physicians, showing to the physicians the patients' advance directives to stimulate and persuade them to follow the patients' needs.

6.3.2 Nurses should not help prepare the medical equipment. Moreover, nurses should explain to the physicians that when the patients rejected the offer of rescue, it should be deemed that it was beyond the duty of physician in treatments; thus, any actions for patients shall be the violation of patients' right.

6.3.3 If the physicians still insisted the same actions, nurses should coordinate with the relatives of patients to be involved in the treatments, which should be subject to patients' intent.

6.3.4 In case that the relatives decided that no prolonged-life equipment should be used, but the physicians insisted the same actions, nurses should note this event in the nursing daily records.

6.3.5 Reporting the attending physician and higher supervisors respectively.

6.3.6 Proposing those problems to the meetings to encourage the hospital management to acknowledge that those problems would be risks of the hospital. There should be the committee monitoring ethics of caring of terminal cancer patients as the guidelines on caring of other patients.

6.4 Guidelines in case of the differences of patients and relatives in respect with gender, age, and occupation. Nurses should follow the step below:

6.4.1 As a whole, there should not be any differences. In case of so young patients, they should have duty representatives. However, most decisions were up to parents; thus, parents should be clarified. In addition, treatments should concern the differences of person and situation.

Section 2: Analytical results from the collection of experts' viewpoints in the second and third rounds

1. Pain Handling

Table 1 Presented the median (Md) and interquartile range (IR) based on experts' viewpoints on the guidelines of pain handling that was suitable for terminal cancer patients. The analysis was subject to second-round data (values above the dotted line) and third-round data (values below the dotted line).

Guidelines	Md	IR
1. Nurses assessed the pain as perceived by patients as a whole, which was caused by the body pain and other grounds that were out of body condition, by applying the proper pain assessment methods.	4.88 4.95	0.29 0.55
2. Nurses set plans with the treatment team to set up the protocol of pain handling for terminal cancer patients. The protocol consisted of the number of regular doses and rescue doses for breakthrough.	4.93 4.97	0.56 0.53
3. Nurses coordinated with the treatment team or knowledgeable person to educate both patients and relatives about pain and pain handling methods such as meditation, creating a diversion, listening the favorite music, deep breathing, massage, and expressing humor, etc.	4.80 4.88	0.77 0.61
4. Nurses arranged the environment and provided assistance in pain handling by encouraging relatives to be involved in.	4.86 4.95	0.64 0.55
5. Nurses assessed patients' pain regularly, both in the normal condition and after the medication or caring to relieve pain, and recording such assessment as well.	4.91 4.97	0.59 0.5
6. Nurses had meetings with the treatment team periodically to adjust the treatment plan until it was suitable for each patient by considering the individual difference.	4.93 4.97	0.57 0.53

Table 1 showed that the experts had consistent viewpoints at the highest level for every step in the guidelines of pain handling that was suitable for terminal cancer.



Table 2 Presented the median (Md) and interquartile range (IR) based on experts' viewpoints concerning the guidelines in case patients confronted pain and torment caused by pain, when patients requested for pain handling but the treatment plan set by the physicians was not insufficient for patients. The analysis was subject to second-round data (values above the dotted line) and third-round data (values below the dotted line).

Guidelines	Md	IR
1. Nurses assessed the pain as a whole to find out grounds of pain apart from the body condition.	4.83	0.67
	4.88	0.61
2. Nurses consulted the treatment team about patients' problems. Nurses might have to consult the anesthetists or pain clinic to jointly evaluate and plan for appropriate treatments, but the operation of medication should be clear so that nurses could operate by themselves.	4.83	0.67
	4.93	0.57
3. Nurses used other pain relief favored by patients by not having the medication such as relaxant massage, attention diversion, music, and environment arrangements, etc.	4.61	1.23
	4.74	0.92
4. If the side effects occurred such as constipation, dry mouth as a result of adding more medicine, nurses should inform patients and relatives of such conditions. If patients insisted that they did not mind those side effects and relatives had the consent, nurses should operate as per patients' needs.	3.79	1.87
	3.86	1.55
5. Nurses cared of patients by extending them the understanding and mercy, not leaving them to stay alone, and encouraging relatives to be involved in caring of patients.	4.95	0.55
	4.98	0.51
6. Nurses followed up and evaluated the treatment results regularly, and reporting such results to the treatment team for the revision of treatment plan.	4.91	0.59
	4.98	0.51

Table 2 showed that

1. The experts had consistent viewpoints at the highest level for 5 steps: Step 1 - Nurses assessed the pain as a whole to find out grounds of pain apart from the body condition.; Step 2 - Nurses consulted the treatment team about patients' problems and they might have to consult the anesthetists or pain clinic to jointly evaluate and plan for appropriate treatments, but the operation of medication should be clear so that nurses could operate by themselves.; Step 3 - Nurses used other pain relief favored by patients by not having the medication such as relaxant massage, attention diversion, music, and environment arrangements, etc.; Step 5 - Nurses cared of patients by extending them the understanding and mercy, not leaving them to stay alone, and encouraging relatives to be involved in caring of patients; and Step 6 - Nurses followed up and evaluated the treatment results regularly, and reporting such results to the treatment team for the revision of treatment plan.

2. The experts had inconsistent viewpoints about Step 4 in the second round when the statement "If the side effects occurred as a result of adding more medicine, nurses told the patients and relatives about those side effects. If patients insisted that they did not mind those side effects and relatives had the consent, nurses should operate as per patients' needs." Was changed to be "If the side effects occurred such as constipation, dry mouth as a result of adding more medicine, nurses should informed patients and relatives of such conditions. If patients insisted that they did not mind those side effects and relatives had the consent, nurses should operate as per patients' needs." The experts still had inconsistent viewpoints in the third round.

Table 3 Presented the median (Md) and interquartile range (IR) based on experts' viewpoints concerning the guidelines in case of the differences of patients in respect with gender, age, and occupation. The analysis was subject to second-round data (values above the dotted line) and third-round data (values below the dotted line).

Guidelines	Md	IR
1. The principle of caring should be based on the same standard for every patient.	4.83	0.14
	4.88	0.61
2. The principle of caring should be suitably applied for each patient since the knowledge about pain handling, gender, age, and personal background resulted to the different pain experience of each person.	4.93	0.57
	4.97	0.53

Table 3 showed that

The experts had consistent viewpoints at the highest level that the guidelines in case of the differences of patients in respect with gender, age, and occupation, nurses should hold the same caring principle and standard for every patient, and the principle of caring should be suitably applied for each patient since the knowledge about pain handling, gender, age, and personal background resulted to the different pain experience of each person.

2. Truth Telling

Table 4 Presented the median (Md) and interquartile range (IR) based on experts' viewpoints concerning the guidelines of telling truth to patients that they got the cancer. The analysis was subject to second-round data (values above the dotted line) and third-round data (values below the dotted line).

Guidelines	Md	IR
1. Nurses assessed patients and relatives' needs and promptness of perception to be the important information for the treatment team in telling the truth; for example, the patients knew or doubted that they got the cancer, the patients with the clear background that they hurt themselves when facing serious matters in life, and reactions and viewpoints of patients and relatives about truth telling. Such key information should be transferred to the treatment team.	4.94	0.64
2. Nurses had a joint meeting of all related physicians, nurses, caregivers, and specialized physicians to find out and assign the suitable person for truth telling by considering the patients' reliability to the physicians. Truth telling should be undertaken as a team with the telling techniques; patients were encouraged and given the relevant information and communication.	4.95	0.55
3. The principle of truth telling might be based on the group support, counseling, or supposing situations depending on the conditions of patients while patients and relatives were willing to be involved in.	4.93	0.57
4. In case that the patients and relatives received the fact, but they had strong emotional reactions, the treatment team had to care of and palliate them so that patients would be able to pass that situation and accept it finally.	4.97	0.53
5. Nurses assessed patients and their family periodically after giving them the truth in order to observe their responses and to give supports for their acceptance of truth.	4.77	0.93
	4.83	0.67
	4.56	1.11
	4.74	0.89
	4.94	0.59
	4.93	0.57

Table 4 Presented the median (Md) and interquartile range (IR) based on experts' viewpoints concerning the guidelines of telling truth to patients that they got the cancer. The analysis was subject to second-round data (values above the dotted line) and third-round data (values below the dotted line). (cont.)

Guidelines	Md	IR
6. After telling the truth, nurses should give some advice to patients about practice and alternatives, as well as to palliate patients' mind.	4.77	1.31
	4.86	0.64

Table 4 showed that

The experts had consistent viewpoints at the highest level at every step in the guidelines of telling the truth that the patients got the cancer.

Table 5 Presented the median (Md) and interquartile range (IR) based on experts' viewpoints concerning the guidelines in case relatives did not want to let patients know that they got the cancer because they were afraid that patients would become worse. Relatives, so, requested nurses not to tell such truth to patients. The analysis was subject to second-round data (values above the dotted line) and third-round data (values below the dotted line).

Guidelines	Md	IR
1. Asking reasons of concealing the truth by giving relatives the opportunities of expressing their feelings, fear, and concerns.	4.94	0.64
	4.95	0.55
2. Explaining about good points of telling truth, which could help patients set their life plans, handle unfinished problems, and prepare to end their life prestigiously and honorably. But, weak points might be that the patients were unable to accept their condition and became worse.	4.83	0.67
	4.93	0.54
3. Setting the family participation so that both the family and treatment team had joint discussions and decisions by reminding relatives to realize that any decision should be made for patients, not for relatives, and based on patients' needs most.	4.95	0.55
	4.95	0.55
4. Planning with relatives and the treatment team for telling the truth. Nurses might consult the psychologists for the assistance or appropriate planning to tell the truth to patients such as indirect telling or supposing situation, and assigning the suitable person to tell such truth while the patients and relatives agreed to be involved in.	4.86	0.11
	4.91	0.59

Table 5 showed that

The experts' viewpoints were consistent at the highest level in every step concerning the guidelines in case relatives did not want to let patients know that they got the cancer because they were afraid that patients would become worse. Relatives, so, requested nurses not to tell such truth to patients.

Table 6 Presented the median (Md) and interquartile range (IR) based on experts' viewpoints concerning the guidelines in case patients required the explanation about the disease progress and treatments to be given as well as the disease prediction for their decision-making on selected treatments. The analysis was subject to second-round data (values above the dotted line) and third-round data (values below the dotted line).

Guidelines	Md	IR
1. Assessing needs of patients and relatives to receive the information.	4.94	0.64
	4.95	0.55
2. Coordinating for patients and relatives to talk to the treatment team officially, and giving them opportunities of discussing, questioning, consulting, and planning for treatments together.	4.98	0.51
Nurses might take part in stimulating patients and relatives to ask questions.	4.98	0.51
3. Clarifying the information if in doubt by patients and relatives after talking with the treatment team. The given information should be in the same way given by the treatment team.	4.88	0.61
	4.91	0.59

Table 6 showed that

The experts' viewpoints were consistent at the highest level in every step concerning the guidelines in case patients required the explanation about the disease progress and treatments to be given as well as the disease prediction for their decision-making on selected treatments.

Table 7 Presented the median (Md) and interquartile range (IR) based on experts' viewpoints concerning the guidelines in case of the difference of patients and relatives in respect with gender, age, and occupation. The analysis was subject to second-round data (values above the dotted line) and third-round data (values below the dotted line).

Guidelines	Md	IR
1. The protocol should be adjusted and fit to each patient by recognizing the individuals' promptness and differences in respect of learning, information perception, interpretation, acceptance, adjustment, and strength to set up the plan, which would be suitable for time, methods, level of wording, language used to explain about the disease, treatment ways, and appropriate supports.	4.97	0.53
	4.98	0.51

Table 7 showed that

The experts' viewpoints were consistent at the highest level in every step concerning the guidelines in case of the difference of patients and relatives in respect with gender, age, and occupation. Nurses should adjust the guidelines to fit each patient by recognizing the individuals' promptness and differences in respect of learning, information perception, interpretation, acceptance, adjustment, and strength to set up the plan, which would be suitable for time, methods, level of wording, language used to explain about the disease, treatment ways, and appropriate supports.

3. Allocated Treatments

Table 8 Presented the median (Md) and interquartile range (IR) based on experts' viewpoints concerning the guidelines in case the patients rejected any treatments causing the torment and uselessness. The analysis was subject to second-round data (values above the dotted line) and third-round data (values below the dotted line).

Guidelines	Md	IR
1. Evaluating the patients' illness condition how they learnt and understood the diagnosis, treatments, treatment results, and disease prediction.	4.95	0.55
	4.97	0.53
2. Evaluating that the patients had the full consciousness, not been overborne by the body torment or socio-mental and spiritual problems.	4.91	0.59
	4.93	0.57
3. Recording the evaluation of patients' status and needs in the nursing daily records.	4.83	0.67
	4.93	0.57
4. Consulting the treatment team for the patients' needs to find out caring methods in conformity with needs of patients.	4.95	0.55
	4.95	0.55
5. Coordinating for patients and relatives to talk to the treatment team to set up the treatment ways; comparing between the expected treatment results and bad points if no treatments were done for the good understanding of patients and relatives. As a result, all related parties would have a joint decision on treatment methods. Nurses might wait until patients and relatives had mental readiness before they specified some undesirable treatments such as CPR, the respiratory apparatus if the patients were seriously ill, etc.	4.93	0.57
	4.95	0.55
6. Preparing patients' advance directives in the written form or in the informed consent as witnessed by patients' relatives.	4.91	0.59
	4.91	0.59
7. Caring and evaluating the treatments regularly so that there were consistent with patients' intent and needs. If patients' illness conditions changed, nurses should evaluate periodically whether patients still had the same needs or not, and informed	4.91	0.59
	4.95	0.55

Table 8 Presented the median (Md) and interquartile range (IR) based on experts' viewpoints concerning the guidelines in case the patients rejected any treatments causing the torment and uselessness. The analysis was subject to second-round data (values above the dotted line) and third-round data (values below the dotted line). (cont.)

Guidelines	Md	IR
the family and relatives of patients' needs.		
8. In case that patients desired to go back home, relatives should be informed of possible illness conditions, caring of patients at home, and advising on nearby hospitals or assistance network	4.97	0.53
such as contacting the home-visit unit to help both patients and family, as well as giving the emergency telephone numbers for 24-hour assistance or consult including caring of patients if they die at home and the legal protocol.	4.98	0.51

Table 8 showed that

The experts' viewpoints were consistent at the highest level in every step concerning the guidelines in case that the patients rejected any treatments causing the torment and uselessness.

Table 9 Presented the median (Md) and interquartile range (IR) based on experts' viewpoints concerning the guidelines in case the patients had no advance directives. The analysis was subject to second-round data (values above the dotted line) and third-round data (values below the dotted line).

Guidelines	Md	IR
1. Assessing the patients and relatives the extent of acknowledging the information in respect with illness diagnosis, treatments, and disease prediction.	4.88	0.61
	4.95	0.55
2. Taking such received information to consult the treatment team for planning and discussing about treatment alternatives and treatment results.	4.95	0.55
	4.95	0.53
3. Coordinating for patients and relatives to talk to the treatment team in order to investigate needs of patients and relatives, treatment alternatives, treatment results, and treatment rejection.	4.95	0.55
	4.98	0.51
As a result, both patients and relatives could be involved in selecting the caring ways in conformity with patients' needs most.		
4. In case of patients' unconsciousness, the close and direct-blood relative would decide for treatment methods. But, if patients had several relatives, all of them might have the appointments with the treatment team (family meeting) to conclude the selected treatments. All relatives should be reminded that the decision was made for patients, not relatives; thus, the decision should meet patients' thought and needs most.	4.93	0.57
	4.93	0.57
5. In case the patients or relatives were unable to undertake anything, nurses should take roles in representing the patients and relatives in giving the information about treatments for the decision-making of patients and relatives.	4	2.71
	4.2	1.4
6. Needs of patients and relatives should be evaluated periodically. If the patients or relatives changed their mind or had hesitation, nurses should provide the useful information	4.93	0.57
	4.95	0.55

Table 9 Presented the median (Md) and interquartile range (IR) based on experts' viewpoints concerning the guidelines in case the patients had no advance directives. The analysis was subject to second-round data (values above the dotted line) and third-round data (values below the dotted line). (cont.)

Guidelines	Md	IR
for their decision-making. Then, nurses forwarded such evaluation to the treatment team for the revision of treatment plan.		
7. Giving some help to the patients and relatives regarding general practice and illness relief to acquire patients' comfort; arranging the environment for tranquility and privacy; and giving opportunities for religious and faith practice.	4.91	0.59
	4.91	0.59
8. In case the patients had no relatives, nurses should not leave the patients die lonely, but stay with them for spiritual guidance and giving some advice on the religious practice.	4.80	0.85
	1.93	0.57

Table 9 showed that

1. The experts' viewpoints were consistent at the highest level in 7 steps: Step 1 - Assessing the patients and relatives the extent of acknowledging the information in respect with illness diagnosis, treatments, and disease prediction; Step 2 - Taking such received information to consult the treatment team for planning and discussing about treatment alternatives and treatment results; Step 3 - Coordinating for patients and relatives to talk to the treatment team in order to investigate needs of patients and relatives, treatment alternatives, treatment results, and treatment rejection. As a result, both patients and relatives could be involved in selecting the caring ways in conformity with patients' needs most; Step 4 - In case of patients' unconsciousness, the close and direct-blood relative would decide for treatment methods. But, if patients had several relatives, all of them might have the appointments with the treatment team (family meeting) to conclude the selected treatments. All relatives should be reminded that the decision was made for patients, not relatives; thus, the decision should meet patients' thought and needs most; Step 6 - Needs of patients and relatives should be

evaluated periodically. If the patients or relatives changed their mind or had hesitation, nurses should provide the useful information for their decision-making. Then, nurses forwarded such evaluation to the treatment team for the revision of treatment plan; and Step 7 - Giving some help to the patients and relatives regarding general practice and illness relief to acquire patients' comfort; arranging the environment for tranquility and privacy; and giving opportunities for religious and faith practice.

2. The experts' viewpoints were inconsistent at the highest level in Step 5 in the second round when the statement "In case the patients or relatives were unable to undertake anything, nurses should take roles in representing the patients and relatives in making the decision about treatments while nurses were still working as a part of the treatment team." to be "In case the patients or relatives were unable to undertake anything, the treatment team should take roles in representing the patients and relatives in giving the information about treatments for the decision-making of patients and relatives. In the third round, the experts had more consistent viewpoints.

