

ACCOMPANY THEM TO LET GO





End-of-Life Nursing Care Profession and Mentality Integrity

Saving lives is the goal of the medical professionals
But when medical treatments reach the limit
How can a nurse take care of the terminally ill
patients' body and soul?

Accompanying patients and families to grasp the
precious final moments:

to say "thank you", express love, say "I'm sorry",
and say goodbye to each other.

Let go at the right time so life ends with grace and
peace.



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Good hospice care is the hope of everyone. However, family members do not understand nor accept the fact that terminally ill patients' condition will not improve, but expect continuous medical care to save lives. When I first joined the clinical care unit in the ICU, National Health Insurance was just started. At the time, most families did not understand the meaning of hospice care, and thought hospitals are meant to save lives. Doctors mostly followed the wishes of families to prolong treatment. As a result, much needed resources were wasted with futile result. Most importantly, patients and their families became exhausted fighting the unavoidable consequence of death, and missed the golden opportunities to express love and bid farewell at the most precious moment.

When faced with terminally ill patients, when should we stop treatment? How do we help patients and families to decide? How do we prepare ourselves mentally and physically with professionalism?

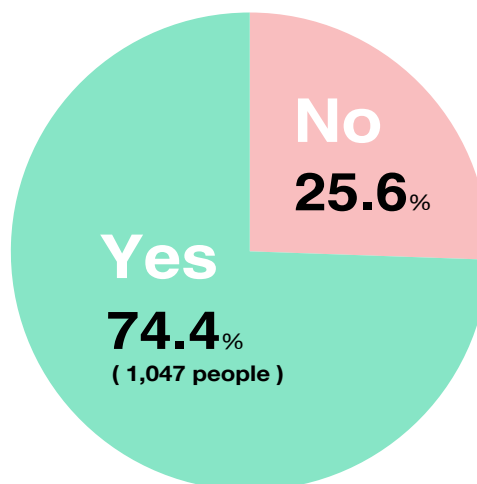
To many newly graduated nurses, the experience with the inevitable death must be overwhelming. How to face it to tell the patients and their families for the first time that "the medical miracles are impossible", but to prepare for the end of life? How to pace the tone and structure the delivery? Should this be done again to remind the next time around? It is very likely that he or she needs consultation or help from veterans.

Basic Statistics

Gender	Number	%
Female	1,367	97.2
Male	40	2.8
Total	1,407	100.0
Age	Number	%
≤ 20 yrs old	44	3.1
21-25 yrs old	366	26.0
26-30 yrs old	297	21.1
31-35 yrs old	279	19.8
36-40 yrs old	206	14.7
>=41 yrs old	215	15.3
Total	1,407	100.0

Grade	Number	%
N	400	28.4
N1	239	17.0
N2	577	41.0
N3	128	9.1
N4	63	4.5
Total	1,407	100.0
Position	Number	%
Registered nurse	1,101	78.3
Deputy head nurse	53	3.8
Head nurse	75	5.3
Supervisor & above	18	1.3
Case manager	54	3.8
Nurse Practitioner/ Senior RN	106	7.5
Total	1,407	100.0
Department	Number	%
Internal medicine	259	18.4
Surgical ward	215	15.3
Pediatrics	55	3.9
Obstetrics & Gynecology	66	4.7
ICU	246	17.5
Functional unit	18	1.3
Kidney dialysis	40	2.8
Operating room	97	6.9
Outpatients	203	14.4
Palliative care ward	32	2.3
Administration	34	2.4
Others	142	10.1
Total	1,407	100.0
Working in this hospital	Number	%
under 1 year	205	14.6
>=1 and <2yrs	197	14.0
>=2 and <3yrs	183	13.0
>=3 and <5yrs	210	14.9
>=5yrs	612	43.5
Total	1,407	100.0

Q1 | Have you taken care of terminally ill patients in your nurse career before? (N = 1,407)



With accumulated experience, will nurses be able to calmly face terminally ill patients and their families by lightening family's sadness, and help themselves to recovery from mood changes? The questionnaires are designed for this issue's cover story. We want to know the difficulties encountered, the readiness of the professional and psychological quality, and the kind of assistance and trainings needed when the clinical nursing staffs are caring for the terminally ill patients.

