

# Reflection on End of Life Care: Experiences and Inspirations of Nursing Care for Terminally Ill Patients

*Caring for patients who are approaching the end of their lives and dealing with death is one of the compulsory courses for clinical nursing staff.*

*Nursing staff are endeavored to provide the best quality of care to their patients; but when parting is inevitable, they also want to help their patients to face death with dignity. Hospice and palliative care has become an active elective for nursing staff of all units, and they learn to create meaning and value for their own lives from the process of end of life care.*



The definition of a terminally patient is one who is expected to die within one year. Hospice and palliative care for terminally patients is the best expression of the humanistic spirit of health care, as it emphasizes the concept of the Five Wholes: Whole person, Whole family, Whole team, Whole journey and Whole community. However, in the medical arena, nursing staff will also be involved in end of life care in other medical and surgical wards or acute care units, not just in hospices. In a survey conducted by Tzu Chi Nursing Journal in 2008, about 25% of nursing staff were willing to transfer to a hospice unit. The main reason for the willingness was that they would provide better quality of care to terminal patients, while the main reason for the unwillingness to transfer was that they did not know how to deal with terminal patients.

### **Taiwan's Palliative Care Ranked as No. 1 in Asia Degree of Preparedness of Nursing Staff for End of Life Care**

The government is highly supportive of hospice policy and its implementation. In 2009, eight non-cancerous end of life illnesses were included in the national health insurance coverage, and in 2013, hospice shared care was introduced, giving terminally ill patients in general wards a chance to receive hospice palliative care. With the enlargement of aged population, the government began introducing community hospice and offer class B community hospice services and home hospice care. According to the Quality of Death Index survey published by the Economist Intelligence Unit (EIU) in 2015, the quality of end of life care in Taiwan is ranked first in Asia and sixth in the world. But what is the level of the experience of our clinical nurses in end of life care, and can they be inspired through end of life care?

### **76% Had End of Life Care Experience, Nearly 90% Patients Received Hospice Care.**

The survey was organized by the nursing department of Hualien Tzu Chi Hospital, and the emphasis is on the experience and inspiration of nursing staff on end of life care. The electronic questionnaires were sent to the nursing staff of six Tzu Chi Hospitals and 1,488 valid copies were recovered; out of which 76% of the subjects, which was 1,131, had end of life care experience, while 24% had not.

Among the nursing staff who had end of life care experience, 87.7% of the patients they had cared for received hospice care, which shows that the prevalence of hospice care for terminally ill patients is relatively high in Tzu Chi Hospital. The percentage of patients cared for who did not receive hospice care was higher in the functional team, surgery and acute care staff than in other departments.

## Basic Statistics

Gender	Number of People	%
Female	1,404	94.4
Male	84	5.6
Total	1,488	100.0
Age	Number of People	%
under 20	39	2.6
21~25	533	35.8
26~30	248	16.7
31~35	197	13.2
36~40	218	14.7
above 40	253	17.0
Total	1,488	100.0

### Increased Awareness of Patient and Family Involvement in Medical Decision-Making

When asked who initiated the hospice care for terminally ill patients, physicians accounted for the highest percentage of encounters (78.8%), followed by nurse practitioners (57.5%), nurse specialists (52.4%), but a significant percentage of encounters also came from the patients' family and friends (44.4%), and the patients themselves (31.4%). These figures show that more and more family members and patients themselves are involved in their own medical decisions.

Established in 1996, the Heart Lotus Ward at Hualien Tzu Chi Hospital has been advocating hospice care in local communities. Over the past years, it has organized activities in various communities in Hualien County since 2006 to provide correct concepts of hospice care and to dispel the misconception that a hospice ward costs a fortune and is a ward for people waiting to die. Emphasis has been placed on patients' health awareness in the recent years, and Shared Decision Making (SDM) has been promoted in intensive care units to allow patients and their families to make decisions about their own medical care according to their own needs. The "Five Benefits of Doctor-Patient Communication" poster is also displayed in the stairwell so that visitors or outpatients know how to talk about their illnesses. Before the clinic visit, there is a medical questionnaire that allow patients to list their concerns that are to be raised, so that they can receive better medical care. However, people are still regard death as a tabooed topic for discussion. The Heart Lotus Ward Lounge and Sky Garden were renovated in August 2019, with the expectation that this space would not only