Table 10 Presented the median (Md) and interquartile range (IR) based on experts' viewpoints concerning the guidelines in case of the differences of patients in respect with gender, age, and occupation. The analysis was subject to second-round data (values above the dotted line) and third-round data (values below the dotted line).

Guidelines	Md	IR
1. The protocol should be suitably applied for each patient	4.93	0.57
depending on the personal difference while the standard quality	4.97	0.53
was maintained.		

Table 10 showed that

The experts' viewpoints were consistent at the highest level concerning the guidelines in case of the differences of patients in respect with gender, age, and occupation, that is, nurses should apply the protocol to suit each patient depending on the personal difference while the standard quality was maintained.

4. Use of medical equipment for prolonged life

Table 11 Presented the median (Md) and interquartile range (IR) based on experts' viewpoints concerning the guidelines in case the patients were terminally ill and unconscious but they had advance directives by rejecting the use of medical equipment to sustain their life, and patients' relatives rejected it as well but the physicians required it. The analysis was subject to second-round data (values above the dotted line) and third-round data (values below the dotted line).

Guidelines	Md	IR
1. Nurses should represent the patients and relatives in transferring needs of patients and relatives to the physicians, and consult the physicians for the patients' needs.	4.80 4.83	0.77 0.67
2. If the physicians insisted on the same treatments, encouraging relatives as patients' representatives to meet the physicians to inform of patients and relatives' desires while the physicians also had chance of explaining about the usefulness of each treatment so that relatives would have better understanding about each treatment way for further decision.	4.91 4.93	0.59 0.57
3. In case the relatives still denied those equipments while the physicians insisted the same undertaking; nurses should note this event in the nursing daily records and reasons of physicians to provide such assistance.	4.86 4.91	0.64 0.59
4. Proposing those problems to the meetings to encourage the hospital management to acknowledge that those problems would be risks of the hospital. There should be the committee monitoring ethics of caring of terminal cancer patients as the guidelines on caring of other patients.	4.86 4.88	0.64 0.61

Table 11 showed that

The experts' viewpoints were consistent at the highest level in every step concerning the guidelines in case the patients were terminally ill and unconscious but

they had advance directives by rejecting the use of medical equipment to sustain their life, and patients' relatives rejected it as well but the physicians required it.



Table 12 Presented the median (Md) and interquartile range (IR) based on experts' viewpoints concerning the guidelines in case the patients had advance directives on rejecting the use of medical equipment to sustain their life, but patients' relatives required it. The analysis was subject to second-round data (values above the dotted line) and third-round data (values below the dotted line).

Guidelines	Md	IR
1. Giving opportunities to patients' relatives for comments, asking their needs and reasons of such desire, and reminding them about patients' needs by emphasizing that any decision should be subject to patients not relatives.	4.95	0.55
	4.97	0.53
2. Transferring the needs of relatives to the treatment team to stimulate the physicians to pay attention in this issue.	4.95	0.55
	4.95	0.55
3. Coordinating for relatives to talk to the treatment team so that they obtained both strengths and weaknesses of bearing tubes or sustaining life, persuading relatives into caring of terminal cancer patients for the prestigious death, and reminding the relatives about the consequences of not respecting for patients' directives for the new decision to be made by relatives.	4.88	0.61
	4.97	0.53
4. Recording relatives' comments in the nursing daily records, and respecting for relatives' decision.	4.74	1.12
	4.74	0.95
5. Evaluating the needs of relatives and periodically giving them the patients' illness conditions. If the relatives changed their mind, nurses should coordinate for relatives to talk to the treatment team.	4.88	0.81
	4.93	0.57

Table 12 showed that

The experts' viewpoints were consistent at the highest level in every step concerning the guidelines in case the patients had advance directives on rejecting the use of medical equipment to sustain their life, but patients' relatives required it.

Table 13 Presented the median (Md) and interquartile range (IR) based on experts' viewpoints concerning the guidelines in case of the differences in respect with gender, age, and occupation. The analysis was subject to second-round data (values above the dotted line) and third-round data (values below the dotted line).

Guidelines	Md	IR
1. The treatments should be adjusted to fit the status of patients and family.	4.83	0.67
	4.93	0.57

Table 13 showed that

The experts' viewpoints were consistent at the highest level concerning the guidelines in case of the differences in respect with gender, age, and occupation, that is, the treatments should be adjusted to fit the status of patients and family.

5. Stopping treatments

Table 14 Presented the median (Md) and interquartile range (IR) based on experts' viewpoints concerning the guidelines in case the patients desired to stop treatments and to die at home. The analysis was subject to second-round data (values above the dotted line) and third-round data (values below the dotted line).

Guidelines	Md	IR
1. Evaluating that the patients had the complete consciousness and were not influenced by the body symptoms, socio-mental and spiritual problems.	4.95	0.55
2. Evaluating that the patients acknowledged and understood, as some partial information for decision-making, the diagnosis, treatments, treatment results, disease prediction, strengths and weaknesses of rejecting the treatments, as well as the torment to be occurring in the future.	4.95	0.55
	4.97	0.53
3. Recording the evaluation of patients' illness condition and needs in the nursing daily records.	4.95	0.55
	4.95	0.55
4. Coordinating for talks between patients and relatives so that relatives understood and accepted the patients' needs, including strengths and weaknesses of rejecting the treatments by informing both patients and relatives of all facts, and giving them opportunities to question and make decisions again.	4.93	0.57
	4.97	0.53
5. In case the patients insisted to stop all treatments and to die at home, a joint meeting between the treatment team and the patients as well as family should be arranged to set planning and give some advice on caring of patients at home (discharge planning), especially ways of controlling the illness condition when patients were nearly dead so that the relatives would be able to confront and handle the situation while the patients had no torment and died peacefully. Nurses might advise the relatives on supporting sources or assistance network by forwarding the treatment information and patients' needs	4.98	0.51
	4.97	0.53

Table 14 Presented the median (Md) and interquartile range (IR) based on experts' viewpoints concerning the guidelines in case the patients desired to stop treatments and to die at home. The analysis was subject to second-round data (values above the dotted line) and third-round data (values below the dotted line). (cont.)

Guidelines	Md	IR
to those sources or network.		
6. Undertaking all related documents in connection with patients' treatment rejection, and preparing patients for moving	4.93	0.57
by realizing that patients might pass away during such moving;	4.95	0.55
thus, relatives should be ready to confront such situation.		

Table 14 showed that

The experts' viewpoints were consistent at the highest level at every step concerning the guidelines in case the patients desired to stop treatments and to die at home.

Table 15 Presented the median (Md) and interquartile range (IR) based on experts' viewpoints concerning the guidelines in case the patients desired to stop treatments but relatives desired to continue the treatments. The analysis was subject to second-round data (values above the dotted line) and third-round data (values below the dotted line).

Guidelines	Md	IR
1. Giving the relatives opportunities for comments, asking for their needs and reasons of continued treatments, and reminding them about patients' needs.	4.95	0.55
	4.95	0.55
2. Transferring the needs of relatives to the treatment team, and recording such needs in the nursing daily records.	4.88	0.61
	4.93	0.57
3. Coordinating for relatives to talk to the treatment team so that they obtained the information, persuading them into caring of terminal cancer patients for the prestigious death, and reminding the relatives about the patients' needs for the new decision to be made by relatives, which should be subject to patients, not relatives.	4.93	0.57
	4.95	0.55
4. If the patients and relatives had inconsistent viewpoints, the treatment team should coordinate for both parties to discuss and share comments with each other, and give time for a new decision.	4.74	1.37
	4.80	0.82

Table 15 showed that

The experts' viewpoints were consistent at the highest level at every step concerning the guidelines in case the patients desired to stop treatments but relatives desired to continue the treatments.

Table 16 Presented the median (Md) and interquartile range (IR) based on experts' viewpoints concerning the guidelines in case of the differences of patients and relatives in respect with gender, age, and occupation. The analysis was subject to second-round data (values above the dotted line) and third-round data (values below the dotted line).

Guidelines	Md	IR
1. The methods and practice should be suitably applied for	4.95	0.55
relatives of each patient depending on the differences of person	4.97	0.53
and situation.		

Table 16 showed that

The experts' viewpoints were consistent at the highest level at every step concerning the guidelines in case of the differences of patients and relatives in respect with gender, age, and occupation, that is, nurses should apply methods and practice suitably for relatives of each patient depending on the differences of person and situation.

6. Advance directives

6.1 Guidelines in case the patients told the caring nurse that they did not want any prolonged-life equipment and the nursing chief on duty recorded such needs in the nursing records. Were those nursing records deemed as the written advance directives?

In this issue, experts' viewpoints were inconsistent and could be divided into 2 issues:

- 18.75%/ 9.375% - The group opined that those nursing records should be deemed as advance directives because they were counted as the legal evidence.

- 75%/ 84.375% - The group opined that those nursing records should not be deemed as advance directives because, currently, there have not yet been any laws prescribing the advance directives although the nursing records could be used as the legal evidence. This issue was on argument and set forth in Section 10 of the National Health Bill, which may be legally acceptable in the future. But, for the clear evidence, the patients might prepare the informed consent instead of nursing records so that everyone in the caring team could notice it.

According to the opinion survey, most experts had consistent viewpoints that the nursing records could not be used as the legal written records.

Table 17 Presented the median (Md) and interquartile range (IR) based on experts' viewpoints concerning the guidelines of preparing the advance directives. The analysis was subject to second-round data (values above the dotted line) and third-round data (values below the dotted line).

Guidelines	Md	IR
1. Evaluating that the patients had the full consciousness, not been overborne by the body torment or socio-mental and spiritual problems.	4.98	0.51
2. Evaluating that the patients acknowledged and understood, as some partial information for decision-making, the diagnosis, treatments, treatment results, disease prediction, strengths and weaknesses of using the prolonged-life equipment in the treatments.	4.98	0.51
3. In case the patients insisted not to get treatments by the use of prolonged-life equipment, nurses should note the evaluation of patients' illness condition and needs in the advance directive and reporting them to the caring team.	4.97	0.53
4. Coordinating for patients and relatives for another talk to the treatment team so that they were provided, for a new decision-making, strengths and weaknesses of treatments by the use of prolonged-life equipment including the torment to be occurring in the future for a new decision made by relatives.	4.98	0.51
5. In case the patients still insisted the same intent, nurses should undertake all related documents by having the patients record their own needs in advance directives that should also be signed by caring physicians who certified that the patients had full and complete consciousness, and relatives as witnesses.	4.98	0.51

Table 17 showed that

The experts' viewpoints were consistent at the highest level at every step concerning the guidelines of preparing the advance directives.

Table 18 Presented the median (Md) and interquartile range (IR) based on experts' viewpoints concerning the guidelines in case of stop treatments with the written advance directives identified by patients for stop treatments and no prolonged-life equipment. The analysis was subject to second-round data (values above the dotted line) and third-round data (values below the dotted line).

Guidelines	Md	IR
1. Evaluating that the patients had the full consciousness, not been overborne by the body torment or socio-mental and spiritual problems.	4.98	0.51
2. Coordinating with the physicians to give patients and relatives the information for their decision-making about inserting the breathing tube, results of inserting such tube, the torment to be occurring in the future if not bearing it, and the disease prediction.	4.97	0.53
3. In case the patients still insisted for not bearing the respiratory apparatus, the nurses should attend the joint meeting with the treatment team, patients, and relatives to note the patients' needs in the written form signed by the patients (patients' signature might not be required if the patients showed their needs in the hand-writing, except signing to prevent any problems with relatives after the patients' death). The record of patients' needs should comprise some witnesses who guaranteed that the patients have full and complete consciousness. Those witnesses should be direct-blood relatives or caring physicians.	4.83	0.67
4. Notifying the physicians or related persons or relatives for the joint caring plan. Although the patients insisted that they did not want the breathing tube or other prolonged-life equipment, other treatments could be done to relieve patients' torment; for example, giving the oxygen by other ways. However, any treatments should mainly concern the patients' needs and	4.93	0.57
	4.95	0.55
	4.98	0.51

Table 18 Presented the median (Md) and interquartile range (IR) based on experts' viewpoints concerning the guidelines in case of stop treatments with the written advance directives identified by patients for stop treatments and no prolonged-life equipment. The analysis was subject to second-round data (values above the dotted line) and third-round data (values below the dotted line). (cont.)

Guidelines	Md	IR
not cause any torment.		
5. Although the patients had advance directives, when their illness became worse, nurses should talk to patients and relatives again whether they still had the same intent or wanted to change their mind. The treatments should be revised as per needs of patients and relatives.	4.88	0.62
	4.93	0.57

Table 18 showed that

The experts' viewpoints were consistent at the highest level at every step concerning the guidelines in case of stop treatments with the written advance directives identified by patients for stop treatments and no prolonged-life equipment.

Table 19 Presented the median (Md) and interquartile range (IR) based on experts' viewpoints concerning the guidelines in case the physicians desired to use the prolonged-life equipment although the patients had advance directives that they did not want it. The analysis was subject to second-round data (values above the dotted line) and third-round data (values below the dotted line).

Guidelines	Md	IR
1. Nurses should represent the patients and relatives in transferring needs of patients and relatives to the physicians, showing to the physicians the patients' advance directives to insist the patients' needs.	4.91	0.59
	4.86	0.64
2. Nurses should not help prepare the medical equipment. Moreover, nurses should explain to the physicians that when the patients rejected the offer of rescue, it should be deemed that it was beyond the duty of physician in treatments; thus, any actions for patients shall be the violation of patients' right.	3.21	1.66
	3.7	1.58
3. If the physicians on duty still insisted the same actions, nurses should coordinate with the relatives of patients to meet the physicians to be compliance with patients' intent.	4.7	1.04
	4.7	1.04
4. In case that the relatives decided that no prolonged-life equipment should be used, but the physicians insisted the same actions; nurses should note this event in the nursing daily records.	4.80	0.82
	4.80	0.82
5. Reporting the attending physician and higher supervisors respectively.	4.74	1.05
	4.91	0.59
6. Proposing those problems to the meetings to encourage the hospital management to acknowledge that those problems would be risks of the hospital. There should be the committee monitoring ethics of caring of terminal cancer patients as the guidelines on caring of other patients.	4.86	0.64
	4.91	0.59

Table 19 showed that

1. The experts had consistent viewpoints at the highest level in 5 steps: Step 1 - Nurses should represent the patients and relatives in transferring needs of patients and relatives to the physicians, showing to the physicians the patients' advance directives to insist the patients' needs; Step 3 - If the physicians on duty still insisted the same actions, nurses should coordinate with the relatives of patients to meet the physicians to be compliance with patients' intent; Step 4 - In case that the relatives decided that no prolonged-life equipment should be used, but the physicians insisted the same actions; nurses should note this event in the nursing daily records; Step 5 - Reporting the attending physician and higher supervisors respectively; and Step 6 - Proposing those problems to the meetings to encourage the hospital management to acknowledge that those problems would be risks of the hospital. There should be the committee monitoring ethics of caring of terminal cancer patients as the guidelines on caring of other patients.

2. The experts had inconsistent viewpoints in Step 2 in the second and third rounds that nurses should not help prepare the medical equipment. Moreover, nurses should explain to the physicians that when the patients rejected the offer of rescue, it should be deemed that it was beyond the duty of physician in treatments; thus, any actions for patients shall be the violation of patients' right; and Step 3 in the second round that "If the physicians still insisted the same actions, nurses should coordinate with the relatives of patients to be involved in the treatments that should be subject to patients' intent", which was changed to be "If the physicians on duty still insisted the same actions, nurses should coordinate with the relatives of patients to meet the physicians to be compliance with patients' intent". In the third round, the experts had inconsistent viewpoints again.

Table 20 Presented the median (Md) and interquartile range (IR) based on experts' viewpoints concerning the guidelines in case of the differences of patients and relatives in respect with gender, age, and occupation. The analysis was subject to second-round data (values above the dotted line) and third-round data (values below the dotted line).

Guidelines	Md	IR
1. As a whole, there should not be any differences. In case of so young patients, they should have duly representatives.	4.91	0.59
However, most decisions were up to parents; thus, parents should be clarified. In addition, treatments should concern the differences of person and situation.	4.97	0.53

Table 20 showed that

The experts' viewpoints were consistent at the highest level concerning the guidelines in case of the differences of patients and relatives in respect with gender, age, and occupation, which should not be treated differently by nurses. In case of so young patients, they should have duly representatives. However, most decisions were up to parents; thus, parents should be clarified. In addition, treatments should concern the differences of person and situation.

CHAPTER 5

DISCUSSION

1. Pain Handling

The experts took emphasis that nurses should assess the pain as perceived by patients and find out other causes of pain apart from the cause of body conditions. After the assessment, nurses should have joint meetings with the treatment team to handle the pain of patients. As the World Health Organization (WHO) viewed that (Pongparadee Chaothakasertrin, translator, 2003:18) the remedy of pain caused by cancer was the palliative care, restrain of other symptoms, and mental, social, and spiritual care. If the pain was cured without realizing the significance of problems apart from the body pain, it did not lead to good points, but failure. The communication regarding evaluating and giving both patients and relatives some information was important as well to allow them understand the treatment results and possible side effects caused by the medication (Pornlert Chadkhaew and Wanna Somboonviboon, Mo.Po.Po.:2). However, most experts had viewpoints that the patients had the existing pain and they had to obtain more pain resulted by the side effects of additional medication such as constipation, dry mouth, etc., which was relevant to the code of ethics regarding non-maleficence. The experts proposed that others methods of pain relief should be used by inviting knowledgeable or experienced persons to educate nurses, patients and relatives to be involved in those methods such as massage, meditation, listening to favorite songs, and use of humorous media, etc.

Nurses were a part of treatment team who have performed their nursing for the best benefit of patients such as health promotion, prevention of illness, health recovery, and torment relief (The Nurses Association of Thailand, 2005:5). Beauchamp & Childress (1994:260) stated that 1) one should prevent the occurrence of harmful or torturous things, 2) one should wipe out what leading to danger and torment, 3) one should do what promoted the merit. When nurses have tried to use

other methods such as environment arrangements, listening to music, massage, touching or holding the patient's hands, and expressing humor to relieve the pain but patients still had some pain, the experts viewed that nurses should report the physicians that the pain-killing drugs as per the treatment plan were insufficient for patients. As stated that nurses had duties of helping patients when the important events occurred, and protecting human rights for incompetent persons such as patients having unsolvable problems or ones not knowing the persons who could give them some help in solving problems, and patients receiving unsafe and unqualified care (Fray, 2002: 38; Farida Ibrahim, 1995:247-248). Therefore, nurses should help patients by asking their illness conditions, and reporting them to the physicians. Nurses had to respect for person; when patients said that they had some pain, it meant that the patients actually had it. The experts also had a viewpoint that pain handling, even the differences of patients in respect with gender, age, status, and occupation, should be based on the same principles of care and nursing standard, which should be adjusted to fit each patient. This was relevant to Clause 4 of the Nursing Code of Ethics B.E. 2546 specifying that the service user should obtain the best help that was relevant to his/her need as much as possible under the respect for person's life, prestige, and right to have the happiness equitably without the limitation of classes, race, religion, financial status, gender, age, rumor, reputation, social status, and disease that one got, which was in compliance with the principle of fairness.