The six Tzu Chi Hospitals survey has a total of 1,407 valid questionnaires.

Nearly 75% Have Experienced Caring for Terminally Ill Patients; Futile Medical Care Bothered Nurses the Most

The first question is to quantify nurses who have taken care of terminally ill patients. The statistics show 74.4% have experience, about three quarters, in contrary, 25.6%, does not.

Question to the nurses with experience: What troubled situations have you encountered while caring for the patients? In the following eight listed categories, the highest scored is "Continuing futile medical treatment", accounted for 54.0%, or more than half; followed by "Patient's symptoms cannot be resolved", 49.0%; "Patients are

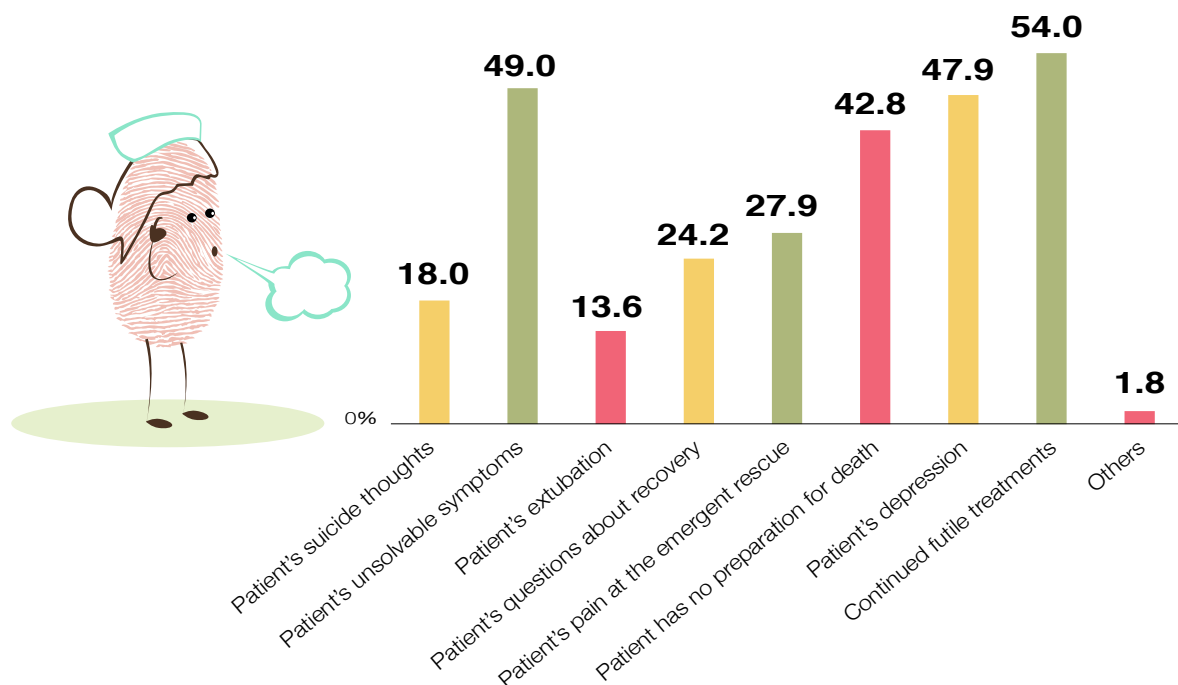
depressed”, 47.9%, close to half; followed by “Patients have no dying preparation”, 42.8%. The next situation is relatively low, “Patients suffering in ER”, 27.9%; “Patients asked about their prognosis”, 24.2%.

