Palliative Care and the ethical issue in Cancer Patients

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Patients with chronic illness often have a more prolonged illness trajectory than cancer patients.

Figure 1. Theoretical trajectories of dying

(Lunney, Lynn, Foley, Lipson, & Guralnik, 2003)
Palliative Care for All

- By THE PEOPLE
- Through THE PEOPLE
- For THE PEOPLE

The goal of the care is to help people who are dying have peace, comfort and dignity.

Worldwide Hospice Palliative Care Alliance (WHPCA, 2014)
Worldwide Cancer Incidence

An estimated 14.1 million adults in the world were diagnosed with cancer in 2012. These cases were not spread evenly across the globe and the reliability of cancer statistics available for each country varies.

Most Common Cancers Worldwide

1. Lung
2. Breast
3. Prostate
4. Colon and Rectum
5. Liver
6. Bladder

Cancer Incidence by Region

- Australia/New Zealand
- Northern America
- Western Europe
- Northern Europe
- Southern Europe
- Central & Eastern Europe
- South America
- Eastern Asia
- Western Asia
- Caribbean
- Eastern Africa
- Western Africa
- South-Central Asia
- Middle East
- Other world regions

Source: GLOBOCAN 2012: Global Cancer Incidence and Mortality Worldwide, IARC, 14th ed. from International Agency for Research on Cancer (IARC). Global population and cancer incidence and mortality data are collected from the GLOBOCAN database, which is a collaborative project between the International Agency for Research on Cancer (IARC) and the World Health Organization (WHO).
### Estimated New Cases

<table>
<thead>
<tr>
<th></th>
<th>Males</th>
<th></th>
<th>Females</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pallium</strong></td>
<td>220,800</td>
<td>26%</td>
<td><strong>Breast</strong></td>
<td>231,840</td>
</tr>
<tr>
<td>Lung &amp; bronchus</td>
<td>115,610</td>
<td>14%</td>
<td>Lung &amp; bronchus</td>
<td>105,590</td>
</tr>
<tr>
<td>Colon &amp; rectum</td>
<td>60,090</td>
<td>8%</td>
<td>Colon &amp; rectum</td>
<td>63,610</td>
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<tr>
<td>Urinary bladder</td>
<td>56,320</td>
<td>7%</td>
<td>Uterine corpus</td>
<td>54,870</td>
</tr>
<tr>
<td>Melanoma of the skin</td>
<td>42,670</td>
<td>5%</td>
<td>Non-Hodgkin lymphoma</td>
<td>32,000</td>
</tr>
<tr>
<td>Non-Hodgkin lymphoma</td>
<td>39,850</td>
<td>5%</td>
<td>Melanoma of the skin</td>
<td>31,200</td>
</tr>
<tr>
<td>Kidney &amp; renal pelvis</td>
<td>38,270</td>
<td>5%</td>
<td>Pancreas</td>
<td>24,120</td>
</tr>
<tr>
<td>Oral cavity &amp; pharynx</td>
<td>32,670</td>
<td>4%</td>
<td>Leukemia</td>
<td>23,370</td>
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<tr>
<td>Leukemia</td>
<td>30,900</td>
<td>4%</td>
<td>Kidney &amp; renal pelvis</td>
<td>23,290</td>
</tr>
<tr>
<td>Liver &amp; intrahepatic bile duct</td>
<td>25,510</td>
<td>3%</td>
<td>Liver &amp; intrahepatic bile duct</td>
<td>7,520</td>
</tr>
<tr>
<td><strong>All Sites</strong></td>
<td>846,200</td>
<td>100%</td>
<td><strong>All Sites</strong></td>
<td>310,170</td>
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</tbody>
</table>

### Estimated Deaths

<table>
<thead>
<tr>
<th></th>
<th>Males</th>
<th></th>
<th>Females</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Pallium</td>
<td>86,380</td>
<td>28%</td>
<td><strong>Lung &amp; bronchus</strong></td>
<td>71,660</td>
</tr>
<tr>
<td>Prostate</td>
<td>27,540</td>
<td>9%</td>
<td>Breast</td>
<td>40,290</td>
</tr>
<tr>
<td>Colon &amp; rectum</td>
<td>26,100</td>
<td>8%</td>
<td>Colon &amp; rectum</td>
<td>23,600</td>
</tr>
<tr>
<td>Pancreas</td>
<td>20,710</td>
<td>7%</td>
<td>Pancreas</td>
<td>19,850</td>
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<tr>
<td>Liver &amp; intrahepatic bile duct</td>
<td>17,030</td>
<td>5%</td>
<td>Ovary</td>
<td>14,180</td>
</tr>
<tr>
<td>Leukemia</td>
<td>14,210</td>
<td>5%</td>
<td>Leukemia</td>
<td>10,240</td>
</tr>
<tr>
<td>Esophagus</td>
<td>12,600</td>
<td>4%</td>
<td>Uterine corpus</td>
<td>10,170</td>
</tr>
<tr>
<td>Urinary bladder</td>
<td>11,510</td>
<td>4%</td>
<td>Non-Hodgkin lymphoma</td>
<td>8,310</td>
</tr>
<tr>
<td>Non-Hodgkin lymphoma</td>
<td>11,480</td>
<td>4%</td>
<td>Liver &amp; intrahepatic bile duct</td>
<td>7,520</td>
</tr>
<tr>
<td>Kidney &amp; renal pelvis</td>
<td>9,070</td>
<td>3%</td>
<td>Brain &amp; other nervous system</td>
<td>6,380</td>
</tr>
<tr>
<td><strong>All Sites</strong></td>
<td>312,150</td>
<td>100%</td>
<td><strong>All Sites</strong></td>
<td>277,280</td>
</tr>
</tbody>
</table>
Cancer