2. Truth Telling

The experts had viewpoints that nurses should evaluate the perception of patients to see what they wanted; nurses should be ready to perceive the disease diagnosis in order to report it to the treatment team, and plan for the time and person to tell such diagnosis to patients. Perlmutter & Hall (Perlmutter & Hall, 1985:513-514) prescribed that learning facts about the disease and treatment methods was the fundamental need of terminally ill patients. In addition, according to the principle of respect for autonomy, Dewit (Dewit, 1992:309) specified that it was the right of terminally ill patients to receive the factual information. Giving the information about illness suitably was the target and standard of caring of terminally ill patients, partly,

to help patients live on willingly. Although telling the truth to patients was a duty of physician; nurses still have the duty of coordinating or mediating between patients and physicians. Nurses were persons staying close to patients; so they were able to give the information about patients to the health team for the consideration of giving appropriate information to patients (Mayer, 1989:75-78, Pikulthip Honghern and Pranee Jatiket, 1996:129).

Moreover, the experts had another viewpoint that, in telling about the diagnosis, the group support should be used, or the patients and relatives were allowed to join the meetings for treatment plans. When the patients and relatives received such factual information, they might have emotional reactions. Hence, the treatment team should palliate the patients until their emotional reactions disappeared, and join the caring team to find out other treatment methods. In addition, the treatment team should not follow the relatives' need to conceal the disease diagnosis from the patients since they were afraid that the patients would become worse. This was consistent with the viewpoints of Dr. Pramote Sudkanit (2002:7-9) and Dr. Sathaporn Leelanantakit (2000:30-45) who stated that the treatment team had to tell the truth, should not tell a lie even one time, avoid to speak openly without considering carefully or evaluating the situation. Gradual telling the truth with continuous caring of patients, and stimulating patients to fight could maintain the patients' full hope. This was relevant to the principles of beneficence and non-maleficence. The relationship between physicians and patients had to be subject to trust and confidence. This relationship could be maintained by loyalty of each other. However, whenever the patients did not want to perceive anything about their illness or facts, it would be a huge mistake to force them to listen to their illness. The family of patients should not prohibit the physicians to talk to the patients about the disease diagnosis and prediction. If the patients desired to know them, it was the right of patients pursuant to Clause 3 of the Announcement of Rights of Patients indicating that patients requesting for the health service held a right of receiving the information sufficiently and understanding it clearly as explained by the health professionals in order that the patients would be able to make decisions on agreeing or disagreeing to be treated by health professionals except in the emergency or necessary help, and Clause 9 indicating that the patients had the right to receive the information about their particular treatments as noted in

the medical records once the patients called on demand. However, such information should not violate the personal right of other persons. In case of the differences of patients and relatives in respect with gender, age, and occupation, the experts advised that the truth telling should be adjusted to fit each person by considering the promptness and differences in respect with learning, perception of information, interpretation, acceptance, adjustment, and strength of each person so that the planning for providing the information would be suitable in terms of time, method, level of wording, language used to explain about the disease, treatment ways, and appropriate supports. Fowler (1989:960-961) stated that 1) The information should be adequate for decision-making.; 2) The information should be subject to needs or willingness of patients based on benefits to patients, respect for the autonomy of patients, and the principle of justice/fairness.

3. Allocated Treatments

The experts had viewpoints that nurses had to evaluate the conditions of patients, understand the information concerning disease diagnosis, treatments, treatment results, and disease prediction. In addition, when the patients rejected the treatments, nurses should evaluate in what extent the patients had full and complete consciousness. In addition, nurses had to note the patients' needs in the nursing records, coordinating with the caring team and relatives of patients to inform of patients' directives, transferring the care or preparing relatives of patients to learn possible illness conditions. These were consistent with the obligations set forth in the Patient Self Determination Act (PSDA) of the United States stipulating the treatment plans that a person shall have right to accept or reject, or plan for his/her own advance treatment plan or for what he/she desires or does not desire subject to individuals' belief. This was another way of respecting for person's right in making the decision on his/her own treatment plan before he/she becomes incompetent or after he/she received the complete information by not minding whether relatives would be able to set the agreement or not. If the patients did not accept any treatments and wanted to go back home, the physician had to explain to the relatives how to care of patients for the

suitable caring (Vitoon Eungprabhanth, 2002:31; Green, 1999:22; Nolan & Bruder, 1997:204-206), which was relevant to the principle of beneficence.

The obligation on Patient Self Determination promoted the respect for rights of patients. The health team should have the following practice (Green, 1999:22-38):

1. The health team had to explain to each patient admitting to the hospital so that he/she understood the right of decision-making on health caring by himself/herself, and led to the development of planning for the legal advance directive.
2. The health team had to note in the medical records of patients about offering them the information on the right of decision-making on health caring by themselves whether the patients had the advance directives or not.
3. The health team implemented the obligation on Patient Self Determination to prevent the enforcement of patients in case the patients did not have the advance directives.
4. The health team should make the patients have confidence that their right would be respected and legally supported by the written advance directives of patients.
5. The health team should provide knowledge to colleagues and people in the community about the planning for the advance directive.

Moreover, Section 31 of the Constitution of the Kingdom of Thailand B.E. 2540 (1997:17) prescribed that; “one has right and freedom for life and body”. By virtue of law, the owner of such right of patient was the patient. Thus, only the patient should lawfully have the right of being protected, except that patient was incompetent to express the directive and while expressing the directive, the patient should have good consciousness, capability of making decision by undertaking as per his/her own right or proxy to represent the patient for the decision-making. When the representative carried on any actions for the patient, it would come into effect although the patient lacked the ability of decision-making. This was consistent with Clause 3 of the announcement of rights of patients jointly announced by professional organizations on 1998 that the patients requested for the health service had the right of receiving the information sufficiently and understanding it clearly as explained by the health professionals in order that the patients would be able to make decisions on agreeing or disagreeing to be treated by health professionals except in the emergency or necessary

help, and Clause 6 indicating that the patients had the right to ask the opinion of other health professionals who did not provide them the health service, and to change the service provider and service places (Visute Fongsiriphaiboon and Chanpim Jaempongpan, 1998:22-23). Regarding the principle of justice/fairness, the experts suggested that care and evaluation of treatment results should be done regularly after the decision on treatments of the patients and relatives so that the patients obtained the treatments in consistence with intent and needs of patients. The family and relatives should also be advised about the needs of patients.

4. Use of Medical Equipment for Prolonged Life

The experts took emphasis that nurses had roles of representing the patients and relatives in transferring needs of patients and relatives to the physicians. According to the study of Carney and Meier (2000:183-209), it was found that giving food substances and water to this group of patients acquired the little usefulness in term of relieving illness conditions but it resulted to many drawbacks such as more sputa, heart attack, abdominal edema, swelling, pneumonia, or inflamed skin at the spot of inserting the tube for intravenous drips, distress, and pain caused by inserting the tube for intravenous drips and the tube for infusion apparatus, etc. In accordance with the qualitative study conducted by Patraporn Chanpradit (2001:80-87) regarding the experience of patients in taking the respiratory apparatus, it was found that the patients experienced a great pain in bearing tubes and sputa drawing. Thus, representing the patients by nurses was to maintain the value, belief, and desires of patients, and to respect for requests of patients (Potter & Perry, 1995:86). This was relevant to the principle of respect for person, beneficence, and non-maleficence.

Pursuant to the study of Wilaiwan Chairatmanokorn (1997:120-130) regarding legal concepts and counselors' acceptance of allowing hopeless patients to die calmly. About 242 counselors responded the questionnaire, and the study found out that in case patients were unconscious and relatives asked physicians to remove the tube for intravenous drips and the respiratory apparatus for hopeless patients, most counselors thought that physicians had the offence of willful kill. The same group of counselors, however, accepted that if those hopeless patients were their relatives or themselves,

they agreed to allow the physicians to make them die calmly. But, in the general principle, curing the patients required the patients' consent. Generally, the consent given by the patients or other persons legally authorized to care of patients had to exist before any medical treatment except in the emergency case because the delayed operation might cause the patients' death (Visute Fongsiriphaiboon and Chanpim Jaempongpan, 1998:39). Dr. Sathaporn Leelanantakit (2000:18) gave the principle of caring of patients whatever the level there were, that is, respect for person, that treatment gave good results to patients, that treatment did not result to or resulted to the least harm to patients, and the allocation of resources to each patient was fair. If the physicians still insisted to use the medical equipment, the experts thought that such problem should be proposed to the meeting so that the hospital management realized it and found out the agreed treatment guidelines for curing other patients and preventing the occurrence of such problem.

5. Stopping Treatments

The experts had viewpoints that upon patients' request for stopping treatments, the first thing to do was to assess whether the patients had full and complete consciousness, were influenced by torment caused by physical, mental, and spiritual conditions, and understood and learnt the information about their disease, strengths and weaknesses of treatment rejection or not including the relationship among relatives of patients. If the patients went back home as per their insistence, nurses should give some advice on caring, possible illness conditions, and solutions. The needs of patients and summaries of illness had to be noted in the nursing daily records before handed them to the relatives and on-the-way hospital could give help immediately in the emergency case. This was relevant to the principle of respect for person, beneficence, and non-maleficence. Powell (2000:305-306; Visute Fongsiriphaiboon and Chanpim Jaempongpan, 1998:42) gave the following guidelines in case of stop treatments:

1. In case the patient had full and complete consciousness, and both patient and relatives disagreed with treatment methods of physicians.

1.1 Revised the suggestions of the health team again so that the patient understood the disease prediction and treatment alternatives by considering that the adult patients who had full and complete consciousness would have right to reject the treatments if provided sufficient information.

1.2 If the patient had the advance directive, revised it again before noting or telling such decision.

1.3 After talks and agreement, noted the decision made by the patient in the record file.

2. In case of incompetent patient and relatives' disagreement with the health team, the guidelines should be as follows:

2.1 Considered who took the role as the representative of that patient. The representatives ranked by the level of importance in compliance with Section 1629 and Section 1635 of the Civil and Commercial Code (2001:653 – 656) were:

- 2.1.1 Person determined by the patient;
- 2.1.2 Spouse and descendant (son and daughter);
- 2.1.3 Parents;
- 2.1.4 Brothers or sisters of full blood;
- 2.1.5 Brothers and sisters of half blood;
- 2.1.6 Grandfather and grandmother; and
- 2.1.7 Uncle and aunt.

2.2 Revised the choices to ensure that the representative understood the disease prediction of patient, conditions of patient, and treatment alternatives before asking that representative to put his/her signature for treatment rejection like the patient's advance directive.

2.3 If other family members disagreed with such representative, Case 5 below shall be applied.

2.4 Consulted the Ethical Committee.

3. In case that the patient and relatives could not make the decision on treatments, the guidelines were as follows:

3.1 The patient had right to reject the treatments or put signature to reject the treatments while the patient understood the information and was able to make the decision.

3.2 The family might be involved in questioning, but the final decision would be made by the patient who had full and complete consciousness.

3.3 The patient might consider dying peacefully.

3.4 Nurses might prepare to help the family.

4. In case that the health team did not give the treatment, but the patient and relatives (in case of the patient's incompetence) required it, the guidelines were as follows:

4.1 The health team should not have the treatment less than it could provide, and provided the patient and relatives the sufficient information about useless treatments, and told the patient and relatives again about reasons of not giving the treatment as required by the patient and relatives since it was not useful and risked the patient's safety.

4.2 Asked the opinion of patient and relatives again.

4.3 Gave alternatives of being cured by other physician or by other hospital.

4.4 Consulted the Ethical Committee of the hospital.

5. In case of the patient's incompetence and relatives could not set the agreement about the acceptance of treatment, the guidelines were as follows:

5.1 Followed the representative's instruction as mentioned in 2 above. But, if there were more than two representatives holding the same level of power or authority, following one who had more power.

5.2 Anyway, tried to make the relatives reach the agreement by realizing the needs of patient; for example, asking the relatives about what the patient used to tell or want, etc. so that the relatives would make the decision as per the needs of patient.

5.3 Probably consulted the Ethical Committee of the hospital.

6. In case that the health team could not set the agreement about treatments, the guidelines were as follows:

6.1 Tried to palliate by expressing viewpoints and considering suggestions fairly.

6.2 Prepared the management structure and determining duties and responsibilities clearly.

6.3 In case that the health team had two different viewpoints while the patient required the useless treatment; Case 4 above should be applied.

7. In case that the health team and relatives agreed with the treatment but the incompetent patient did not have the advance directive, the guidelines were as follows:

7.1 Followed Case 2 above and focusing on the profit of this decision.

8. In case it was unclear whether the patient had full and complete consciousness and/or agreed with the treatment or not, the guidelines were as follows:

8.1 Evaluated the problems of making decision and/or grounds of uncertainty.

8.2 Consulted the psychologist in case it was unclear whether the patient had full and complete consciousness or not.

8.3 If still being unable to make decision, consulting the Ethical Committee.

Under the principle of justice, the experts suggested that the guidelines should be applied to fit each patient by considering the differences of person and situation.

6. Advance Directives

Three experts had viewpoints that the nursing records could be used as the documentary evidence in the court whereas another 27 experts viewed that the nursing records were not the same to the advance directive since no witness acknowledged those records and no laws supported this issue. The experts advised that it was better to prepare the informed consent. The experts viewed that it was good to have the advance directive because if the patient became incompetent, the caring team would know needs of patient about his/her required treatment. If any problem between the patient's relatives occurred later, the caring team would be able to explain it to the relatives, and to set planning as per the advance directive. In the advance directive, it should be noted that who would make the decision in case that the patient were incompetent and unable to make any decision. In the meantime, the caring team had to evaluate and be sure that the patient prepared the advance directive without any pressure, whether the disease, mental, social and financial problems, and he/she learnt

the disease condition well, including advantages/disadvantages of rejecting the treatment. Hall (1996: 240-255) defined the planning for advance directive as a kind of legal document showing the authorization of health care indicating the rejection or acceptance for future treatment plans under the personal right of the patient in relation to the body of such patient. Some laws permitted the patient's parents to have the planning for advance directive for their children. In addition, the planning for advance directive should be made up by a person with the ability of considering the profit for himself/herself. The written advance directive would come into effect when the patient became incompetent. Every patient had a right to select how to die. In 1990, the United States issued the Act prescribing all hospitals to provide the information to patients, who had the right of knowing, at the final stage of his/her life, what was noted in the document concerning planning for advance directive before he/she would be unable to speak or tell what he/she wanted based on his/her profit. However, the experts suggested that it should be in the form of informed consent since, in Thailand, there have not yet been any laws to support this matter whereas the certain form of preparing the advance directive has not been set up yet. When the patients went to the hospital and the physician provided them the information about their disease and disease prediction, the patients had to make decision if something happened and the required treatment methods before noting them in the informed consent. Therefore, nurses should hold the principle of planning for the patients' advance directive always done on the patients' profit. In addition, nurses helped the health team have the direction for quicker decision on the period of treatment and rescue. The patients with the advance directive usually had the directive denying the rescue operation more than those without the advance directive. Moreover, the patients with the advance directive usually had the period of staying in the ICU, budgets and expenses less than those without the advance directive. This was relevant to 4 principles of nursing ethics, that is, respect for person, beneficence, non-maleficence, and justice/fairness. According to the study of Johnston, Pfeifer, and McNutt (1995: 1025-1029) regarding the planning for advance directive, they found out that talks about the advance directive should be done immediately after the patients admitted to the hospital; it deemed the responsibility of physician to start such discussion. The planning for advance directive was an action showing the respect for patients' autonomy. The planning for advance

directive was also the joint discussion between patients and health team that when the last period of life arrived, what treatments the patients required from the health team. The guidelines on planning for advance directive should be as follows (Wanwisa Sangprasert, 2003:188-189; Dusit Sathavorn, 2005:243-244):

1. The patient should tell about his/her needs concerning treatments in particular situations.
2. Planning for advance directive would come into force when that patient arrived the last period of life, and was incompetent in decision-making.
3. After the planning for advance directive was done, the patient might change it anytime.
4. If the patient authorized any person to make decision for him/her on health caring, the patient had to tell his/her needs to that authorized person.
5. If the patient prepared or changed the planning for advance directive, the patient should inform the physician or health team of such so that it was noted in the record file, then the patient got the treatment in consistence with his/her needs.

In other countries, some laws prescribed that each hospital has undertaken to promote the planning for advance directive as per the following steps (Rice, Beck and Stevenson, 1997:30):

1. Preparing the information for patients about the right of acceptance or rejection for treatments, and developing the form of planning for advance directive.
2. Preparing the treatment records to ensure that the planning for advance directive was followed.
3. No criteria, conditions, or discrimination of treatments for patients who did not have the planning for advance directive.
4. Preparing the community, persons giving knowledge about laws, hospital polity, and use of planning for advance directive.
5. Writing the policy, methods, and supports for the principle of self-decision.

The planning for advance directive required the signature of witness(es) and date in the record form because this document would be deemed a legal commitment that one communicates the needs of each patient on caring in the event that he/she was unable to inform of his/her needs. The physicians and nurses could take actions to the patients once the patients thought or decided by themselves. The patients' decision

had to be respected after receiving the required information as the fundamental information for making decision sufficiently (Vithoon Eungprabhanth, 2002:45). The patients had to show their consent by oral or put signature to accept the treatments. An obligation specified the direct respect for the right of patients as the informed consent. If the patients did not get enough information about treatment procedures, they did not have the autonomy of accepting those actions. There were 2 ethical principals that were the basis of acceptance for those actions but they had the different meanings:

1) Autonomy of self-handling that focused on the right of patients to make decision by themselves on what should or should not be done for them.; 2) Beneficence that focused on good results by giving the best to patients and preventing harmful things for patients (Coy, 1989:827).