Job Title	Number of People	%
Registered nurse	1,185	79.6
Deputy head nurse	62	4.2
Head nurse	58	3.9
Supervisor	23	1.5
Functional unit/case manager	49	3.3
Nurse practitioner/senior RN	111	7.5
<b>Total</b>	<b>1,488</b>	<b>100.0</b>
Department	Number of People	%
Internal Medicine	295	19.8
Surgery	219	14.7
Pediatrics	48	3.2
Obstetrics & Gynecology	63	4.2
Intensive Care & ER	295	19.8
Functional Unit	22	1.5
Kidney Dialysis	46	3.1
Operating Room	102	6.9
Outpatient Clinic	198	13.3
Palliative Care	40	2.7
Administration	36	2.4
Psychiatry	51	3.4
Others	73	4.9
<b>Total</b>	<b>1,488</b>	<b>100.0</b>

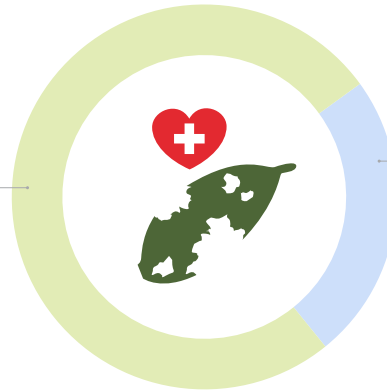
be a more comfortable space for patients, but also a place for education about life and death. Therefore, the Heart Lotus Ward of Hualien Tzu Chi Hospital invited the Department of Art and Design of National Dong Hua University to design and produce the “Wishing Wall”. The design is intended to be an interactive exchange, which not only allows patients to say their final farewells to their families and the medical team, but also allows young people in their early twenties to take this opportunity to better understand the issues of life, as they need to interview patients, the patients’ families, caregivers, and even their own families before creating the wall. After interviewing a patient, one student felt that life is impermanent, and time with families should be treasured. The wishing wall in the Heart Lotus Ward became the best life lesson for these students, and there will be more life education in this space in the future.

Q1

Do you have end of life care experience?

( N = 1,488, single choice)

76.0% Yes



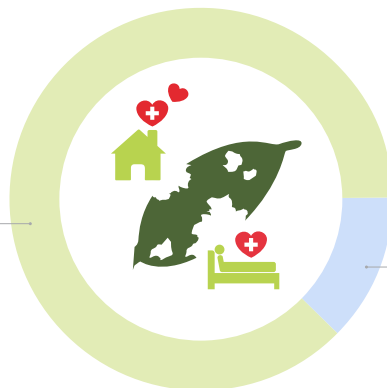
No 24.0%



Q2

Have the terminal ill patient(s) you have cared for received hospice care (including hospice co-care, admission to a hospice unit, home hospice)? ( N = 1,131, single choice)