“Futile medical treatments” were encountered by many nurses and happened quite often. According to the statistics from NHI Bureau, more than 30% (One hundred fifty billion Yuan) of the expenditures were in the last 3-6 months category. It includes huge expense on the futile medical treatments, therefore delaying death and adding to patients’ suffering. In addition, regardless of patients’ conditions, suffering from depression, pain, and emergency treatment bothered nurses because no one bears to see patient suffering the pain.

Medical Treatment Has Its Limit, Everyone Should Be Well Prepared

Q2

What bothered you while taking care of the terminally ill patients? (N = 1,047, mutiple choice)



Nursing around the clock is the most intimate tasks among patients and their families. It is also the most vulnerable moment in life for the caring medical staff. Sometimes prognosis cannot be resolved, creating a sense of disappointment and helplessness in the process. In medicine, we know the limits of medical treatment based on our experience with survival rates. Not everyone can survive, not everyone can be cured. To accept the fact that there is limitation in medical treatment is also a major indicator of nurses' growth.

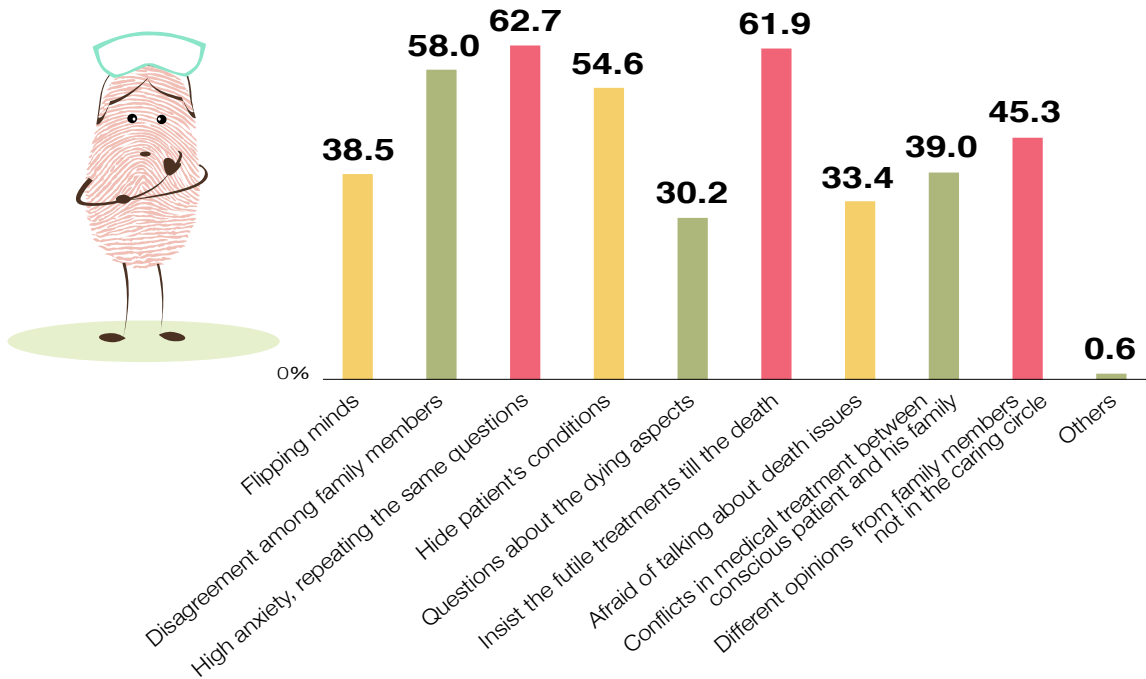
"Patients have no preparation for death - 42.8%" is higher than expected. Over these years, people in Taiwan have begun to discuss "death". Willingness to prepare a will before death is a very open-minded deed. There are many hospice related treatment regulations and choices, organ donation, etc. For example, Tzu Chi's originated a cadaver program, which many medical schools followed. In recent years, there are many books and movies that talk about death and death preparation: The Bucket List, Departures, and The Accuracy of Death. There are also the death cafés that encourage open discussion on death preparation. Maybe that is because of more people are becoming aware of the necessity of death preparation. But from a clinical nursing perspective, we still hope there are more patients who can ready themselves mentally in preparation for the unavoidable death.