The forms of acceptance and giving the acceptance could be done as follows (Visuit Fongsiriphaiboon and Chanpim Jaempongpan, 1998:36):

1. Oral form – The physician or medical personnel asked permission from the patients and legally authorized persons to check up or undertake any medical operation for treatments or remedies.

2. Written form – The acceptance was done in the written form, which was the favorite method for health service centers now since it was the clear evidence identifying that the patients had actual acceptance and it was witnessed by at least 2 persons. However, the acceptance signed by the witnesses did not mean that it would always come into force. Nurses should be responsible for ensuring that the patients had the right acceptance and agreed that the treatment procedures continued.

3. Expressing impliedly – Nodding to sign the permission or manners to acknowledge the check-up and to coordinate with the physician; for example, in case the patient handed his/her arm for inserting the tube for intravenous drips, or in case the patient was unconscious, the patient who bled in the emergency unit and required the urgent medical help.

The acceptance given by the patients prior to any treatments resulted to the good cooperation between service providers and service users, and it could be deemed the respect for rights. This acceptance also prevented the service providers not to violate the professional ethics and laws.

Therefore, in principle, any medical undertakings required the acceptance from patients or authorized persons. Any undertaking without the patients' acceptance would lead to the offence. However, sometimes, if the physicians or medial personnel waited for the acceptance of patients or persons legally authorized by patients until the damages occurred, it could be counted as the offence as well. Thus, the decision prior to any action had to be done carefully.



CHAPTER 6

CONCLUSION AND RECOMMENDATIONS

The objective of this study was to set up nursing ethical guidelines on caring of terminal cancer patients based on the Ethnographic Delphi Futures Research (EDFR). The sample populations consisted of 3 groups: Group 1 comprising 12 experts in caring of terminal cancer patients, Group 2 comprising 10 experts in medical laws and public health, and Group 3 comprising 10 experts in moral problems about caring of terminal cancer patients, or 32 experts in total. The instrument for the first round of the study was the semi-structure and situational questionnaire extracted from the interviews of 6 terminal cancer patients done by Wanwisa Sangprasert concerning 6 issues. The instrument for the second and third round was the questionnaire. The period of data collection was from 15 December 2005 to 8 June 2006 or 175 days in total.

The first-round questionnaire was the protocol constructed from the interview of experts in the 5 rating scale, and the second-round questionnaire was the revision of the first-round one as advised by most experts in the first round. The positions of median, interquartile range, and positions of answers responded by the experts in the first round were also added in the second-round questionnaire before the results obtained from the second round were analyzed to find out the values of median and interquartile range; statements that the experts had consistent viewpoints achieved the median not less than 3.5 and the interquartile range not more than 1.5, and taking all revised and concluded statements as the guidelines of caring of terminal cancer patients in conformity with the nursing ethics.

Conclusion of the Study

The results of the study could summarize the guidelines of caring of terminal cancer patients in conformity with 4 nursing ethics: respect for person, beneficence, non-maleficence, and justice/fairness as listed below:

1. Pain handling

1.1 Guidelines of proper pain handling for terminal cancer patients

1.1.1 Assessing the pain as perceived by patients as a whole, which was caused by the body pain and other grounds that were out of body condition, by applying the proper pain assessment methods.

1.1.2 Setting plans with the treatment team to set up the protocol of pain handling for terminal cancer patients. The protocol consisted of the number of regular doses and rescue doses for breakthrough. The treatment instruction should be flexible so that nurses were able to adjust the number of doses for patients.

1.1.3 Coordinating with the treatment team or other knowledgeable person to educate both patients and relatives about pain and pain handling methods apart from medicine taking such as meditation, creating a diversion, listening the favorite music, deep breathing, massage, and expressing the humor, etc.

1.1.4 Arranging the environment and providing assistance in pain handling by encouraging relatives to be involved in.

1.1.5 Assessing patients' pain regularly, both in the normal condition and after the medication or caring to relieve pain, and recording such assessment as well.

1.1.6 Meeting with the treatment team periodically to adjust the treatment plan until it was suitable for each patient by considering the individual difference.

1.2 Guidelines in case patients confronted pain and torment caused by pain. When patients requested for pain handling but the treatment plan set by the physicians was not insufficient for patients. Nurses should follow the guidelines below:

1.2.1 Assessing the pain as a whole to find out grounds of pain apart from the body condition.

1.2.2 Consulting the treatment team about patients' problems. Nurses might have to consult the anesthetists or pain clinic to jointly evaluate and plan for appropriate treatments, but the operation of medication should be clear so that nurses could operate by themselves.

1.2.3 Using other pain relief favored by patients by not having the medication such as relaxant massage, attention diversion, music, and environment arrangements, etc.

1.2.4 Caring of patients by extending them the understanding and mercy, not leaving them to stay alone, and encouraging relatives to be involved in caring of patients.

1.2.5 Following up and evaluating the treatment results regularly, and reporting such results to the treatment team for the revision of treatment plan.

1.3 Guidelines in case of the differences of patients in terms of gender, age, and occupation. Nurses should follow the guidelines below:

1.3.1 The principle of caring should be based on the same standard for every patient.

1.3.2 The principle of caring should be suitably applied for each patient since the knowledge about pain handling, gender, age, and personal background resulted to the different pain experience of each person.

For the guidelines of pain handling, most nurses considered the beneficence and non-maleficence first; so they dared not to give the pain-killing drugs to the patients since they were afraid that patients would get some side effects caused by such drugs such as drug addiction or stop breathing. As a result, the patients were stuck in pain and torment. Another reason that nurses dared not to give the pain-killing drugs was that they lacked the knowledge about pain and right medication. For the principle of justice, it was found that if the hospital officers were patients and had pain, these patients would get the pain-killing drugs immediately when they asked for. In case that the pain-killing drugs were not sufficient, nurses should represent the patients to report it to the physician to get the drug immediately. But, in practice, nurses usually had conflicts among colleagues; thus they could not represent the patients with full abilities due to the shortage of communication skills, no fear to present in the appropriate ways, and arranging the working environment to respect the opinion of personnel in every department, which helped the patients receive the profit from caring by personnel in every department completely.

2. Truth telling

2.1 Guidelines of telling truth to patients that they got the cancer. Nurses should perform as per the following steps:

2.1.1 Assessing patients and relatives' needs and promptness of perception to be the important information for the treatment team in telling the truth; for example, the patients knew or doubted that they got the cancer, the patients with the clear background that they hurt themselves when facing serious matters in life, and reactions and viewpoints of patients and relatives about truth telling. Such key information should be transferred to the treatment team.

2.1.2 Having joint meetings of all related physicians, nurses, caregivers, and specialized physicians to find out and assign the suitable person for truth telling by considering the patients' reliability to the physicians. Truth telling should be undertaken as a team with the telling techniques; patients were encouraged and given the relevant information and communication.

2.1.3 The principle of truth telling might be based on the group support, counseling, or supposing situations depending on the conditions of patients and willingness of patients and relatives to be involved in.

2.1.4 In case that the patients received the fact, but they were unable to accept it or they had strong emotional reactions, nurses had to care of and palliate them so that patients would be able to pass that situation and accept it finally.

2.1.5 Assessing patients and their family periodically after giving them the truth in order to observe their responses and to give supports for their acceptance of truth.

2.1.6 After telling the truth, nurses and treatment team should give the patients some advice about practice and alternatives, some time to make decision, as well as to palliate patients and relatives' mind.

2.2 Guidelines in case relatives did not want to let patients know that they got the cancer because relatives were afraid that patients would become worse. The relatives requested nurses not to tell such truth to patients; thus, nurses should follow the steps below:

2.2.1 Asking reasons of concealing the truth by giving the relatives opportunities of expressing their feelings, fear, and concerns.

2.2.2 Explaining about good points of telling truth, which could help patients set their life plans, handle unfinished problems, and prepare to end their life prestigiously and honorably. But, weak points might be that the patients might lose their mental strength and became worse.

2.2.3 Setting the family participation so that both the family and treatment team had joint discussions and decisions by reminding relatives to realize that any decision should be made for patients, not for relatives, and based on patients' needs most.

2.2.4 Planning with relatives and the treatment team in telling the truth, appropriate methods of telling the truth to patients such as using the supposing situation, and assigning the suitable person to tell such truth while the patients and relatives agreed to be involved in.

2.3 Guidelines in case patients required the explanation about the disease progress and treatments to be given as well as the disease prediction for their decision-making on selected treatments. Nurses should coordinate with the health team in telling the truth to patients under the following steps:

2.3.1 Assessing needs of patients and relatives to receive the information.

2.3.2 Coordinating for patients and relatives for official talks to the treatment team, and giving them opportunities of discussing, questioning, consulting, and planning for treatments together. Nurses might take part in stimulating patients and relatives to ask questions.

2.3.3 Clarifying the information if in doubt by patients and relatives after talking with the treatment team. The clarified information should be consistent with that of the treatment team.

2.4 Guidelines in case of the differences of patients and relatives in respect with gender, age, and occupation. Nurses should follow the steps below:

2.4.1 The guidelines should be adjusted and fit to each patient by recognizing the individuals' promptness and differences in respect of personal learning, information perception, interpretation, acceptance, adjustment, and strength to set up the plan, which would be suitable in terms of time, methods, level of

wording, language used to explain about the disease, treatment ways, and appropriate supports.

In fact, it was found that the treatment team rarely told the truth to patient, and usually followed the desire of relatives by concealing the truth since they were afraid that such truth was unacceptable for patients, which made patients have torment, lack the spirit to fight against the illness, and reject treatments until the illness became worse quicker. The treatment team focused on the principle of non-maleficence. It was the policy of each hospital that the physicians told the truth to patients, and nurses did not want to have any conflicts with the physicians; so nurses always avoided to answer the questions of patients and relatives. However, if nurses had good knowledge about laws and rights of patients as well as the code of ethics, they should tell the diagnosis results to patients as required.

3. Allocated Treatments

3.1 Guidelines in case the patients rejected any treatments causing the torment and uselessness. Nurses should follow the steps below:

3.1.1 Evaluating the patients' illness condition how they learnt and understood the diagnosis, treatments, treatment results, and disease prediction.

3.1.2 Evaluating that the patients had the full consciousness, not been overborne by the body torment or socio-mental and spiritual problems.

3.1.3 Recording the evaluation of patients' status and needs in the nursing daily records.

3.1.4 Consulting the treatment team for the patients' needs to find out caring methods in conformity with needs of patients.

3.1.5 Coordinating for patients and relatives for talks to the treatment team to set up the treatment ways; comparing between the expected treatment results and bad points if no treatments were done for the good understanding of patients and relatives. As a result, all related parties would have a joint decision on treatment methods, and specify some undesirable treatments such as CPR, the respiratory apparatus if the patients were seriously ill, etc.

3.1.6 If possible, preparing patients' advance directives in the written form or in the informed consent as witnessed by patients' relatives.

3.1.7 Caring and evaluating the treatments regularly so that there were consistent with patients' intent and needs. If patients' illness conditions changed, nurses should evaluate whether patients still had the same needs or not, and informed the family and relatives of patients' needs.

3.1.8 In case that patients desired to go back home, all relatives including nearby hospitals or assistance network should be prepared; for example, contacting the home-visit unit to help both patients and family, as well as giving the emergency telephone numbers for 24-hour assistance or consult, , caring of patients who died at home, and legal practice.

3.2 Guidelines in case the patients had no advance directives. Nurse should follow the steps below.

3.2.1 Evaluating the information acknowledgement of patients and relatives regarding illness diagnosis, treatments, and disease prediction.

3.2.2 Taking such received information to consult the treatment team for planning and discussing about treatment alternatives and treatment results.

3.2.3 Coordinating for patients and relatives for talks to the treatment team in order to investigate needs of patients and relatives, treatment alternatives, treatment results, and treatment rejection. As a result, both patients and relatives could be involved in selecting the caring ways in conformity with patients' needs most.

3.2.4 In case of patients' unconsciousness, the relative in direct would decide for treatment methods. But, if patients had several relatives, all of them might have the appointments with the treatment team (family meeting) to conclude the selected treatments. All relatives should be reminded that the decision was made for patients, not relatives; thus, the decision should meet patients' thought and needs.

3.2.5 In case the patients or relatives were unable to undertake anything, the treatment team should take roles in representing the patients and relatives in giving them the information about treatments for decision-making.

3.2.6 While giving patients some care, their needs or those of relatives should be evaluated periodically. If the patients or relatives changed their mind or had confusion/ hesitation, nurses should provide them the useful information and time for their decision-making. Then, nurses forwarded such evaluation to the treatment team for the revision of treatment plan.

3.2.7 Giving some help to the patients and relatives regarding general practice and illness relief to acquire patients' comfort; arranging the environment for tranquility and privacy; and giving opportunities for religious and faith practice.

3.2.8 In case the patients had no relatives, nurses should not leave the patients die lonely, but stay with them for spiritual guidance and giving some advice on the religious practice.

3.3 Guidelines in case of the differences of patients in respect with gender, age, and occupation. Nurses should follow the steps below.

3.3.1 The guidelines should be suitably applied for each patient depending on the personal difference while the standard quality was maintained.

It was found that, in most hospitals, when the patients admitted to the hospital and they were terminal cancer ones, the treatment team did not permit them to go back home and die there even the patients' request since they were afraid that the patients would get harm or torment under the principle of beneficence/ preventing the danger to be occurring.

4. Use of medical equipment for prolonged life

4.1 Guidelines in case the patients were terminally ill and unconscious but they had advance directives by rejecting the use of medical equipment for prolonged life, and relatives rejected it as well but the physicians required it. Nurses should follow the steps below.

4.1.1 Nurses should coordinate for patients and relatives to see the physicians.

4.1.2 If the physicians insisted on the same treatments, encouraging relatives as patients' representatives to meet the physicians to inform of patients and relatives' desires while the physicians also had chance of explaining about the usefulness of each treatment so that relatives would have better understanding about each treatment way for further decision.

4.1.3 In case the relatives still denied those equipments while the physicians insisted the same undertaking; nurses should note this event in the nursing daily records as well as the reasons of providing help by the physicians.

4.1.4 Proposing those problems to the meetings to encourage the hospital management to acknowledge that those problems would be risks of the hospital. There should be the committee monitoring ethics of caring of terminal cancer patients as the guidelines on caring of other patients.

4.2 Guidelines in case the patients had advance directives on rejecting the use of medical equipment for prolonged life, but patients' relatives required it. Nurses should follow the steps below.

4.2.1 Giving opportunities to relatives for comments, asking their needs and reasons of such desire, and reminding them about patients' needs by emphasizing that any decision should be subject to patients not relatives.

4.2.2 Transferring the needs of relatives to the treatment team to stimulate the physicians to pay attention in this issue.

4.2.3 Coordinating for relatives for talks to the treatment team so that they obtained both strengths and weaknesses of using the medical equipment for prolonged life so that the relatives had the information about caring of terminally ill patients, prestigious death, and reminding the relatives about the consequences of not respecting for patients' directives for the new decision-making of relatives.

4.2.4 Recording relatives' comments in the nursing daily records, and respecting for decision of relatives (legally authorized persons).

4.2.5 Evaluating relatives' needs and periodically giving them the patients' illness conditions. If the relatives changed their mind, coordinating for relatives to talk to the treatment team.

4.3 Guidelines in case of the differences in respect with gender, age, and occupation. Nurses should follow the steps below.

4.3.1 The treatments should be adjusted to fit the status of patients and family.

In most cases, when the terminally ill patients were worse and treated in the ICU, the physicians have tried to give full treatments so that the patients would be recovering by using necessary medical equipment, special and necessary hand-massage and check-up, and closely monitoring and evaluating the functions of working systems under the principle of beneficence. The treatment team would take roles in providing the information and advice, but the decision should be made by

patients and relatives; consequently, the treatment team had to respect for such decision. This was different from the past that the treatment team took roles in making decision and selecting the treatment plans believed they were and good and suitable for patients and relatives.

5. Stopping Treatment

5.1 Guidelines in case the patients desired to stop treatments and to die at home. Nurses should coordinate with the health team under the following steps:

5.1.1 Evaluating that the patients had the complete consciousness and were not influenced by the body symptoms, socio-mental and spiritual problems.

5.1.2 Evaluating that the patients acknowledged and understood, as some partial information for decision-making, the diagnosis, treatments, treatment results, disease prediction, strengths and weaknesses of rejecting the treatments, as well as the torment to be occurring in the future.

5.1.3 Recording the evaluation of patients' illness condition and needs in the nursing daily records.

5.1.4 Coordinating for talks between patients and relatives so that relatives understood and accepted the patients' needs, including strengths and weaknesses of rejecting the treatments by informing both patients and relatives of all facts, and giving them opportunities to question and make decisions again.

5.1.5 In case the patients insisted to stop all treatments and to die at home, a joint meeting between the treatment team and the patients as well as family should be arranged to set planning and give some advice on caring of patients at home (discharge planning), especially ways of controlling the illness condition when patients were nearly dead so that the relatives would be able to confront and handle the situation while the patients had no torment and die peacefully. Nurses might advise the relatives on supporting sources or assistance network by forwarding the treatment information and patients' needs to those sources or network.

5.1.6 Undertaking all related documents in connection with patients' treatment rejection, and preparing patients for moving by realizing that patients might pass away during such moving; thus, relatives should be ready to confront such situation.

5.2 Guidelines in case the patients desired to stopping treatments but relatives desired to continue the treatments. Nurses should follow the steps below.

5.2.1 Giving the relatives opportunities for comments, asking for their needs and reasons of continued treatments, and reminding them about patients' needs.

5.2.2 Transferring the needs of relatives to the treatment team, and recording such needs in the nursing daily records.

5.2.3 Coordinating for relatives for talks to the treatment team so that they obtained the information, persuading them into caring of terminal cancer patients for the prestigious death, and reminding the relatives about the patients' needs for the new decision to be made by relatives, which should be subject to patients, not relatives.

5.2.4 The treatment team should coordinate for patients and relatives to discuss and listen to comments with each other, and give them time for the new decision.

5.3 Guidelines in case of the differences of patients and relatives in respect with gender, age, and occupation. Nurses should follow the guidelines below:

5.3.1 The methods and practice should be suitably applied for relatives of each patient depending on the differences of person and situation.

At present, although there were requests for the treatment team to realize and follow the rights of patients, when the terminal cancer patients admitted to the hospital and desired the treatment team to stop all treatments, the treatment team was unable to follow those needs because they held the principle of doing the best for patients/non-maleficence, and not allowing the patients to have torment because of no treatment.