87.7% Yes

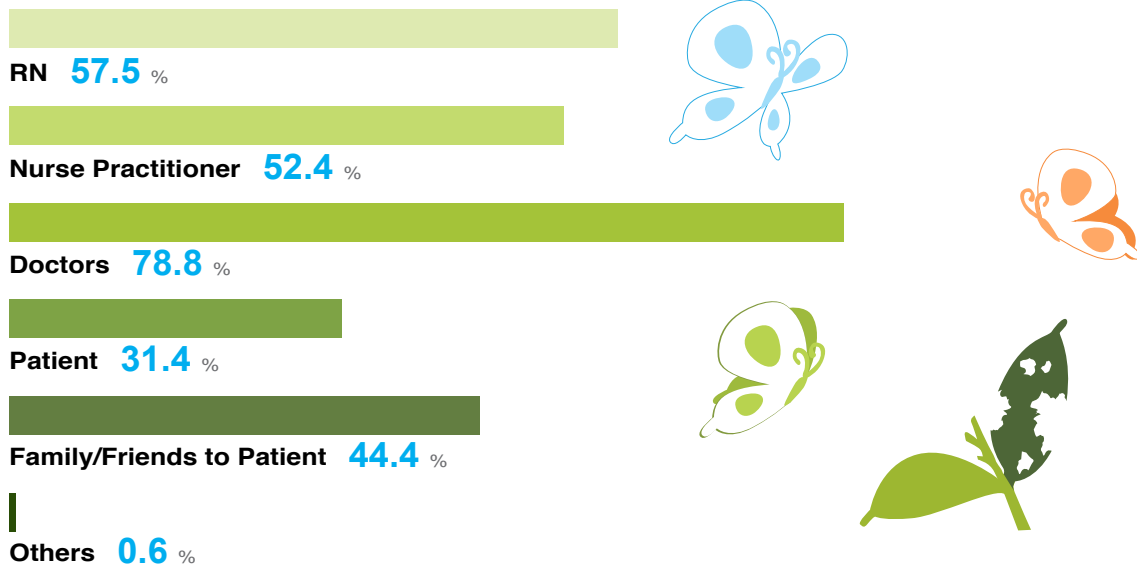


No 12.3%

# Q3

## Who initiated or advised the hospice consultation in your experience with terminally ill patients?

( N = 992, multi-choice)



### Difficulties in End of Life Care:

#### Whether to Say or Not to Say, and How to Say It

When asked about the most difficult aspect of end of life care, the highest proportion of nursing staff with end of life care experience answered “family members wishing to conceal the patients’ illness” (38.3%), followed by “informing them of the illness” (33.6%), followed by “patients’ or family members’ feelings of abandonment upon hearing about the transfer to hospice” (30.7%) and “family members’ emotions, such as sadness, anger, anxiety, and etc.” (30.7%), and lastly “family members have expectations for the patients’ recovery”, 30.6%.

According to the in-depth analysis of the 241 acute and intensive care nurses, the most difficult aspects of end of life care were the following: “family members have expectations for the patients’ recovery” (37.3%), “family members wish to conceal the patients’ illness” (36.2%), and “the patient’s or family members’ feelings of abandonment upon hearing about the transfer to hospice” (30.2%). Because the rate of unanticipated hospitalization is higher among patients with acute and severe illnesses, the family’s expectation that the patient will be saved is also higher, and their sense

of loss will be stronger when they are informed that the patients will be transferred to a hospice unit. Because nursing staff are directly facing the issues regarding these patients and their families, since 2018, the acute and intensive care unit of Hualien Tzu Chi Hospital has their nursing staff attending basic and advanced hospice training from the Taiwan Association of Hospice Palliative Nursing, as well as in-service training and case discussions within the unit, with the expectation of assisting the nursing staff to overcome these challenges.