Although terminally ill patients cannot be cured, the medical team still strives for a way to alleviate patients' discomfort. Nurses will try their best to teach patient's families care techniques to help patients reduce pain. However, the techniques can only alleviate the symptoms that cause pain, but not cure the incurables. Nursing care does not rely entirely on instructions; it requires full medical knowledge, in addition to details in the care process, and must be delivered with the human touch, such as voices, emotions and both hands to carry out the nurse caring. But the clinical care is still focused on taking care of the disease rather than the patients. Depression and the lack of advanced preparation is the most common that medical personnel sometimes feel helpless.

The Myth of Dying - Patients' Families Need Time to Accept the Fact

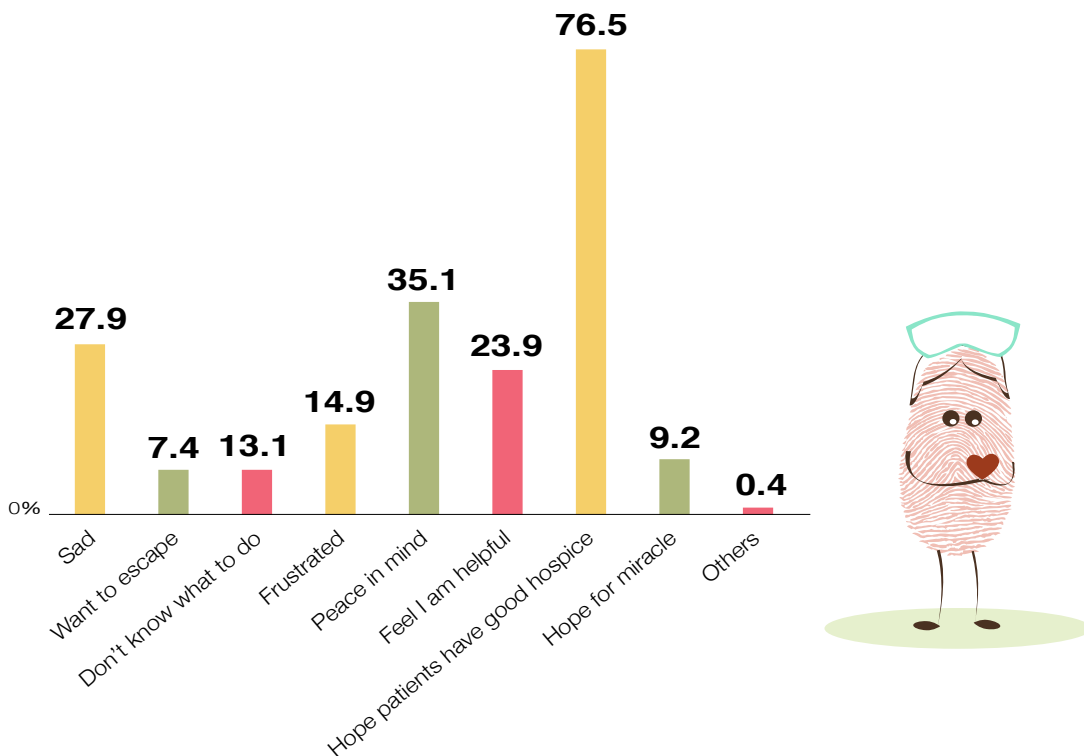
During the process of caring for terminally ill patients, there are many stories and reactions from families during the encounters. An example from our experience is, "Money is not necessary a good thing."