6. Advance Directives

6.1 Guidelines in case the patients told the caring nurse that they did not want any prolonged-life equipment and the nursing chief on duty recorded such needs in the nursing records. Those nursing records could not be counted as the legal written document. The advance directives to be counted as the legal written documents should be prepared pursuant to the following steps:

6.1.1 Evaluating that the patients had the full consciousness, not been overborne by the body torment or socio-mental and spiritual problems.

6.1.2 Evaluating that the patients acknowledged and understood, as some partial information for decision-making, the diagnosis, treatments, treatment results, disease prediction, strengths and weaknesses of using the prolonged-life equipment in the treatments.

6.1.3 In case the patients insisted not to get treatments by the use of prolonged-life equipment, nurses should note the evaluation of patients' illness condition and needs in the advance directive and reporting them to the treatment team.

6.1.4 Coordinating for patients and relatives for another talk to the treatment team so that they were provided, for a new decision-making, strengths and weaknesses of treatments by the use of prolonged-life equipment including the torment to be occurring in the future.

6.1.5 In case the patients still insisted the same intent, nurses should undertake all related documents by having the patients record their own needs in advance directives that should also be signed by caring physicians who certified that the patients had full and complete consciousness, and relatives as witnesses.

6.2 Guidelines in case of stopping treatments with the written advance directives identified by patients for stop treatments and no prolonged-life equipment. Nurses should follow the steps below:

6.2.1 Evaluating that the patients had the full consciousness, not been overborne by the body torment or socio-mental and spiritual problems.

6.2.2 Coordinating with the physicians to give patients and relatives the information for their decision-making about inserting the breathing tube, results of inserting such tube, the torment to be occurring in the future if not bearing it, and the disease prediction.

6.2.3 In case the patients still insisted for not bearing the respiratory apparatus, the nurses should attend the joint meeting with the treatment team, patients, and relatives to note the patients' needs in the written form signed by the patients (patients' signature might not be required if the patients showed their needs in the hand-writing, except signing to prevent any problems with relatives after the patients' death). The record of patients' needs should comprise some witnesses who guaranteed

that the patients have full and complete consciousness. Those witnesses should be relatives in direct or caring physicians.

6.2.4 Notifying the physicians or related persons or relatives for the joint caring plan. Although the patients insisted that they did not want the breathing tube or other prolonged-life equipment, other treatments could be done to relieve patients' torment; for example, giving the oxygen by other ways. However, any treatments should mainly concern the patients' needs and not cause any torment.

6.2.5 Although the patients had advance directives, when their illness became worse, nurses should talk to patients and relatives again whether they still had the same intent or wanted to change their mind. The treatments should be revised as per needs of patients and relatives.

6.3 Guidelines in case the physicians desired to use the prolonged-life equipment although the patients had advance directives that they did not want it. Nurses should follow the steps below:

6.3.1 Nurses should represent the patients and relatives in transferring needs of patients and relatives to the physicians, showing to the physicians the patients' advance directives to stimulate and persuade them to follow the patients' needs.

6.3.2 If the physicians still insisted the same actions, nurses should coordinate with the relatives of patients to be involved in the treatments, which should be subject to patients' intent.

6.3.3 In case that the relatives decided that no prolonged-life equipment should be used, but the physicians insisted the same actions, nurses should note this event in the nursing daily records.

6.3.5 Reporting the attending physician and higher supervisors respectively.

6.3.6 Proposing those problems to the meetings to encourage the hospital management to acknowledge that those problems would be risks of the hospital. There should be the committee monitoring ethics of caring of terminal cancer patients as the guidelines on caring of other patients.

6.4 Guidelines in case of the differences of patients and relatives in respect with gender, age, and occupation. Nurses should follow the step below:

6.4.1 As a whole, there should not be any differences. In case of so young patients, they should have duly representatives. However, most decisions were up to parents; thus, parents should be clarified. In addition, treatments should concern the differences of person and situation.

At present, it was found that when the patients were unable to make any decision and terminally ill, the treatment team always realized the ethical principle of doing the best and useful things for patients. The treatment team also represented the patients by making decision to continue treatments rather than following the advance directive of patients since the team had the Buddhist belief that it was a sin not to provide some assistance to the patients until they died.

Suggestions

1. The results of this study allow nurses and other medical personnel to have the guidelines on moral problems frequently found in terminal cancer patients. However, such results are only the viewpoints of experts in caring of terminal cancer patients since, now, there have not yet been laws or certain obligations concerning these issues. Therefore, these results are only the guidelines to be suitably applied for the context of Thailand and many hospitals under the careful consideration.

2. Regarding the advance directive, although there are no laws to support it now, Section 10 of the National Health Bill stipulated that:

“A person has right to prepare the advance directive expressing his/her intent not to get the public service performed to sustain the last period of life.

Undertaking pursuant to Paragraph One of the advance directive shall be in compliance with criteria and procedures set forth in the Ministerial Regulation.

Public health professionals have the duty to comply with that person’s desire as mentioned in Paragraph One above. Complying with such desire shall not be deemed the offence and shall be relieved from all liabilities.”

The problem found was the form of advance directive. The results of the study found out that most experts have not accepted that nursing records could be used as the legal evidence. However, the advance directive of a patient noted in the nursing records was unacceptable; so, in the future, the form of advance directive should be clear and legally acceptable so that the medical personnel have guidelines to be

applied in the future when the patients have some changes such as inserting the breathing tube, rescue, etc.

3. The physicians and nurses caring of terminal cancer patients should have skills and expertise in caring of such patients. They should offer the treatments by considering strengths and weaknesses to be affecting the patients, family, and society. The most important matter is that any treatment should give the best profit to patients with the least impact to the family of patients. Those treatments must be subject to actual needs of patients, be done to reduce pain and torment of patients, and not to cause persons close to patients to have torment or bear unnecessary expenses.

4. Each hospital should lay down the standard principles on treatments to be given to terminally ill patients or what is useless for them under the approval of the committee specially appointed for these matters.

5. To reduce the embarrassment of performers, the consultation team or ethical committee should be set up to provide some advice and solutions for those problems.

6. The information concerning moral problems found by nurses should be collected to find out solutions or to construct additional guidelines.

7. The project promoting skills of confronting moral problems found in caring of patients should be organized; nurses should be trained to face moral problems frequently found in real situations. The training should be divided into many classes until it covered all service providers.

Recommendations for Further Study

1. There should be more studies of using these guidelines for the groups of medical personnel and nurses who have been caring of terminal cancer patients to find out the possibilities of implementing the results of this study and revising them to fit the current situation.

2. There should be studies on guidelines according moral problems in caring of terminally ill patients who get other diseases. Then, there should be the comparison on those guidelines to see the similarity and difference.

3. There should be more studies on the argument concerning the advance directive and its form that shall be legally acceptable and actually implemented.

4. There should be more studies seeking for other moral problems probably found in caring of terminally ill patients except those found in the study so that they can be used to set up the guidelines in conformity with nursing ethics, and to prevent the legal claims in the future.



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จริยธรรม. เอกสารประกอบการสัมมนาพยาบาลศาสตรศึกษาแห่งชาติ ครั้งที่ 3 การ

พัฒนาการจัดการศึกษาหลักสูตรพยาบาลศาสตรบัณฑิตเพื่อตอบสนองการปฏิรูประบบ

บริการสุขภาพไทย วันที่ 23-25 กรกฎาคม 2544. กรุงเทพมหานคร: ศักดิ์โสภารพิมพ์.

อรัญญา เชาวลิต, วันดี สุทธรังษี และณอมศรี อินทนนท์. (2544). การพัฒนาเครื่องมือประเมิน

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การพยาบาล. วารสารวิจัยทางการแพทย์, 5(2), 140-155.



List of Experts

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2. Assoc.Prof. Dr. Isarang Nuchprayoon Chulalongkorn Hospital
3. Miss Piengjai Dalopakorn Chulalongkorn Hospital
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5. Dr. Noppadon Sopharatanaphaisarn Siriraj Hospital
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10. Miss Umaporn Phaisarnsutthidej Ramathibodi Hospital
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12. Dr. Patama Vajamon Maharaj Nakhon Ratchasima Hospital

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1. Mrs. Surang Singhkachain Chulalongkorn Hospital
2. Prof. Dr. Virat Panitpongse Chulalongkorn Hospital
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4. Miss Pairat Booncharas Public Health, Ubon Ratchathani Province
5. Mrs. Jariya Panya Director of Division of Personnel,
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10. Asst.Prof. Anchalee Nuanklai Faculty of Nursing, Ramathibodi Hospital

Group 3 – Experts in Ethical Problems about Caring of Terminal Cancer Patients

1. Mrs. Pranee Assavarat	Thai Red Cross College of Nursing
2. Dr. Chonpachong Pengchad	Thai Red Cross College of Nursing
3. Assoc. Prof. Siwalee Sirilai	Pensioner
4. Assoc. Prof. Farida Ibrahim	Pensioner
5. Dr. Tassanee Thongprateep	Kuakarun College of Nursing
6. Mr. Chatchai Kumthaveeporn	Rangsit University
7. Asst.Prof. Col. Dr. Dusit Sathapron	King Mongkut College of Medicine Phramongkutklao
8. Asst. Prof. Sureeporn Thanasilpa	Faculty of Nursing, Chulalongkorn University
9. Asst.Prof. Dr. Phornlert Chatrkaew	Chulalongkorn Hospital
10. Assoc.Prof. Dr. Temsak Puengrasamee	Songkhlanakarin Hospital



Documentary Proof of Ethical Clearance
The Committee on Human Rights Related to
Human Experimentation
Mahidol University, Bangkok

Date of Expiration: 25 JAN 2007

The First-Round Interview of Experts' Viewpoints

Background and Rationale of the Study

At present, there is the great progress of medical science that helps sustain the life of terminal cancer patients, but holds those patients in the torment caused by disease pain. In this case, rescuing terminal cancer patients who are impossibly irreversible is the right and suitable action or not; it makes the patients die restlessly without any human prestige or not; and it violates the rights of patients or not.

Although nurses have not the sole right in making decision on death and treatment, they are counted as the health team. According to rights, duties, and professional ethics, nurses have to provide the service to maintain good health of humans. Any actions under the proper scope and good results to patients should be duly done by nurses. Due to the closeness between nurses and patients, nurses have to confront many problems directly, and it is necessary to find out solutions. Therefore, the ethical concepts on nursing operation were used as the guidelines on solving those problems:

1. Patient advocacy referred to taking roles in protecting the fundamental human rights.

2. Accountability/Responsibility referred to helping each patient obtain quality health caring and serving needs of patients.

3. Cooperation referred to the participation with others for the quality of caring of patients.

4. Caring referred to the behavior expressing mercy such as not leaving the patients, respecting the patients, sympathy, and familiarity.

Definitions of the Study

Moral problem referred to a situation requiring the ethical consideration about what should or should not be done by which ethics was the reason for explanation.

Nursing referred to a profession to treat service recipients based on the knowledge about caring of and helping service recipients on health problems, surrounding arrangements, as well as giving assistance to physicians in the treatment.

Terminal cancer patients referred to cancer patients diagnosed by the physicians that cancer was the cause of disease spreading, which could not be remedied absolutely. Also, according to the existing information, it was likely that such cancer patients would be alive not longer than 6 months.

Caring guidelines for terminal cancer patients in conformity with nursing ethics referred to the content prepared as guidelines on roles and duties of nurses in caring of terminal cancer patients to meet the set goals.

1. Personal information of interviewees

Date of Interview Time

1.1 First name Last name

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1.2 Education degree

1.3 Working place

1.4 Current title

1.5 Duration of working in the current title year(s)

1.6 Working experience

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1.7 Performance concerning caring of terminal cancer patients

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Direction of the Interview

This interview consisted of the sample situations adapted from the interview by Wanwisa Sangprasert (2003) about needs of terminal cancer patients. The following 6 situations were used for experts' explanation about the guidelines on caring of terminal cancer patients in conformity with nursing ethics.

Situation 1

A female patient, 36, has got the breast cancer since 1996. She has got treatments from a hospital by having the operation. After the operation, she did not get any irradiation or chemotherapy. Later, she got the breast cancer again and has been remedied by the chemotherapy method for 6 times. This patient had to admit the hospital for several times since she has worked so hard until her disease became more severe. The patient learnt that she was the terminal cancer patient as the physician notified her and the nurse explained her the situation. What the patient needed at that time was to receive the sufficient pain-killing drugs since she was in much torment. However, nurses advised her that the pain-killing drugs had to be subject to the physician's treatment plan, which was insufficient to relieve her torment. **"It was so painful, but the nurse dared not to give the medicine because she had to wait for the physician's report. Sometimes, I had so much pain that I could not sleep, but the nurse had to wait and consult with the physician. I had to wait until the physician ordered and gave me the medicine. It was so painful."**

From Situation 1, what are the guidelines on caring of terminal cancer patient in conformity with nursing ethics regarding the pain handling?

1. What should be the proper guidelines on pain handling that are suitable for terminal cancer patient?

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2. In case that the patient faced the pain and had torment caused by pain, when the patient had requests but the treatment plan of physician is insufficient for the patient's needs. In your opinion, what should nurses do?

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3. In case of the difference of patients in respect with gender, age, and occupation. In your opinion, should nurses have different guidelines? How?

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Situation 2

A male patient, 54, has got many treatments from several hospitals and the doctors gave him the different diagnosis, but each told him that he got a tumor. Later, he learnt that he got the lung cancer because it spread out to his brain. He has got 10 irradiations. This patient knew that he got the cancer so late since **his wife and friends jointly concealed this truth and asked the physician not to tell him about it.** "For something, they don't think that I've known it, but, actually, I've known it and more than what they have known." The patients desired that the physicians and relatives disclosed the disease, steps of treatments, even other alternatives as well as disease prediction so that they would have time to set their mind and decide to select **a way not making them torturous and die calmly.**

From Situation 2, what are the guidelines on caring of terminal cancer patient in conformity with nursing ethics regarding the truth telling?

1. In your opinion, how should nurses perform in telling the patient that he has got the cancer?

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2. In case that the relatives desired to conceal the patient that he has got the cancer since they are afraid that the patient will become worse by requesting the nurses not to disclose this truth to the patient? In your opinion, what should nurses do?

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3. If the patient required the explanation about the disease progress and treatments as well as disease prediction for making decision on selected treatments. In your opinion, how should nurses coordinate with the health team in telling this truth to the patient?

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4. In case of the difference of patients in respect with gender, age, and occupation. In your opinion, should nurses have different guidelines? How?

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Situation 3

A male patient, 68, has got the lung cancer. He has got 9 chemotherapies and irradiations. While staying in the hospital, he had some weakness, quick but short breaths, and gasped for breath sometimes. This patient desired that the physicians explained him clear medical treatments and treatment results; treatments should not be done subject to the physicians' demands only. The treatment methods should be explained to the patient so that he could take it for decision-making about allocated treatments. But, in fact, the physicians rarely told the adequate information. The patient said, "I would like to have a right of selecting how I will be cured. But, I don't know what I should do. In most cases, the doctors have never informed us in advance; they carry on at once. **If we were at the final stage of illness that was irreversible, we want to reject some treatments.** Inserting or bearing any equipment, I reject it" The patient also said, "If my illness is beyond any treatment, I want to go back home. It's warmer if I die there. Frankly, I want to die at home. In the worst case, I want to go back home. I want to die happily. Let me die. Staying in the hospital, I'm close to the doctors, but it is not the same as staying at home."

From Situation 3, what are the guidelines on caring of terminal cancer patient in conformity with nursing ethics regarding the allocated treatments?

1. In case that the patient rejects the treatments causing torment and uselessness. In your opinion, what should nurses do?

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2. In case that the patient does not have the advance directive. In your opinion, what should the guidelines be?

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3. In case of the difference of patients in respect with gender, age, and occupation. In your opinion, should nurses have different guidelines? How?

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Situation 4

A male patient, 74, got the stomach cancer and used to have an operation including a full course of chemotherapy and irradiation two years ago. While obtaining such treatments in the hospital, this patient had the difficult breathing, vomited blood, has severe stomach ache, and had too much gas; so the physician inserted the breathing tube, tube for intravenous drips, and tube for infusion apparatus. Before admitting in the hospital, this patient told his children that, **“If anything happens again, do not permit the doctor to insert or put something for me. I don’t want to be painful anymore. No more torment is required. I want to die peacefully; do not treat me like I’m not a human and treat me for the case study only.”** His children reported those needs to the doctors, but they still insisted to insert many tubes into the patient’s body, and told his children that **“Anyway, the treatment must continue since it’s my duty.”**

From Situation 4, what are the guidelines on caring of terminal cancer patient in conformity with nursing ethics regarding the use of medical equipment for prolonged life?

1. In case that the patient becomes worse and unconscious, but he has the advance directive for no use of medical equipment for prolonged life and relatives do not require it as well, but the physicians required it. In your opinion, what should nurses do?

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2. In case that the patient has the advance directive for no use of medical equipment for prolonged life but relatives require it. In your opinion, what should nurses do?

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3. In case of the difference of patients in respect with gender, age, and occupation. In your opinion, should nurses have different guidelines? How?

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Situation 5

A female patient, 55, has got the ovary cancer. She has got treatments in a hospital by having the operation to cut off her ovary and the chemotherapy. About 8 months later, she admitted the hospital again because she could have less food, and her belly became stiff. According to the body check-up, it was found that the cancer spread out over her pelvic cavity. Her children wanted the patient to continue the treatments, **but the patient requested the physician to stop treatments, and wanted to go back home to die with her children. However, when her children met her, they asked the physician to have the full remedies without any concerns about payments.**

From Situation 5, what are the guidelines on caring of terminal cancer patient in conformity with nursing ethics regarding stopping treatments?

1. In case that the patient requires stopping the treatment and going back home to die there. In your opinion, how should nurses coordinate with the health team?

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2. In case that the patient requires stopping treatment but the relatives require continuing it. In your opinion, what should nurses do?

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3. In case of the difference of patients in respect with gender, age, and occupation. In your opinion, should nurses have different guidelines? How?

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Situation 6

A male patient, 68, has got the lung cancer, and were admitted to the ICU for 2 times. After leaving the hospital, he told his wife and children not to take him to the hospital again if his illness became severe again; he wanted to die at home, did not want to get any torment caused by treatments anymore. Later, when this patient's illness was severe, his wife and children decided to take him to admit the hospital and stayed in the ICU. When he felt better, he told nurses that **he did not want treatments with the use of any equipment for prolonged life. The nurse chief on duty recorded the patient's needs in the nursing records** before informing the nursing team and the attending physician of such needs. Later, when the patient's illness was more severe, the physician on duty instructed the nurse to insert the breathing tube and respiratory apparatus although the caring nurse informed the physician on duty of the patient's needs, and, at that time, no relatives of patient stayed there.