### **Hospice Interdisciplinary Teams Encourage the Development of a Common Language**

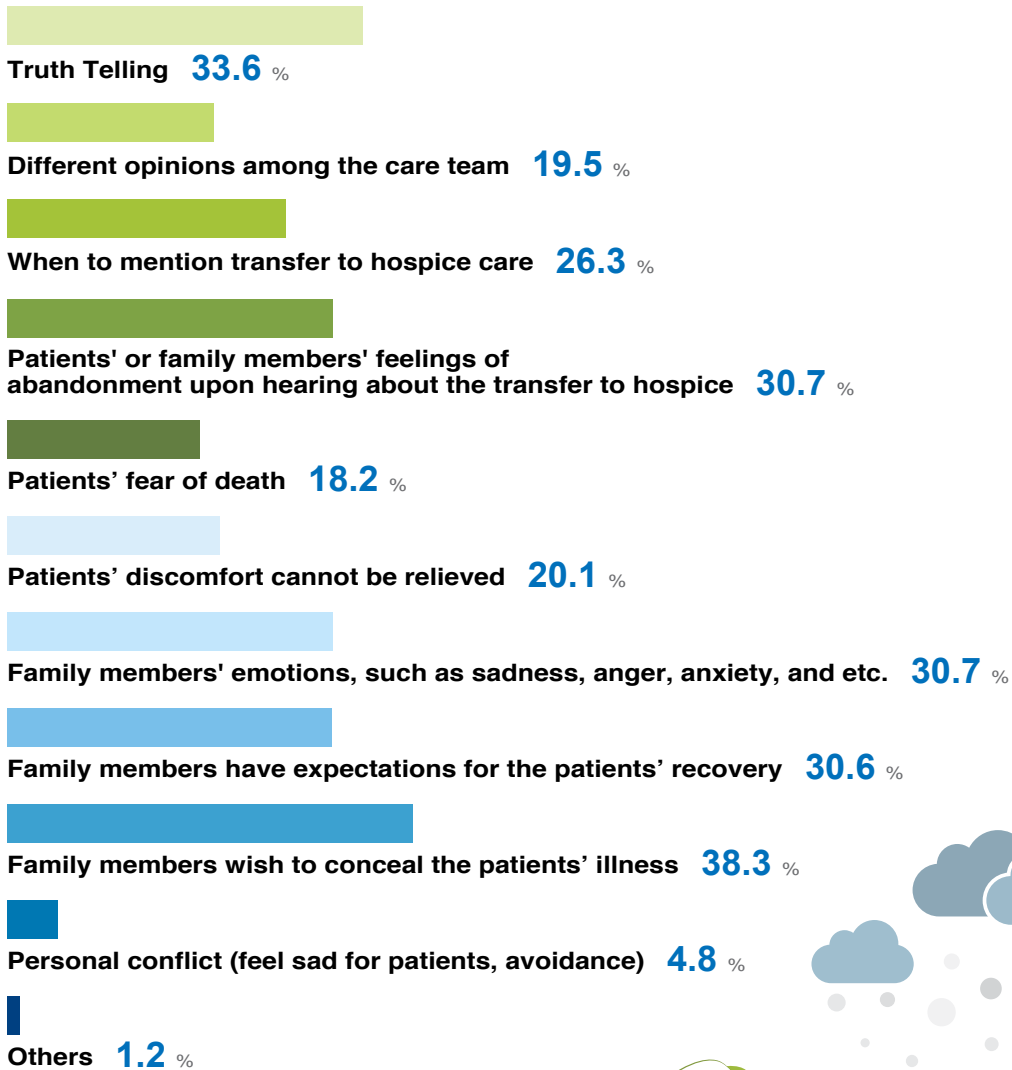
For the 40 nursing staff of the Heart Lotus Ward, their take on the most difficult aspects of end of life care slightly differs from the rest. The highest percentages were 37.5% for each of the three items: family members wishing to conceal the patients' illness, family members having expectations for the patients' recovery, and different opinions among the care team. The second popular choice, which occupied 32.5%, was family members' emotions, such as sadness, anger, anxiety, and etc. The result shows that the family members' request to conceal the patients' illness causes greater distress to the nursing staff regardless of the unit, and that a noticeable issue in the Heart Lotus Ward is the divergence of opinions among the care team, which goes to show the importance of the concept of whole team care in the "Four Wholes: Whole-Person, Whole-Family, Whole-Process, Whole-Team" of hospice care. In August 2019, Hualien Tzu Chi Hospital invited Professor Claire Johnson, an expert from Australia's national program, the Palliative Care Outcome Cooperation (PCOC), to speak at the hospital. The professor pointed out that Australia uses PCOC as a common language for the teams, and interdisciplinary teams use the standardized tools and methods of the PCOC program in their discussions, which improves the collaboration among the care team members.

### **Provide Comfortable Care to the Patients and to Fulfill the Patients' Wishes**

During end of life care, the highest percentage of nursing staffs' psychological feelings was "to provide comfortable care to patients" (74.4%), with nearly three-quarters of nursing staff having this self-expectation; followed by "trying their best to help patients fulfill their wishes" (39.1%) and "wishing the patients well" (35.7%). The aforementioned are positive feelings. However, some nursing staff felt "sadness" (30.6%) and "powerlessness" (24.6%).