Q3 | What are patient family's reactions while taking care of the terminally ill patients? (N = 1,047, multiple choice)



There was a grandfather aged 90 with chronic diseases suffering a septic shock after a cold which lead to pneumonia. After the medical team's rescue and assessment, they believed he had reached the end of the life stage. And at such an age, they suggested to the families to let grandpa leave without further suffering. But the family members insisted on all possible rescue attempts to keep him alive. From the endotracheal tube placement to cardiac resuscitation, even continuous hemodialysis was given later due to low blood pressure and kidney failure. The family insisted on maintaining unnecessary medical treatments, even with albumin and other drugs at their own expense. Finally, grandpa's limbs suffered from cyanosis, his heart beat relied on a booster, and breathing was through a machine respirator; he lost the humane dignity. We thought it was grandma decision to keep him alive. And later we realized from social workers that these futile medical treatments were insisted by his children because the estate had not been settled. Grandpa did not have a dignified hospice care. We all felt sorry for him because of the family bad decision.

Q4 | Describe your feelings while taking care of the terminally ill patients? (N = 1,047, multiple choice)



This is one example of a futile treatment case that nurses don't want to see, and the causes mostly come from the patient's family or the patient did not communicate well with his family while conscious and able.

While taking care of the terminally ill patients, nurses most frequently encounter with the families are the following: "Repeating the same question with anxiety" at 62.7%, followed by "Families do not give up the futile medical treatment, rescue till the last breath" at 61.9%. "Family members with different views" at 58.0%, this is one of the reasons why medical team sometimes gets caught in the middle when family members have differences. Next but not last is "Hiding patient's condition" at 54.6%, accounting for more than half of the respondents. "Difference in opinions among family members who never involved in caring the patient" accounted for 45.3%. "Inconsistency between patient's will while still conscious and family's will in medical treatment" accounted for 39.0%.

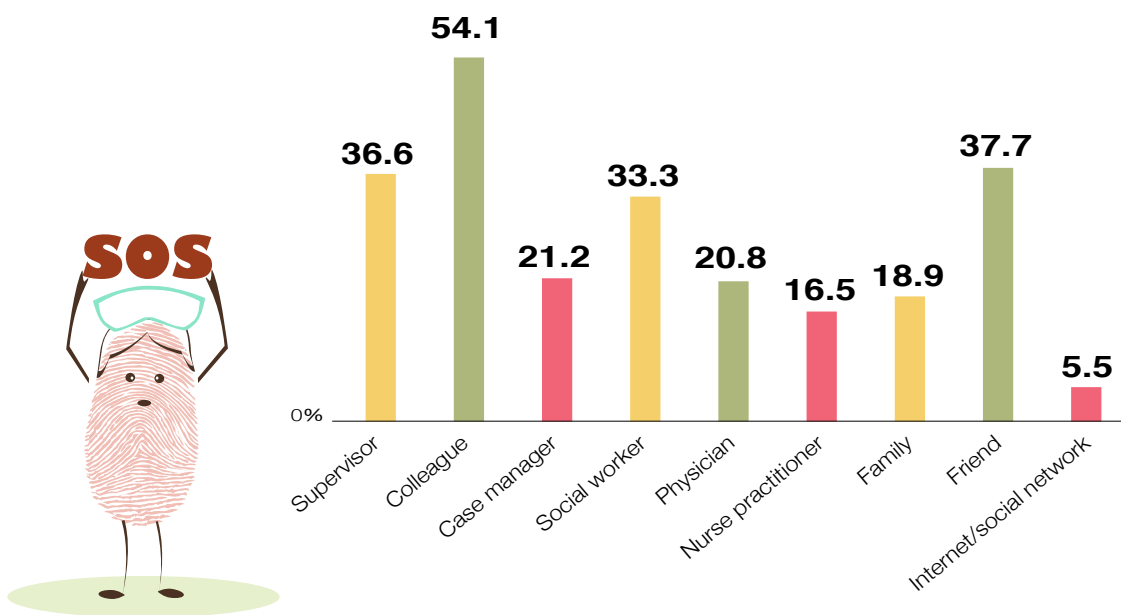
When a patient is declared terminally ill, the family must “face it, accept it, handle it, and let go of it”. Nurses often encounter families who are stuck at the beginning stage. Therefore, the most commonly questions asked are: “Will he get better?”; “He was discharged after two days in hospital last time, how could it happen this time?”