From Situation 6, what are the guidelines on caring of terminal cancer patient in conformity with nursing ethics regarding advance directive?

1. In case the patient tells the caring nurse that he does not want any prolonged-life equipment and the nursing chief on duty records such needs in the nursing records. In your opinion, can this nursing record be deemed as the written document? And how should nurses do?

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2. In case of stop treatments with the written advance directives identified by patients for stop treatments and no prolonged-life equipment. In your opinion, what should nurses do?

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3. In case the physician desires to use the prolonged-life equipment although the patient has advance directive he does not want it. In your opinion, what should nurses do?

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4. In case of the difference of patients in respect with gender, age, and occupation. In your opinion, should nurses have different guidelines? How?

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The Frist-Round Questionnaire

The sample situations adapted from the interview by Wanwisa Sangprasert (2003) about needs of terminal cancer patients. The researcher collected the opinion of 3 expert groups: experts in caring of terminal cancer patients, experts in medical laws and public health, and experts in moral problems about caring of terminal cancer patients in order to acquire the guidelines on caring of terminal cancer patients in conformity with nursing ethics. The interviews of experts' viewpoints in the first round were summarized and constructed as 6 matters of guidelines in form of the 5 rating-scale questionnaire to evaluate the experts' opinion towards the statements indicating guidelines on caring of terminal cancer patients in conformity with nursing ethics, as well the level of opinion. In addition, if you have any other suggestions, please note them in the space provided below each issue so that the questionnaire will be suitably revised for the second-round questionnaire.

Levels of opinion have the following meanings:

- 5 - You agree with the statement most strongly.
- 4 - You agree with the statement strongly.
- 3 - You agree with the statement moderately.
- 2 - You agree with the statement slightly.
- 1 - You agree with the statement most slightly.

Please mark ✓ to indicate your answer in the provided blank that is relevant to your opinion.

Situation 1

A female patient, 36, has got the breast cancer since 1996. She has got treatments from a hospital by having the operation. After the operation, she did not get any irradiation or chemotherapy. Later, she got the breast cancer again and has been remedied by the chemotherapy method for 6 times. This patient had to admit the hospital for several times since she has worked so hard until her disease became more severe. The patient learnt that she was the terminal cancer patient as the physician notified her and the nurse explained her the situation. What the patient needed at that time was to receive the sufficient pain-killing drugs since she was in much torment. However, nurses advised her that the pain-killing drugs had to be subject to the physician's treatment plan, which was insufficient to relieve her torment. **"It was so painful, but the nurse dared not to give the medicine because she had to wait for the physician's report. Sometimes, I had so much pain that I could not sleep, but the nurse had to wait and consult with the physician. I had to wait until the physician ordered and gave me the medicine. It was so painful."**

From Situation 1, what are the guidelines on caring of terminal cancer patient in conformity with nursing ethics regarding the pain handling?

1. In your opinion, should the guidelines on caring of terminal cancer patient in conformity with nursing ethics regarding the pain handling be in accordance with the following steps? How?

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
1. Nurses assess the pain as perceived by patients as a whole, which is caused by the body pain and other grounds that are out of body condition, by applying the proper pain assessment methods.						

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
2. Nurses set plans with the treatment team to set up the protocol of pain handling for terminal cancer patients. The protocol consists of the number of regular doses and rescue doses for breakthrough. The treatment instructions should be flexible so that nurses are able to adjust the medicine for patients.						
3. Nurses coordinate with the treatment team or knowledgeable person to educate both patients and relatives about pain and pain handling methods such as meditation, creating a diversion, listening the favorite music, deep breathing, massage, and expressing humor, etc.						
4. Nurses arrange the environment and provide assistance in pain handling by encouraging relatives to be involved in.						
5. Nurses assess patients' pain regularly, both in the normal condition and after the medication or caring to relieve pain, and recording such assessment as well.						
6. Nurses have meetings with the treatment team periodically to adjust the treatment plan until it was suitable for each patient by considering the individual difference.						

Suggestions

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2. In case that the patients face the pain and have torment caused by pain, when the patients have requests but the treatment plan of physician is insufficient for the patient's needs. In your opinion, should nurses follow the steps below? How?

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
1. Nurses assess the pain as a whole to find out grounds of pain apart from the body condition.						
2. Nurses consult the treatment team about patients' problems. Nurses may have to consult the anesthetists or pain clinic to jointly evaluate and plan for appropriate treatments, but the operation of medication should be clear so that nurses can operate by themselves.						
3. Nurses use other pain relief favored by patients by not having the medication such as relaxant massage, attention diversion, music, and environment arrangements, etc.						
4. If the side effects occur as a result of adding more medicine, nurses should inform patients and relatives of such conditions. If patients insist that they do not mind those side effects and relatives have the consent, nurses should operate as per patients' needs.						
5. Nurses care of patients by extending them the understanding and mercy, not leaving them to stay alone, and encouraging relatives to be involved in caring of patients.						
6. Nurses follow up and evaluated the treatment results regularly, and reporting such results to the treatment team for the revision of treatment plan.						

Suggestions

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3. In case of the difference of patients in respect with gender, age, and occupation. In your opinion, should nurses have different guidelines? How?

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
1. The principle of caring should be based on the same standard for every patient.						
2. The principle of caring should be suitably applied for each patient since the knowledge about pain handling, gender, age, and personal background resulted to the different pain experience of each person. Therefore, the nursing principle should be suitably applied to fit such factors but the standard quality is still maintained.						

Suggestions

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Situation 2

A male patient, 54, has got many treatments from several hospitals and the doctors gave him the different diagnosis, but each told him that he got a tumor. Later, he learnt that he got the lung cancer because it spread out to his brain. He has got 10 irradiations. This patient knew that he got the cancer so late since **his wife and friends jointly concealed this truth and asked the physician not to tell him about it.** “For something, they don’t think that I’ve known it, but, actually, I’ve known it and more than what they have known.” The patients desired that the physicians and relatives disclosed the disease, steps of treatments, even other alternatives as well as disease prediction so that they would have time to set their mind and decide to select **a way not making them torturous and die calmly.**

From Situation 2, what are the guidelines on caring of terminal cancer patient in conformity with nursing ethics regarding the truth telling?

1. In your opinion, should the guidelines on caring of terminal cancer patient in conformity with nursing ethics regarding the truth telling be in accordance with the following steps? How?

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
1. Nurses assess patients and relatives' needs and promptness of perception to be the important information for the treatment team in telling the truth; for example, the patients knew or doubted that they got the cancer, the patients with the clear background that they hurt themselves when facing serious matters in life, and reactions and viewpoints of patients and relatives about truth telling. Such key information should be transferred to the treatment team.						
2. Nurses have a joint meeting of all related physicians, nurses, caregivers, and specialized physicians to find out and assign the suitable person for truth telling by considering the patients' reliability to the physicians. Truth telling should be undertaken as a team with the telling techniques; patients were encouraged and given the relevant information and communication.						
3. The principle of truth telling may be based on the group support, counseling, or supposing situations depending on the conditions of patients.						
4. In case that the patients and relatives receive the fact, but they have strong emotional reactions, nurses have to care of and palliate them so that patients will be able to pass that situation and accept it finally.						

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
5. Nurses assess patients and their family periodically after giving them the truth in order to observe their responses and to give supports for their acceptance of truth.						
6. After telling the truth, nurses should give some advice to patients about practice and alternatives, as well as to palliate patients' mind.						

Suggestions

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2. In case that the relatives desire to conceal the patient that he has got the cancer since they are afraid that the patient will become worse by requesting the nurses not to disclose this truth to the patient? In your opinion, should nurses comply with the following steps or not? How?

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
1. Asking reasons of concealing the truth by giving relatives the opportunities of expressing their feelings, fear, and concerns.						
2. Explaining about good points of telling truth, which can help patients set their life plans, handle unfinished problems, and prepare to end their life prestigiously and honorably. But, weak points may be that the patients are unable to accept their condition and become worse.						

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
3. Setting the family participation so that both the family and treatment team had joint discussions and decisions by reminding relatives to realize that any decision should be made for patients, not for relatives, and based on patients' needs most.						
4. Planning with relatives and the treatment team for telling the truth. Nurses may consult the psychologists for the assistance or appropriate planning to tell the truth to patients such as indirect telling or supposing situation, and assigning the suitable person to tell such truth.						

Suggestions

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3. If the patient requires the explanation about the disease progress and treatments as well as disease prediction for making decision on selected treatments. In your opinion, should nurses coordinate with the health team in telling this truth to the patient? How?

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
1. Assessing needs of patients and relatives to receive the information.						
2. Coordinating for patients and relatives to talk to the treatment team officially, and giving them opportunities of discussing, questioning,						

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
consulting, and planning for treatments together. Nurses may take part in stimulating patients and relatives to ask questions.						
3. Clarifying the information if in doubt by patients and relatives after talking with the treatment team.						

Suggestions

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4. In case of the difference of patients in respect with gender, age, and occupation. In your opinion, should nurses have different guidelines? How?

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
- The protocol should be adjusted and fit to each patient by recognizing the individuals' promptness and differences in respect of learning, information perception, interpretation, acceptance, adjustment, and strength to set up the plan, which would be suitable for time, methods, level of wording, language used to explain about the disease, treatment ways, and appropriate supports.						

Suggestions

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Situation 3

A male patient, 68, has got the lung cancer. He has got 9 chemotherapies and irradiations. While staying in the hospital, he had some weakness, quick but short breaths, and gasped for breath sometimes. This patient desired that the physicians explained him clear medical treatments and treatment results; treatments should not be done subject to the physicians' demands only. The treatment methods should be explained to the patient so that he could take it for decision-making about allocated treatments. But, in fact, the physicians rarely told the adequate information. The patient said, "I would like to have a right of selecting how I will be cured. But, I don't know what I should do. In most cases, the doctors have never informed us in advance; they carry on at once. **If we were at the final stage of illness that was irreversible, we want to reject some treatments.** Inserting or bearing any equipment, I reject it" The patient also said, "If my illness is beyond any treatment, I want to go back home. It's warmer if I die there. Frankly, I want to die at home. In the worst case, I want to go back home. I want to die happily. Let me die. Staying in the hospital, I'm close to the doctors, but it is not the same as staying at home."

From Situation 3, what are the guidelines on caring of terminal cancer patient in conformity with nursing ethics regarding the allocated treatments?

1. In case that the patient rejects the treatments causing torment and uselessness.

In your opinion, should nurses comply with the following steps? How?

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
1. Evaluating the patients' illness condition how they learnt and understood the diagnosis, treatments, treatment results, and disease prediction.						
2. Evaluating that the patients had the full consciousness, not been overborne by the body torment or socio-mental and spiritual problems.						
3. Recording the evaluation of patients' status and needs in the nursing daily records.						
4. Consulting the treatment team for the patients' needs to find out caring methods in conformity with needs of patients.						
5. Coordinating for patients and relatives to talk to the treatment team to set up the treatment ways; comparing between the expected treatment results and bad points if no treatments were done for the good understanding of patients and relatives. As a result, all related parties will have a joint decision on treatment methods. Nurses may wait until patients and relatives had mental readiness before they specify some undesirable treatments such as CPR, the respiratory apparatus if the patients were seriously ill, etc.						
6. Preparing patients' advance directives in the written form or in the informed consent as witnessed by patients' relatives.						
7. Caring and evaluating the treatments regularly						

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
so that there were consistent with patients' intent and needs. If patients' illness conditions changes, nurses should evaluate periodically whether patients still have the same needs or not, and informed the family and relatives of patients' needs.						
8. In case that patients desired to go back home, relatives should be informed of possible illness conditions, caring of patients at home, and advising on nearby hospitals or assistance network such as contacting the home-visit unit to help both patients and family, as well as giving the emergency telephone numbers for 24-hour assistance or consult.						

Suggestions

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2. In case that the patient does not have the advance directive. In your opinion, should there be the following steps? How?

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
1. Surveying the opinion of patients and relatives the extent of acknowledging the information in respect with illness diagnosis, treatments, and disease prediction.						

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
2. Taking such received information to consult the treatment team for planning and discussing about treatment alternatives and treatment results.						
3. Coordinating for patients and relatives for talks to the treatment team in order to investigate needs of patients and relatives, treatment alternatives, treatment results, and treatment rejection. As a result, both patients and relatives can be involved in selecting the caring ways in conformity with patients' needs most.						
4. In case of patients' unconsciousness, the close and direct-blood relative will decide for treatment methods. But, if patients have several relatives, all of them may have the appointments with the treatment team (family meeting) to conclude the selected treatments. All relatives should be reminded that the decision is made for patients, not relatives; thus, the decision should meet patients' thought and needs most.						
5. In case the patients or relatives are unable to undertake anything, nurses should take roles in representing the patients and relatives in giving the information about treatments for the decision-making while nurses were still in the treatment team.						
6. Needs of patients and relatives should be evaluated periodically. If the patients or relatives change their mind or had hesitation, nurses should provide the useful information for their decision-making. Then, nurses forward such evaluation to						

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
the treatment team for the revision of treatment plan.						
7. Giving some help to the patients and relatives regarding general practice and illness relief to acquire patients' comfort; arranging the environment for tranquility and privacy; and giving opportunities for religious and faith practice.						
8. In case the patients have no relatives, nurses should not leave the patients die lonely, but stay with them for spiritual guidance and giving some advice on the religious practice.						

Suggestions

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3. In case of the difference of patients in respect with gender, age, and occupation. In your opinion, should nurses have different guidelines? How?

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
The protocol should be suitably applied for each patient depending on the personal difference while the standard quality was maintained.						

Suggestions

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Situation 4

A male patient, 74, got the stomach cancer and used to have an operation including a full course of chemotherapy and irradiation two years ago. While obtaining such treatments in the hospital, this patient had the difficult breathing, vomited blood, has severe stomach ache, and had too much gas; so the physician inserted the breathing tube, tube for intravenous drips, and tube for infusion apparatus. Before admitting in the hospital, this patient told his children that, **“If anything happens again, do not permit the doctor to insert or put something for me. I don’t want to be painful anymore. No more torment is required. I want to die peacefully; do not treat me like I’m not a human and treat me for the case study only.”** His children reported those needs to the doctors, but they still insisted to insert many tubes into the patient’s body, and told his children that **“Anyway, the treatment must continue since it’s my duty.”**

From Situation 4, what are the guidelines on caring of terminal cancer patient in conformity with nursing ethics regarding the use of medical equipment for prolonged life?

1. In case that the patient becomes worse and unconscious, but he has the advance directive for no use of medical equipment for prolonged life and relatives do not require it as well, but the physicians required it. In your opinion, should nurses comply with the following steps? How?

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
1. Nurses should represent the patients and relatives in transferring needs of patients and relatives to the physicians, and consult the physicians for the patients’ needs.						

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
2. If the physicians insist on the same treatments, encouraging relatives as patients' representatives to meet the physicians to inform of patients and relatives' desires while the physicians also have chance of explaining about the usefulness of each treatment so that relatives will have better understanding about each treatment way for further decision.						
3. In case the relatives still deny those equipments while the physicians insist the same undertaking; nurses should note this event in the nursing daily records and reasons of physicians to provide such assistance.						
4. Proposing those problems to the meetings to encourage the hospital management to acknowledge that those problems will be risks of the hospital. There should be the committee monitoring ethics of caring of terminal cancer patients as the guidelines on caring of other patients.						

Suggestions

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2. In case that the patient has the advance directive for no use of medical equipment for prolonged life but relatives require it. In your opinion, should nurses comply with the following steps? How?

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
1. Giving opportunities to patients' relatives for comments, asking their needs and reasons of such desire, and reminding them about patients' needs by emphasizing that any decision should be subject to patients not relatives.						
2. Transferring the needs of relatives to the treatment team to stimulate the physicians to pay attention in this issue.						
3. Coordinating for relatives to talk to the treatment team so that they obtained both strengths and weaknesses of bearing tubes or sustaining life, persuading relatives into caring of terminal cancer patients for the prestigious death, and reminding the relatives about the consequences of not respecting for patients' directives for the new decision to be made by relatives.						
4. Recording relatives' comments in the nursing daily records, and respecting for relatives' decision.						
5. Evaluating the needs of relatives and periodically giving them the patients' illness conditions. If the relatives change their mind, nurses should coordinate for relatives to talk to the treatment team.						

Suggestions

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3. In case of the difference of patients in respect with gender, age, and occupation. In your opinion, should nurses have different guidelines? How?

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
- The treatments should be adjusted to fit the status of patients and family. But, there are some issues to be clarified to patients and relatives; if treatment expenses are high, they may select it or not in case the patients are unable to bear the expenses incurred by the treatments.						

Suggestions

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Situation 5

A female patient, 55, has got the ovary cancer. She has got treatments in a hospital by having the operation to cut off her ovary and the chemotherapy. About 8 months later, she admitted the hospital again because she could have less food, and her belly became stiff. According to the body check-up, it was found that the cancer spread out over her pelvic cavity. Her children wanted the patient to continue the treatments, **but the patient requested the physician to stop treatments, and wanted to go back home to die with her children. However, when her children met her, they asked the physician to have the full remedies without any concerns about payments.**

From Situation 5, what are the guidelines on caring of terminal cancer patient in conformity with nursing ethics regarding stop treatments?

1. In case that the patient requires stopping the treatment and going back home to die there. In your opinion, should nurses coordinate with the health team according the following steps? How?

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
1. Evaluating that the patients have the complete consciousness and are not influenced by the body symptoms, socio-mental and spiritual problems.						
2. Evaluating that the patients acknowledge and understand, as some partial information for decision-making, the diagnosis, treatments, treatment results, disease prediction, strengths and weaknesses of rejecting the treatments, as well as the torment to be occurring in the future.						
3. Recording the evaluation of patients' illness condition and needs in the nursing daily records.						
4. Coordinating for talks between patients and relatives so that relatives understood and accepted the patients' needs, including strengths and weaknesses of rejecting the treatments by informing both patients and relatives of all facts, and giving them opportunities to question and make decisions again.						
5. In case the patients insist to stop all treatments and to die at home, a joint meeting between the treatment team and the patients as well as family should be arranged to set planning and give some advice on caring of patients at home (discharge planning), especially ways of controlling the illness condition when patients are nearly dead so that the relatives will be able to confront and						

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
handle the situation while the patients have no torment and die peacefully. Nurses may advise the relatives on supporting sources or assistance network by forwarding the treatment information and patients' needs to those sources or network.						
6. Undertaking all related documents in connection with patients' treatment rejection, and preparing patients for moving by realizing that patients might pass away during such moving; thus, relatives should be ready to confront such situation.						