# Q4

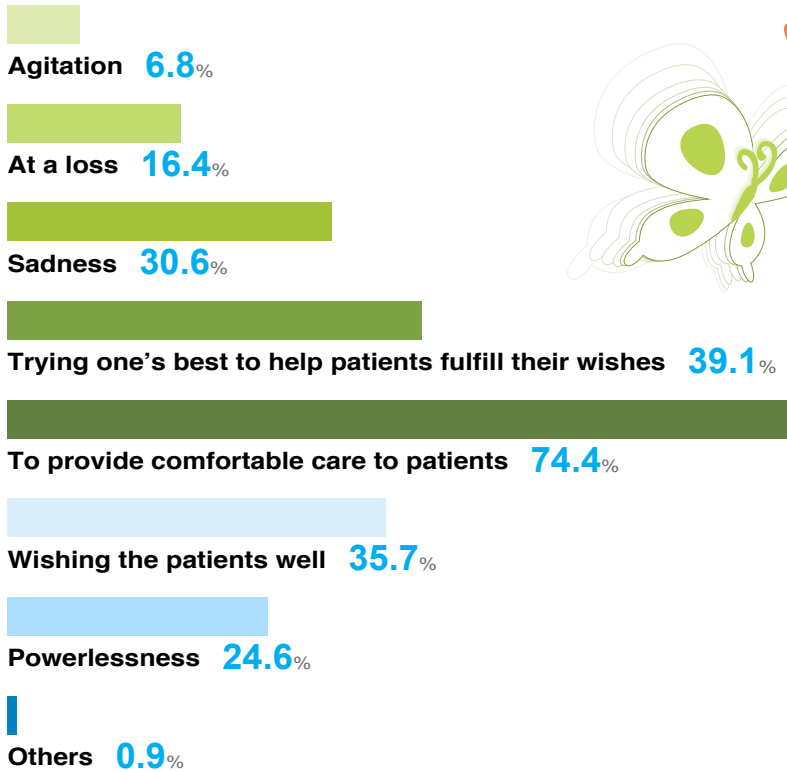
What do you find as the most difficult part of caring for a terminally ill patient? ( N = 1,131, multi-choice)





# Q5

**The most common psychological feelings you have when you're facing the end of a terminally ill patient.**  
( N = 1,131, multi-choice)



This question was further analyzed for the acute and critical care nurses ( n = 241 ). Their feelings from end of life care agrees with the results of overall nursing staff, but the emotions such as “sadness” (23.5%) and “powerlessness” (15.3%) were lower than those of the overall nursing staff. When asked the same question, the statistics of the Heart Lotus Ward nursing staff ( n = 40 ) showed that their strongest psychological feelings were “expecting the patient to feel comfortable” (92.5%), “wishing the patient well” (72.5%) and “trying their best to help patients fulfill their wishes” (57.5%), which echoed the value of hospice care; “sadness” (5%) and “powerlessness” (22.5%) were also lower than the overall responses.

# Q6

What do you normally do when you experience stress care for terminally ill patients? ( N = 1,131, multi-choice)



### **Addressing Grief and Powerlessness in Hospice Care**

As a matter of fact, hospice wards are more likely to participate in classes related to communication and grief care, and the hospice care team includes psychologists and religious teachers, all of which provide great psychological support to the nursing staff.

For example, the Heart Lotus Ward of Hualien Tzu Chi Hospital organizes an annual support group for bereaved families in the ward, giving the nursing staff a chance to care for the families again and offer the families an opportunity to speak their minds. The 2019 event was themed on horticultural therapy, where bereaved families use a combination of plants to reminisce about their memories of the past. There was a Mr. Wu whose father passed away in the Heart Lotus Ward. When he walked into the ward again to participate in the event, he was quiet and indifferent. At the end of the event, when the horticulture therapist invited everyone to write down on two pieces of paper their impressions of the deceased and what they wanted to say to them, Mr. Wu began to talk about how irritated his father was and how violent he was to the family; he also mentioned that he hopes to deal with his emotional baggage now that his father is gone. After the program, Mr. Wu felt emotionally brighter and looked forward to attending the event every year.

### **Manage End of Life Care Stress by Talking to Someone**

When the nursing staff were asked how they usually cope with stress from end of life care, the majority of them talked to their peers (54.8%), followed by going out (37.4%) and sleeping (28.3%). Acute and intensive care nursing staff ( n = 241 ) also had the highest percentage of talking to their peers, which was 46.6%, followed by going out (40.7%) and sleeping (38.4%). The top two items for nursing staff ( n = 40 ) in the Heart Lotus Ward were also talking to peers (52.5%), followed by going out (45.0%) and eating and drinking (35.0%), while 27.5% choose to talk to psychologists and 12.5% to religious teachers. On the contrary, all nursing staff and acute and intensive care unit nursing staff were less likely to talk to these two professions.