By means of communication and understanding, patient’s family needs time to digest and to accept the fact that the patient is near the endpoint. Nurses always patiently explain the options, more preparation before death when the family is more rational and calm. During the care for the terminally ill and their families, nurses should reflect on their own preparation and communicate with their family at an early time. Nevertheless, it is the last major event in life.

From Sadness to Peacefulness; Patients Get Good Hospice Care

Q5

Who can you ask for help if you are distressed while taking care of the terminally ill patients? (N = 1,047, multiple choice)





While caring for the terminally ill patients, what are the most common feelings among nurses?

In nursing, there is the need to alleviate a patient's physical pain, but also the mental emotion, such as the interaction between patients and their families, and family problems. When impermanence happens, nurses need to know how to help patients to remain at ease till the end of life with little discomfort. Therefore, "Hoping patients have good hospice care" and "Live with your heart" accounted for 76.5% and 31.1%, respectively; while 27.9% and 23.9%, voted for "Still with mixed feelings or sadness" and "The feeling of helping people", respectively.

There was a young lady, married for many years with two children, was admitted with a terminal stage of breast cancer. The day she came to the emergency room, her husband insisted on resuscitation, he believed she could survive just like the other hospital emergency visits. After doctors had determined emergency treatment would not work, Yu-Ru, the ER head nurse, set aside her work right away, and gathered social workers and hospice care personnel to communicate with her husband and family, to explain the need to give up treatment. At the same time, nurses listened to the family's sadness, and tried to draw the children to bid farewell to the mother; and let the husband to express love and gratitude to his wife. This patient passed away a few hours later, but she received good hospice care under the entire nursing team. The family did not regret to let her bear the unnecessary pain and the futile treatment, they had the opportunity to bid farewell to their loved one within the last hours. The husband and children were fully appreciative of the process. This husband later became a cancer volunteer at the hospital. He channeled his love to his wife to positive energy and let that love continues.

With Psychological Distress, First Consult with Colleagues, Then Supervisors and Social Workers