Suggestions

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2. In case that the patient requires stopping the treatment but the relatives require continuing it. In your opinion, should nurses comply with the following steps? How?

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
1. Giving the relatives opportunities for comments, asking for their needs and reasons of continued treatments, and reminding them about patients' needs.						
2. Transferring the needs of relatives to the treatment team, and recording such needs in the nursing daily records.						
3. Coordinating for relatives to talk to the						

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
treatment team so that they obtained the information, persuading them into caring of terminal cancer patients for the prestigious death, and reminding the relatives about the patients' needs for the new decision to be made by relatives, which should be subject to patients, not relatives.						
4. If the patients and relatives have inconsistent viewpoints, the treatment team should coordinate for both parties to discuss and share comments with each other, and give time for a new decision.						

Suggestions

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3. In case of the difference of patients in respect with gender, age, and occupation. In your opinion, should nurses have different guidelines? How?

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
The methods and practice should be suitably applied for relatives of each patient depending on the differences of person and situation.						

Suggestions

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Situation 6

A male patient, 68, has got the lung cancer, and were admitted to the ICU for 2 times. After leaving the hospital, he told his wife and children not to take him to the hospital again if his illness became severe again; he wanted to die at home, did not want to get any torment caused by treatments anymore. Later, when this patient's illness was severe, his wife and children decided to take him to admit the hospital and stayed in the ICU. When he felt better, he told nurses that **he did not want treatments with the use of any equipment for prolonged life. The nurse chief on duty recorded the patient' needs in the nursing records** before informing the nursing team and the attending physician of such needs. Later, when the patient's illness was more severe, the physician on duty instructed the nurse to insert the breathing tube and respiratory apparatus although the caring nurse informed the physician on duty of the patient's needs, and, at that time, no relatives of patient stayed there.

From Situation 6, what are the guidelines on caring of terminal cancer patient in conformity with nursing ethics regarding advance directive?

1. In case the patient tells the caring nurse that he does not want any prolonged-life equipment and the nursing chief on duty records such needs in the nursing records. In your opinion, can this nursing record be deemed as the written document?

In this issue, experts' viewpoints were inconsistent and could be divided into 2 issues. Please select one that is the most relevant to your opinion and propose your reasons to be summarized as the guidelines in the second-round questionnaire.

☐ The group opined that those nursing records should be deemed as advance directives because they were counted as the legal evidence.

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☐ The group opined that those nursing records should not be deemed as advance directives because, currently, there have not yet been any laws prescribing the advance directives although the nursing records could be used as the legal evidence. This issue was on argument and set forth in Section 10 of the National Health Bill, which may be legally acceptable in the future. But, for the clear evidence, the patients might prepare the informed consent instead of nursing records so that everyone in the caring team could notice it.

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In addition, should the guidelines on preparing the advance directive comply with the following steps? How?

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
1. Evaluating that the patients had the full consciousness, not been overborne by the body torment or socio-mental and spiritual problems.						
2. Evaluating that the patients acknowledge and understand, as some partial information for decision-making, the diagnosis, treatments, treatment results, disease prediction, strengths and weaknesses of using the prolonged-life equipment in the treatments.						
3. In case the patients insisted not to get treatments by the use of prolonged-life equipment, nurses should note the evaluation of patients' illness condition and needs in the advance directive and reporting them to the caring team.						
4. Coordinating for patients and relatives for another talk to the treatment team so that they were provided, for a new decision-making, strengths and weaknesses of treatments by the use of						

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
prolonged-life equipment including the torment to be occurring in the future for a new decision made by relatives.						
5. In case the patients still insisted the same intent, nurses should undertake all related documents by having the patients record their own needs in advance directives that should also be signed by caring physicians who certified that the patients had full and complete consciousness, and relatives as witnesses.						

Suggestions

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2. In case of stop treatments with the written advance directives identified by patients for stop treatments and no prolonged-life equipment. In your opinion, should there be the following steps? How?

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
1. Evaluating that the patients had the full consciousness, not been overborne by the body torment or socio-mental and spiritual problems.						
2. Coordinating with the physicians to give patients and relatives the information for their decision-making about inserting the breathing tube, results of inserting such tube, the torment to be occurring in the future if not bearing it, and the						

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
disease prediction.						
3. In case the patients still insist for not bearing the respiratory apparatus, the nurses should attend the joint meeting with the treatment team, patients, and relatives to note the patients' needs in the written form signed by the patients (patients' signature might not be required if the patients showed their needs in the hand-writing, except signing to prevent any problems with relatives after the patients' death). The record of patients' needs should comprise some witnesses who guaranteed that the patients have full and complete consciousness. Those witnesses should be direct-blood relatives or caring physicians.						
4. Notifying the physicians or related persons or relatives for the joint caring plan. Although the patients insist that they do not want the breathing tube or other prolonged-life equipment, other treatments can be done to relieve patients' torment; for example, giving the oxygen by other ways. However, any treatments should mainly concern the patients' needs and not cause any torment.						
5. Although the patients had advance directives, when their illness becomes worse, nurses should talk to patients and relatives again whether they still have the same intent or want to change their mind. The treatments should be revised as per needs of patients and relatives.						

Suggestions

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3. In case the physician desires to use the prolonged-life equipment although the patient has advance directive he does not want it. In your opinion, should nurses perform the following steps? How?

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
1. Nurses should represent the patients and relatives in transferring needs of patients and relatives to the physicians, showing to the physicians the patients' advance directives to insist the patients' needs.						
2. Nurses should not help prepare the medical equipment. Moreover, nurses should explain to the physicians that when the patients reject the offer of rescue, it should be deemed that it is beyond the duty of physician in treatments; thus, any actions for patients shall be the violation of patients' right.						
3. If the physicians on duty still insist the same actions, nurses should coordinate with the relatives of patients to meet the physicians to be compliance with patients' intent.						
4. In case that the relatives decide that no prolonged-life equipment should be used, but the physicians insist the same actions; nurses should note this event in the nursing daily records.						
5. Reporting the attending physician and higher						

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
supervisors respectively.						
6. Proposing those problems to the meetings to encourage the hospital management to acknowledge that those problems will be risks of the hospital. There should be the committee monitoring ethics of caring of terminal cancer patients as the guidelines on caring of other patients.						

Suggestions

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4. In case of the difference of patients in respect with gender, age, and occupation. In your opinion, should nurses have different guidelines? How?

Guidelines	Level of Opinion					Note
	5	4	3	2	1	
- As a whole, there should not be any differences. In case of so young patients, they should have duly representatives. However, most decisions were up to parents; thus, parents should be clarified. In addition, treatments should concern the differences of person and situation.						

Suggestions

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Thank you for your cooperation.

The Second-Round Questionnaire

Direction

The objective of this second-round Delphi questionnaire is to ask the experts for the assistance in revising the opinion given in the first-round questionnaire. The analysis and processed results from the first-round Delphi questionnaire were presented in this questionnaire.

- * - Scores of answer you gave in the first round.
- ♠ - Median or the scores ranged at the midpoint of experts' answers.
- ↔ - Interquartile range or the scope of opinion value that is consistent with the group of experts.

You may confirm your same answers by marking ✓ in the same column containing * (in case that * does not exist at any statement, this means that you have no answer or no comment about that statement in the first round. However, you may show your opinion towards that statement in this second round) or if you desire to change the answer, please mark ✓ in the new column you require and note a brief reason (if any), or if any of your answers in this second round is greatly out of the consistent scope of group opinion (↔), please note your brief opinion (if any).

To evaluate the levels of your opinion in the questionnaire, they have the following meanings:

- 5 - You agree with the statement most strongly.
- 4 - You agree with the statement strongly.
- 3 - You agree with the statement moderately.
- 2 - You agree with the statement slightly.
- 1 - You agree with the statement most slightly.

Example

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
1. Coordinating with the treatment team or knowledgeable person to educate both patients and relatives about pain and pain handling methods such as meditation, creating a diversion, listening the favorite music, deep breathing, massage, and expressing humor, etc.	✓	♠ ↔ *				Inviting some persons having knowledge about those matters will enhance righter and safer information.

From the above example, the processed results of the first round presented the median ($Md = 4$) and the Interquartile Range 1 and 3 ($\leftrightarrow$) in the range of 3.0-4.0 scores. The comparison results of answers given by experts in the first round were presented by *, that is, you marked for the level of opinion in the column of 4 scores in the first round. In considering the second-round questionnaire, you would like to change the answer from Level 4 to Level 5 to show your strong agreement, so you marked ✓ in the column of 5 scores and also presented your “reason”.

Therefore, in the second-round Delphi questionnaire, please mark ✓ again to confirm or change your answer, and to give your opinion or reason (if any).

Situation 1

A female patient, 36, has got the breast cancer since 1996. She has got treatments from a hospital by having the operation. After the operation, she did not get any irradiation or chemotherapy. Later, she got the breast cancer again and has been remedied by the chemotherapy method for 6 times. This patient had to admit the hospital for several times since she has worked so hard until her disease became more severe. The patient learnt that she was the terminal cancer patient as the physician notified her and the nurse explained her the situation. What the patient needed at that time was to receive the sufficient pain-killing drugs since she was in much torment. However, nurses advised her that the pain-killing drugs had to be subject to the physician's treatment plan, which was insufficient to relieve her torment. **“It was so painful, but the nurse dared not to give the medicine because she had to wait for the physician's report. Sometimes, I had so much pain that I could not sleep, but the nurse had to wait and consult with the physician. I had to wait until the physician ordered and gave me the medicine. It was so painful.”**

From Situation 1, what are the guidelines on caring of terminal cancer patient in conformity with nursing ethics regarding the pain handling?

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
1. Nurses assessed the pain as perceived by patients as a whole, which was caused by the body pain and other grounds that were out of body condition, by applying the proper pain assessment methods.	♠ ↔ *					
2. Nurses set plans with the treatment team to set up the protocol of pain handling for terminal cancer patients. The protocol consisted of the number of regular doses and rescue doses for breakthrough.	♠ ↔ *					

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
3. Nurses coordinated with the treatment team or knowledgeable person to educate both patients and relatives about pain and pain handling methods such as meditation, creating a diversion, listening the favorite music, deep breathing, massage, and expressing humor, etc.	♠ ↔ *					
4. Nurses arranged the environment and provided assistance in pain handling by encouraging relatives to be involved in.	♠ ↔ *					
5. Nurses assessed patients' pain regularly, both in the normal condition and after the medication or caring to relieve pain, and recording such assessment as well.	♠ ↔ *					
6. Nurses had meetings with the treatment team periodically to adjust the treatment plan until it was suitable for each patient by considering the individual difference.	♠ ↔ *					

2. In case that the patients face the pain and have torment caused by pain, when the patients have requests but the treatment plan of physician is insufficient for the patient's needs. In your opinion, should nurses follow the steps below? How?

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
1. Nurses assessed the pain as a whole to find out grounds of pain apart from the body condition.	♠ ↔ *					

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
2. Nurses consulted the treatment team about patients' problems. Nurses might have to consult the anesthetists or pain clinic to jointly evaluate and plan for appropriate treatments, but the operation of medication should be clear so that nurses could operate by themselves.	♠ ↔ *					
3. Nurses used other pain relief favored by patients by not having the medication such as relaxant massage, attention diversion, music, and environment arrangements, etc.	♠ ↔ *					
4. If the side effects occurred such as constipation, dry mouth as a result of adding more medicine, nurses should inform patients and relatives of such conditions. If patients insisted that they did not mind those side effects and relatives had the consent, nurses should operate as per patients' needs.	♠ ↔ *					
5. Nurses cared of patients by extending them the understanding and mercy, not leaving them to stay alone, and encouraging relatives to be involved in caring of patients.	♠ ↔ *					
6. Nurses followed up and evaluated the treatment results regularly, and reporting such results to the treatment team for the revision of treatment plan.	♠ ↔ *					

3. In case of the difference of patients in respect with gender, age, and occupation. In your opinion, should nurses have different guidelines? How?

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
1. The principle of caring should be based on the same standard for every patient.	♠ ↔ *					
2. The principle of caring should be suitably applied for each patient since the knowledge about pain handling, gender, age, and personal background resulted to the different pain experience of each person.	♠ ↔ *					

Situation 2

A male patient, 54, has got many treatments from several hospitals and the doctors gave him the different diagnosis, but each told him that he got a tumor. Later, he learnt that he got the lung cancer because it spread out to his brain. He has got 10 irradiations. This patient knew that he got the cancer so late since **his wife and friends jointly concealed this truth and asked the physician not to tell him about it.** “For something, they don’t think that I’ve known it, but, actually, I’ve known it and more than what they have known.” The patients desired that the physicians and relatives disclosed the disease, steps of treatments, even other alternatives as well as disease prediction so that they would have time to set their mind and decide to select **a way not making them torturous and die calmly.**

From Situation 2, what are the guidelines on caring of terminal cancer patient in conformity with nursing ethics regarding the truth telling?

1. In your opinion, how should nurses perform in telling the patient that he has got the cancer?

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
1. Nurses assessed patients and relatives' needs and promptness of perception to be the important information for the treatment team in telling the truth; for example, the patients knew or doubted that they got the cancer, the patients with the clear background that they hurt themselves when facing serious matters in life, and reactions and viewpoints of patients and relatives about truth telling. Such key information should be transferred to the treatment team.	♠ ↔ *					
2. Nurses had a joint meeting of all related physicians, nurses, caregivers, and specialized physicians to find out and assign the suitable person for truth telling by considering the patients' reliability to the physicians. Truth telling should be undertaken as a team with the telling techniques; patients were encouraged and given the relevant information and communication.	♠ ↔ *					
3. The principle of truth telling might be based on the group support, counseling, or supposing situations depending on the conditions of patients while patients and relatives were willing to be involved in.	♠ ↔ *					

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
4. In case that the patients and relatives received the fact, but they had strong emotional reactions, the treatment team had to care of and palliate them so that patients would be able to pass that situation and accept it finally.	♠ ↔ *					
5. Nurses assessed patients and their family periodically after giving them the truth in order to observe their responses and to give supports for their acceptance of truth.	♠ ↔ *					
6. After telling the truth, nurses should give some advice to patients about practice and alternatives, as well as to palliate patients' mind.	♠ ↔ *					

2. In case that the relatives desire to conceal the patient that he has got the cancer since they are afraid that the patient will become worse by requesting the nurses not to disclose this truth to the patient? In your opinion, should nurses comply with the following steps or not? How?

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
1. Asking reasons of concealing the truth by giving relatives the opportunities of expressing their feelings, fear, and concerns.	♠ ↔ *					

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
2. Explaining about good points of telling truth, which could help patients set their life plans, handle unfinished problems, and prepare to end their life prestigiously and honorably. But, weak points might be that the patients were unable to accept their condition and became worse.	♠ ↔ *					
3. Setting the family participation so that both the family and treatment team had joint discussions and decisions by reminding relatives to realize that any decision should be made for patients, not for relatives, and based on patients' needs most.	♠ ↔ *					
4. Planning with relatives and the treatment team for telling the truth. Nurses might consult the psychologists for the assistance or appropriate planning to tell the truth to patients such as indirect telling or supposing situation, and assigning the suitable person to tell such truth while the patients and relatives agreed to be involved in.	♠ ↔ *					

3. If the patient requires the explanation about the disease progress and treatments as well as disease prediction for making decision on selected treatments. In your opinion, should nurses coordinate with the health team in telling this truth to the patient? How?

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
1. Assessing needs of patients and relatives to receive the information.	♠ ↔ *					
2. Coordinating for patients and relatives to talk to the treatment team officially, and giving them opportunities of discussing, questioning, consulting, and planning for treatments together. Nurses might take part in stimulating patients and relatives to ask questions.	♠ ↔ *					
3. Clarifying the information if in doubt by patients and relatives after talking with the treatment team. The given information should be in the same way given by the treatment team.	♠ ↔ *					

4. In case of the difference of patients in respect with gender, age, and occupation. In your opinion, should nurses have different guidelines? How?

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
1. The protocol should be adjusted and fit to each patient by recognizing the individuals' promptness and differences in respect of learning, information perception, interpretation, acceptance, adjustment, and strength to set up the plan, which would be suitable for time, methods, level of wording, language used to explain about the disease, treatment ways, and appropriate supports.	♠ ↔ *					

Situation 3

A male patient, 68, has got the lung cancer. He has got 9 chemotherapies and irradiations. While staying in the hospital, he had some weakness, quick but short breaths, and gasped for breath sometimes. This patient desired that the physicians explained him clear medical treatments and treatment results; treatments should not be done subject to the physicians' demands only. The treatment methods should be explained to the patient so that he could take it for decision-making about allocated treatments. But, in fact, the physicians rarely told the adequate information. The patient said, "I would like to have a right of selecting how I will be cured. But, I don't know what I should do. In most cases, the doctors have never informed us in advance; they carry on at once. **If we were at the final stage of illness that was irreversible, we want to reject some treatments.** Inserting or bearing any equipment, I reject it" The patient also said, "If my illness is beyond any treatment, I want to go back home. It's warmer if I die there. Frankly, I want to die at home. In the worst case, I want to go back home. I want to die happily. Let me die. Staying in the hospital, I'm close to the doctors, but it is not the same as staying at home."

From Situation 3, what are the guidelines on caring of terminal cancer patient in conformity with nursing ethics regarding the allocated treatments?

1. In case that the patient rejects the treatments causing torment and uselessness. In your opinion, should nurses comply with the following steps? How?