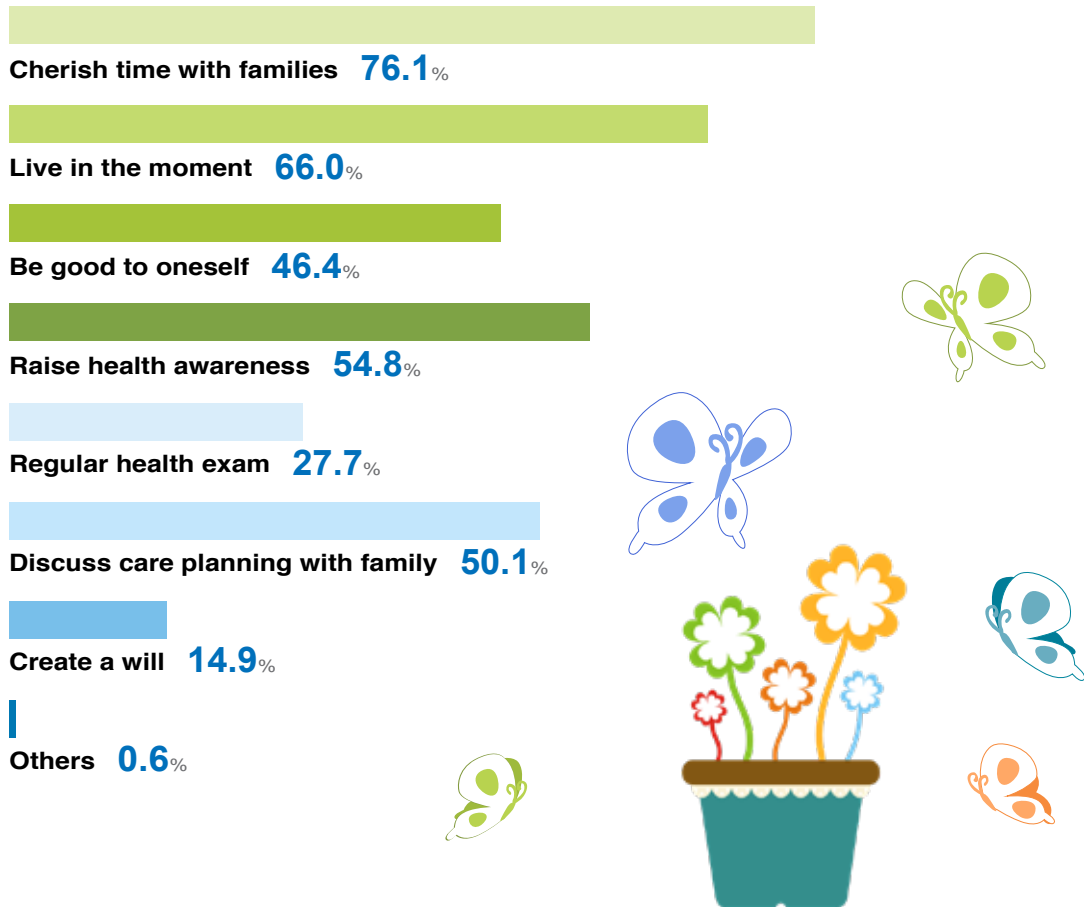
### **Seize the Moment and Cherish Family and Health**

When asked about the inspiration of the nursing staff from end of life care, 76.1% said that they should cherish the opportunity to spend time with their family, 66.0% said that they should live in the present, 54.8% said that they should take care of their body, and about half said that they should discuss medical decisions with their family beforehand (50.1%).

# Q7

## My inspiration from caring for terminally ill patients?

( N = 1,131, multi-choice)



End of life care places caregivers in a difficult situation: they are forced to provide the patients with the best care possible as the patients face the impending death. That is why the nursing staff will inevitably endure the stress of the patients' death, and the stress from the family members. On the other hand, they have a chance to create meanings in their lives from end of life care, and an opportunity to witness how all the patient faces death in their own ways, showing the sincerity of humanity. Whether it is an apology, a thank you, a love you, or a farewell, it is never too late before the moment of death arrives.