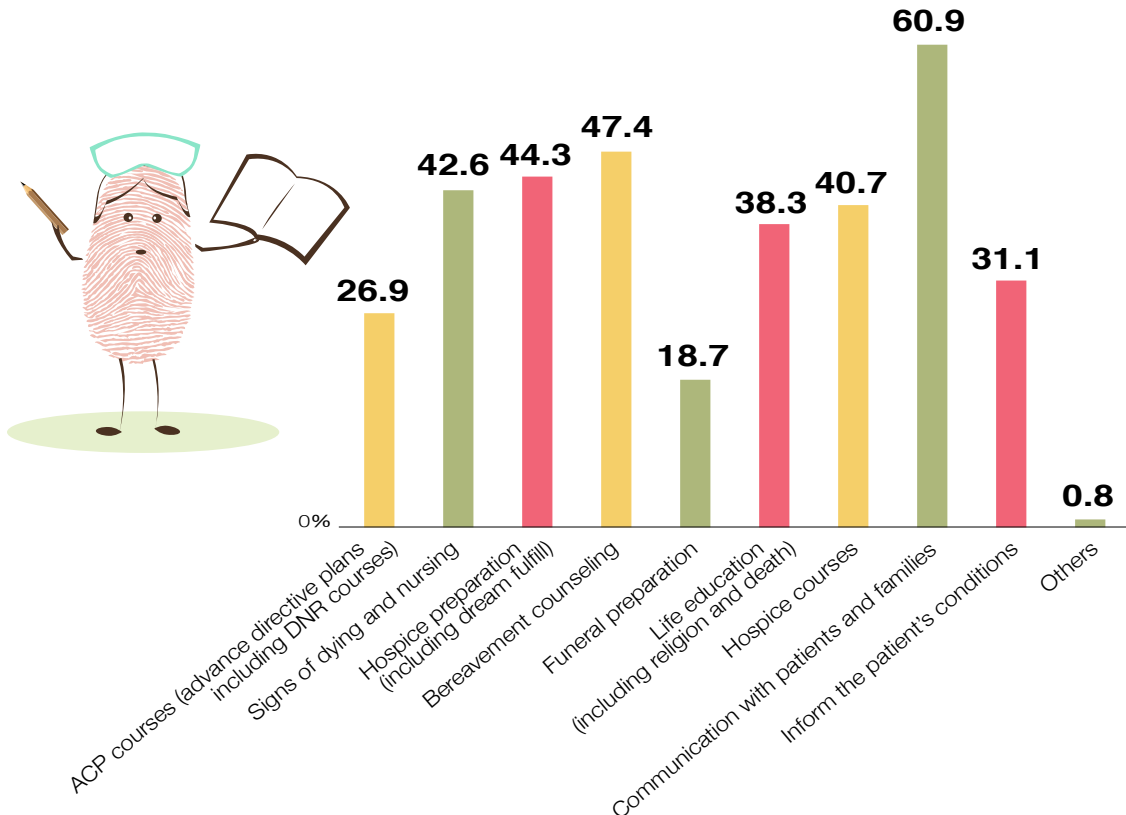
But if the nurses encounter psychological distress while caring for terminally ill patients, who do they seek support from?

The survey found that about 54.1% of nurses asked peers' support while 37.7% seek support from friends. When nurses have psychological issues or conflicts while taking care of the patients, they often make use of time during shifts to clarify and resolve issues before seeking support. They also hope to relieve their stress from sharing their experience with colleagues and friends. In addition, 36.6% of the nurses seek further support from management, and 33.3% from social workers.

Q6

What training courses you would like to take in order to improve yourself regarding end-of-life care?

(N = 1,407, multiple choice)



I believe most of the nurses like to discuss with colleagues and friends first and get a good start in solving the issues. Nursing supervisors may have competence and experience, however, it is usually more formal and some might feel uncomfortable when interacting with supervisors. To discuss with colleagues first may allow the supervisors understand the thinking of their colleagues better. The ultimate goal is to handle stress and deal with colleagues' inner struggle, so that the psychological barriers would be overcome. It is major growth at the personal level.

End of Life Communication and Bereavement Counseling

The questionnaires also surveyed the type of training classes most helpful for care of terminally ill patients. The result: "Classes of communications between terminally ill patients and their families" accounted for 60.9%, followed by "Bereavement



counseling” 47.4%, “Hospice preparation (including fulfill the dream courses)” accounted for 44.3%, “Sign of death and nursing care” accounted for 42.6%, and “Palliative ordinance course” at 40.7%.

Life education, discovery and sharing of prognosis, ACP programs (medical autonomy plan DNR courses) also accounted for nearly thirty percent. Nurse supervisors can refer to the contents in hospital’s courses, or remind colleagues to make use of training resources at the union and the public sector.

Communication in nursing is already a very profound field. If it is to inform a young father that the son weighs four kilograms, or your wife is well, or to tell the patient’s family that the patient is fine is relatively simple. Good news like these, we don’t need to learn; but if it is a bad news, we’ll have to learn how to communicate. First, we’ll have to build good relationship with the patient and family. After gaining their trust, try to understand patient and the family’s thinking and their expectations about the disease. Furthermore, wait for the signs of calmness and readiness to communicate with each other. It is simply an art of communication. But through practice and classes, coupled with good intentions, many of our nurses have become the masters of communication.