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
1. Evaluating the patients' illness condition how they learnt and understood the diagnosis, treatments, treatment results, and disease prediction.	♠ ↔ *					
2. Evaluating that the patients had the full consciousness, not been overborne by the body torment or socio-mental and spiritual problems.	♠ ↔ *					
3. Recording the evaluation of patients' status and needs in the nursing daily records.	♠ ↔ *					
4. Consulting the treatment team for the patients' needs to find out caring methods in conformity with needs of patients.	♠ ↔ *					
5. Coordinating for patients and relatives to talk to the treatment team to set up the treatment ways; comparing between the expected treatment results and bad points if no treatments were done for the good understanding of patients and relatives. As a result, all related parties would have a joint decision on treatment methods. Nurses might wait until patients and relatives had mental	♠ ↔ *					

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
readiness before they specified some undesirable treatments such as CPR, the respiratory apparatus if the patients were seriously ill, etc.						
5. Coordinating for patients and relatives to talk to the treatment team to set up the treatment ways; comparing between the expected treatment results and bad points if no treatments were done for the good understanding of patients and relatives. As a result, all related parties would have a joint decision on treatment methods. Nurses might wait until patients and relatives had mental readiness before they specified some undesirable treatments such as CPR, the respiratory apparatus if the patients were seriously ill, etc.	♠ ↔ *					
6. Preparing patients' advance directives in the written form or in the informed consent as witnessed by patients' relatives.	♠ ↔ *					
7. Caring and evaluating the treatments regularly so that there were consistent with patients' intent and needs. If patients' illness conditions changed, nurses should evaluate periodically whether patients still had the same needs or not, and informed the family and relatives of patients' needs.	♠ ↔ *					

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
8. In case that patients desired to go back home, relatives should be informed of possible illness conditions, caring of patients at home, and advising on nearby hospitals or assistance network such as contacting the home-visit unit to help both patients and family, as well as giving the emergency telephone numbers for 24-hour assistance or consult including caring of patients if they die at home and the legal protocol.	♠ ↔ *					

2. In case that the patient does not have the advance directive. In your opinion, should there be the following steps? How?

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
1. Assessing the patients and relatives the extent of acknowledging the information in respect with illness diagnosis, treatments, and disease prediction.	♠ ↔ *					
2. Taking such received information to consult the treatment team for planning and discussing about treatment alternatives and treatment results.	♠ ↔ *					
3. Coordinating for patients and relatives to talk to the treatment team in order to investigate needs of patients and relatives, treatment alternatives, treatment results, and treatment rejection. As a result, both patients	♠ ↔ *					

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
and relatives could be involved in selecting the caring ways in conformity with patients' needs most.						
4. In case of patients' unconsciousness, the close and direct-blood relative would decide for treatment methods. But, if patients had several relatives, all of them might have the appointments with the treatment team (family meeting) to conclude the selected treatments. All relatives should be reminded that the decision was made for patients, not relatives; thus, the decision should meet patients' thought and needs most.	♠ ↔ *					
5. In case the patients or relatives were unable to undertake anything, nurses should take roles in representing the patients and relatives in giving the information about treatments for the decision-making of patients and relatives.	*	♠ ↔				
6. Needs of patients and relatives should be evaluated periodically. If the patients or relatives changed their mind or had hesitation, nurses should provide the useful information for their decision-making. Then, nurses forwarded such evaluation to the treatment team for the revision of treatment plan.	♠ ↔ *					

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
7. Giving some help to the patients and relatives regarding general practice and illness relief to acquire patients' comfort; arranging the environment for tranquility and privacy; and giving opportunities for religious and faith practice.	♠ ↔ *					
8. In case the patients had no relatives, nurses should not leave the patients die lonely, but stay with them for spiritual guidance and giving some advice on the religious practice.	♠ ↔ *					

3. In case of the difference of patients in respect with gender, age, and occupation. In your opinion, should nurses have different guidelines? How?

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
1. The protocol should be suitably applied for each patient depending on the personal difference while the standard quality was maintained.	♠ ↔ *					

Situation 4

A male patient, 74, got the stomach cancer and used to have an operation including a full course of chemotherapy and irradiation two years ago. While obtaining such treatments in the hospital, this patient had the difficult breathing, vomited blood, has severe stomach ache, and had too much gas; so the physician inserted the breathing tube, tube for intravenous drips, and tube for infusion apparatus. Before admitting in the hospital, this patient told his children that, **"If anything happens again, do not permit the doctor to insert or put something for me. I don't want to be painful anymore. No more torment is required. I want to die**

peacefully; do not treat me like I'm not a human and treat me for the case study only.”
His children reported those needs to the doctors, but they still insisted to insert many tubes into the patient's body, and told his children that “Anyway, the treatment must continue since it's my duty.”

From Situation 4, what are the guidelines on caring of terminal cancer patient in conformity with nursing ethics regarding the use of medical equipment for prolonged life?

1. In case that the patient becomes worse and unconscious, but he has the advance directive for no use of medical equipment for prolonged life and relatives do not require it as well, but the physicians required it. In your opinion, should nurses comply with the following steps? How?

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
1. Nurses should represent the patients and relatives in transferring needs of patients and relatives to the physicians, and consult the physicians for the patients' needs.	♠ ↔ *					
2. If the physicians insisted on the same treatments, encouraging relatives as patients' representatives to meet the physicians to inform of patients and relatives' desires while the physicians also had chance of explaining about the usefulness of each treatment so that relatives would have better understanding about each treatment way for further decision.	♠ ↔ *					
3. In case the relatives still denied those equipments while the physicians insisted the same undertaking; nurses should note this	♠ ↔					

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
event in the nursing daily records and reasons of physicians to provide such assistance.	*					
4. Proposing those problems to the meetings to encourage the hospital management to acknowledge that those problems would be risks of the hospital. There should be the committee monitoring ethics of caring of terminal cancer patients as the guidelines on caring of other patients.	♠ ↔ *					

2. In case that the patient has the advance directive for no use of medical equipment for prolonged life but relatives require it. In your opinion, should nurses comply with the following steps? How?

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
1. Giving opportunities to patients' relatives for comments, asking their needs and reasons of such desire, and reminding them about patients' needs by emphasizing that any decision should be subject to patients not relatives.	♠ ↔ *					
2. Transferring the needs of relatives to the treatment team to stimulate the physicians to pay attention in this issue.	♠ ↔ *					

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
3. Coordinating for relatives to talk to the treatment team so that they obtained both strengths and weaknesses of bearing tubes or sustaining life, persuading relatives into caring of terminal cancer patients for the prestigious death, and reminding the relatives about the consequences of not respecting for patients' directives for the new decision to be made by relatives.	♠ ↔ *					
4. Recording relatives' comments in the nursing daily records, and respecting for relatives' decision.	♠ ↔ *					
5. Evaluating the needs of relatives and periodically giving them the patients' illness conditions. If the relatives changed their mind, nurses should coordinate for relatives to talk to the treatment team.	♠ ↔ *					

3. In case of the difference of patients in respect with gender, age, and occupation. In your opinion, should nurses have different guidelines? How?

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
1. The treatments should be adjusted to fit the status of patients and family.	♠ ↔ *					

Situation 5

A female patient, 55, has got the ovary cancer. She has got treatments in a hospital by having the operation to cut off her ovary and the chemotherapy. About 8 months later, she admitted the hospital again because she could have less food, and her belly became stiff. According to the body check-up, it was found that the cancer spread out over her pelvic cavity. Her children wanted the patient to continue the treatments, **but the patient requested the physician to stop treatments, and wanted to go back home to die with her children. However, when her children met her, they asked the physician to have the full remedies without any concerns about payments.**

From Situation 5, what are the guidelines on caring of terminal cancer patient in conformity with nursing ethics regarding stop treatments?

1. In case that the patient requires stopping the treatment and going back home to die there. In your opinion, should nurses coordinate with the health team according to the following steps? How?

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
1. Evaluating that the patients had the complete consciousness and were not influenced by the body symptoms, socio-mental and spiritual problems.	♠ ↔ *					
2. Evaluating that the patients acknowledged and understood, as some partial information for decision-making, the diagnosis, treatments, treatment results, disease prediction, strengths and weaknesses of rejecting the treatments, as well as the torment to be occurring in the future.	♠ ↔ *					

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
3. Recording the evaluation of patients' illness condition and needs in the nursing daily records.	♠ ↔ *					
4. Coordinating for talks between patients and relatives so that relatives understood and accepted the patients' needs, including strengths and weaknesses of rejecting the treatments by informing both patients and relatives of all facts, and giving them opportunities to question and make decisions again.	♠ ↔ *					
5. In case the patients insisted to stop all treatments and to die at home, a joint meeting between the treatment team and the patients as well as family should be arranged to set planning and give some advice on caring of patients at home (discharge planning), especially ways of controlling the illness condition when patients were nearly dead so that the relatives would be able to confront and handle the situation while the patients had no torment and died peacefully. Nurses might advise the relatives on supporting sources or assistance network by forwarding the treatment information and patients' needs to those sources or network.	♠ ↔ *					

Guideline	Level of Opinion					Reason (if any)
	5	4	3	2	1	
6. Undertaking all related documents in connection with patients' treatment rejection, and preparing patients for moving by realizing that patients might pass away during such moving; thus, relatives should be ready to confront such situation.	♠ ↔ *					

2. In case that the patient requires stopping the treatment but the relatives require continuing it. In your opinion, should nurses comply with the following steps? How?

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
1. Giving the relatives opportunities for comments, asking for their needs and reasons of continued treatments, and reminding them about patients' needs.	♠ ↔ *					
2. Transferring the needs of relatives to the treatment team, and recording such needs in the nursing daily records.	♠ ↔ *					
3. Coordinating for relatives to talk to the treatment team so that they obtained the information, persuading them into caring of terminal cancer patients for the prestigious death, and reminding the relatives about the patients' needs for the new decision to be made by relatives, which should be subject to patients, not relatives.	♠ ↔ *					

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
4. If the patients and relatives had inconsistent viewpoints, the treatment team should coordinate for both parties to discuss and share comments with each other, and give time for a new decision.	♠ ↔ *					

3. In case of the difference of patients in respect with gender, age, and occupation. In your opinion, should nurses have different guidelines? How?

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
1. The methods and practice should be suitably applied for relatives of each patient depending on the differences of person and situation.	♠ ↔ *					

Situation 6

A male patient, 68, has got the lung cancer, and were admitted to the ICU for 2 times. After leaving the hospital, he told his wife and children not to take him to the hospital again if his illness became severe again; he wanted to die at home, did not want to get any torment caused by treatments anymore. Later, when this patient's illness was severe, his wife and children decided to take him to admit the hospital and stayed in the ICU. When he felt better, he told nurses that **he did not want treatments with the use of any equipment for prolonged life. The nurse chief on duty recorded the patient's needs in the nursing records** before informing the nursing team and the attending physician of such needs. Later, when the patient's illness was more severe, the physician on duty instructed the nurse to insert the breathing tube and respiratory apparatus although the caring nurse informed the physician on duty of the patient's needs, and, at that time, no relatives of patient stayed there.

From Situation 6, what are the guidelines on caring of terminal cancer patient in conformity with nursing ethics regarding advance directive?

1. In case the patient tells the caring nurse that he does not want any prolonged-life equipment and the nursing chief on duty records such needs in the nursing records. In your opinion, can this nursing record be deemed as the written document?

In this issue, experts' viewpoints were inconsistent and could be divided into 2 issues. Please select one that is the most relevant to your opinion and propose your reasons to be summarized as the guidelines in the second-round questionnaire.

☐ 18.75% The group opined that those nursing records should be deemed as advance directives because they were counted as the legal evidence.

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☐ 75% The group opined that those nursing records should not be deemed as advance directives because, currently, there have not yet been any laws prescribing the advance directives although the nursing records could be used as the legal evidence. This issue was on argument and set forth in Section 10 of the National Health Bill, which may be legally acceptable in the future. But, for the clear evidence, the patients might prepare the informed consent instead of nursing records so that everyone in the caring team could notice it.

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In addition, should the guidelines on preparing the advance directive comply with the following steps? How?

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
1. Evaluating that the patients had the full consciousness, not been overborne by the body torment or socio-mental and spiritual problems.	♠ ↔ *					

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
2. Evaluating that the patients acknowledged and understood, as some partial information for decision-making, the diagnosis, treatments, treatment results, disease prediction, strengths and weaknesses of using the prolonged-life equipment in the treatments.	♠ ↔ *					
3. In case the patients insisted not to get treatments by the use of prolonged-life equipment, nurses should note the evaluation of patients' illness condition and needs in the advance directive and reporting them to the caring team.	♠ ↔ *					
4. Coordinating for patients and relatives for another talk to the treatment team so that they were provided, for a new decision-making, strengths and weaknesses of treatments by the use of prolonged-life equipment including the torment to be occurring in the future for a new decision made by relatives.	♠ ↔ *					
5. In case the patients still insisted the same intent, nurses should undertake all related documents by having the patients record their own needs in advance directives that should also be signed by caring physicians who certified that the patients had full and complete consciousness, and relatives as witnesses.	♠ ↔ *					

2. In case of stop treatments with the written advance directives identified by patients for stop treatments and no prolonged-life equipment. In your opinion, should there be the following steps? How?

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
1. Evaluating that the patients had the full consciousness, not been overborne by the body torment or socio-mental and spiritual problems.	♠ ↔ *					
2. Coordinating with the physicians to give patients and relatives the information for their decision-making about inserting the breathing tube, results of inserting such tube, the torment to be occurring in the future if not bearing it, and the disease prediction.	♠ ↔ *					
3. In case the patients still insisted for not bearing the respiratory apparatus, the nurses should attend the joint meeting with the treatment team, patients, and relatives to note the patients' needs in the written form signed by the patients (patients' signature might not be required if the patients showed their needs in the hand-writing, except signing to prevent any problems with relatives after the patients' death). The record of patients' needs should comprise some witnesses who guaranteed that the patients have full and complete consciousness. Those witnesses should be direct-blood relatives or caring physicians.	♠ ↔ *					

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
4. Notifying the physicians or related persons or relatives for the joint caring plan. Although the patients insisted that they did not want the breathing tube or other prolonged-life equipment, other treatments could be done to relieve patients' torment; for example, giving the oxygen by other ways. However, any treatments should mainly concern the patients' needs and not cause any torment.	♠ ↔ *					
5. Although the patients had advance directives, when their illness became worse, nurses should talk to patients and relatives again whether they still had the same intent or wanted to change their mind. The treatments should be revised as per needs of patients and relatives.	♠ ↔ *					

3. In case the physician desires to use the prolonged-life equipment although the patient has advance directive he does not want it. In your opinion, should nurses perform the following steps? How?

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
1. Nurses should represent the patients and relatives in transferring needs of patients and relatives to the physicians, showing to the physicians the patients' advance directives to insist the patients' needs.	♠ ↔ *					

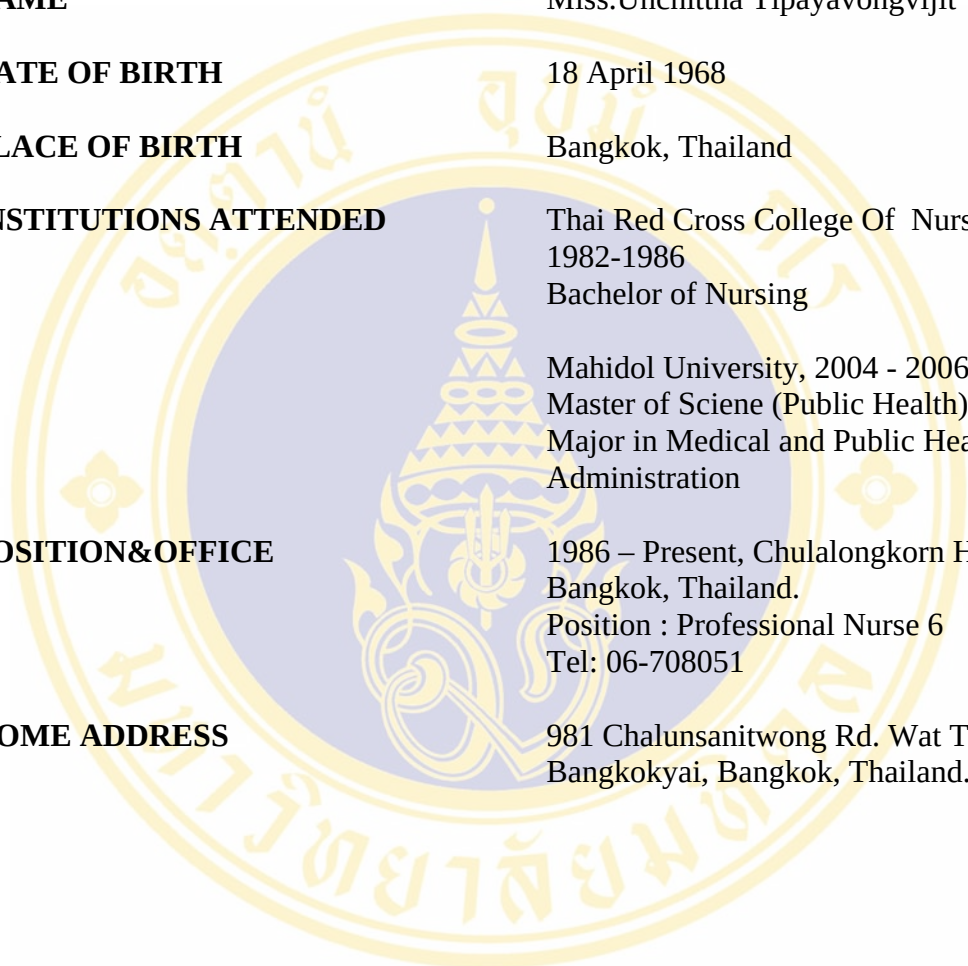
Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
2. Nurses should not help prepare the medical equipment. Moreover, nurses should explain to the physicians that when the patients rejected the offer of rescue, it should be deemed that it was beyond the duty of physician in treatments; thus, any actions for patients shall be the violation of patients' right.		♠				
3. If the physicians on duty still insisted the same actions, nurses should coordinate with the relatives of patients to meet the physicians to be compliance with patients' intent.	♠ ↔ *					
4. In case that the relatives decided that no prolonged-life equipment should be used, but the physicians insisted the same actions; nurses should note this event in the nursing daily records.	♠ ↔ *					
5. Reporting the attending physician and higher supervisors respectively.	♠ ↔	*				
6. Proposing those problems to the meetings to encourage the hospital management to acknowledge that those problems would be risks of the hospital. There should be the committee monitoring ethics of caring of terminal cancer patients as the guidelines on caring of other patients.	♠ ↔ *					

4. In case of the difference of patients in respect with gender, age, and occupation. In your opinion, should nurses have different guidelines? How?

Guidelines	Level of Opinion					Reason (if any)
	5	4	3	2	1	
1. As a whole, there should not be any differences. In case of so young patients, they should have duly representatives. However, most decisions were up to parents; thus, parents should be clarified. In addition, treatments should concern the differences of person and situation.	♠ ↔ *					

Thank you for your cooperation.

BIOGRAPHY



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