The Right to Choose DNR, Learning the Right Timing to Let Go

Have all our busy nursing colleagues signed their “DNR (Do-Not-Resuscitate Order)?

From the questionnaire survey, 13.6% signed the DNR, 6.5% do not remember, and 79.9% have not signed the DNR.

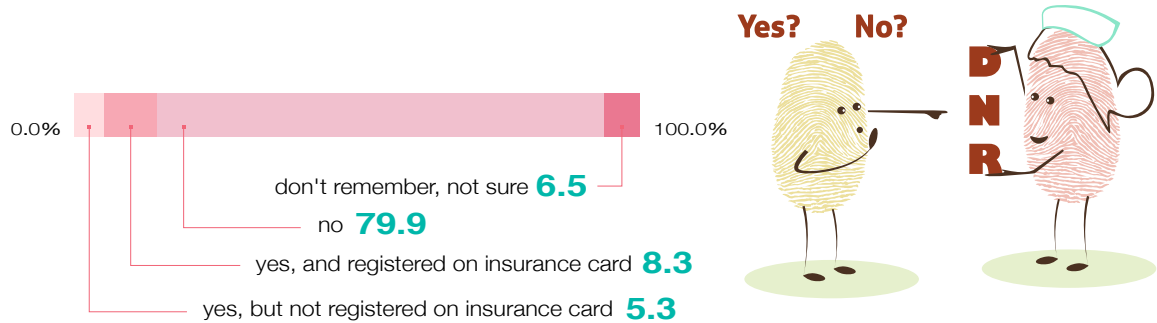
If we compare our statistics with the general public, 13.6% of our colleagues have signed the DNR - a relatively a high ratio. Nurses encounter many uncertainties in life, so the ratio should be higher. We believe our nurses are relatively younger, and their busy work schedule may be causing some to delay on it. For the small percentage of colleagues who answered “Do not remember”, we would like them to please take action right away.

Patients and their families have to deal with impermanence in a vacuum, with fear and confusion. Many could not believe that death is approaching, and don’t know how to talk about the death issues, and missed the opportunities. We finally asked all nurses: Have you or family or friends seriously discussed about the medical choices when reaching the end of life?

I remembered our school had terminally ill caring classes. Teachers made nursing students to think the meaning of death, and also guided students to choose their own

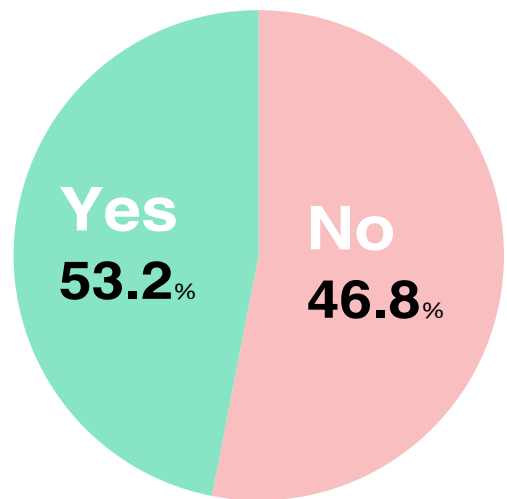
Q7

Have you signed a DNR agreement? (N = 1,407)



Q8

Have you discussed the end-of-life medical choice with your family or friends? (N = 1,407)



way of facing death. At clinical work, we have hospice care related training but the depth of training is based on personal preferences. Questionnaire results showed that 53.2% of nurses had seriously discussed the alternatives for final medical treatments.

When life reaches the end, patient in good hospice care is the biggest wish of all nurses. Accompanying and communicating with family members is a tough challenge. When nurses themselves are educated on impermanence, with professionalism in taking care of the end term patients, and the courage to discuss death, they are more ready to accompany patients and their family to let go at the right time so that the living has peace in mind, and the dead has peace in soul.