Treatments
- Surgery
- Chemotherapy
- Radiotherapy
- Psychotherapy

Stages of Cancer

Stage 1: Early Stage
- A small, invasive mass or tumor has been found.
- No spread to lymph nodes or other tissues.
- Sometimes called early-stage or "localized" cancer.

Stage 2: Localized
- Cancer has started to affect nearby tissue.
- Mass may have grown in size.
- Spread to lymph nodes near the mass.

Stage 3: Regional Spread
- Cancer affects more surrounding tissue.
- Mass may have grown in size.
- Spread to distant lymph nodes away from the mass.

Stage 4: Distant Spread
- Cancer has spread to other tissues or organs beyond the region where it originated.
- Sometimes called "advanced or "metastatic" cancer.

For more cancer topics and advice visit: www.shine365.marshfieldclinic.org/category/cancer-care

To learn about oncology specialty services at Marshfield Clinic: www.marshfieldclinic.org/specialties/cancer-care
(A) Acute stage IV GVHD, following a myeloablative conditioning chemotherapy.
(B) Chronic skin GVHD, following conditioning chemotherapy with TBI and cyclophosphamide.
(C) Chronic GVHD, following reduced intensity conditioning chemotherapy.
Survivorship programs-
Symptoms in HCT patients’ muscles, fascia or joints can be key indicators of chronic GVHD.
Many patients will want to know their prognosis.

More rapid decline the last months and weeks

Gradual decline over years or months with intermittent crises or serious episodes; more frequent crises and hospitalizations in the last year.

Illness trajectories: A) Cancer trajectory vs B) end-stage heart or lung failure trajectory. Reproduced with permission from Pallium Canada. Adapted with permission from Lunney et al.

FIGURE 1. Supportive care issues for cancer patients. From the time of diagnosis, cancer patients experience a multitude of issues, including supportive care, psychological distress, information needs, caregiver support, and end of life issues. Survivorship programs address these issues during the curable cancer phase, while palliative care and hospice care programs are focused on issues related to incurable cancer and bereavement.
Treatment for All

- Improved cancer data for public health use
- Access to early detection and diagnosis
- Timely and accurate treatment
- Supportive and palliative care

Supportive Care Needs

- **Emotional Needs**
  - Stress & Anxiety
  - Guilt & Blame
  - Uncertainty & Worry
  - Anger & Frustration
  - Powerlessness
  - Shock & Denial
  - Fear

- **Social Needs**
  - Isolation & loneliness
  - Family & friends support
  - HCP partnerships
  - Work/Life balance
  - Partner & siblings relationship
  - Social expectations

- **Informational Needs**
  - Information easy to access & is relevant
  - Early & definitive diagnosis
  - Information on child's illness
  - Resources for family & friends
  - Child's future health needs
  - Available services

- **Psychological Needs**
  - Depression & Anxiety
  - Stress
  - Coping
  - Self-worth

- **Practical Needs**
  - Finances
  - Work & Employment
  - Respite & Leisure
  - Accessing services & support
  - Childcare & Other carers
  - Transport
  - Home modifications
Palliative Care: Not an “Either-Or”

Traditional Care Model
A New Model: 
Integrating Palliative Care

Disease Modifying Therapy 
Curative, or restorative intent

Life Closure

Death & Bereavement

Palliative Care Hospice

Do Everything AND Palliate

Curative, Palliative and Life-Extending Efforts

Comfort, Palliative Care and Dignity
Model of palliative cancer care

Focus of Care

Anticancer therapy (curative, life-prolonging, or palliative intent)

Palliative Cancer Care

Bereavement Care

Diagnosis → Time → 6-Month Prognosis → Death

Acute Chronic Advanced Life-Threatening Illness

Bereavement

Person with Illness
Family
Caregivers
Disease Progression
Support services for families and caregivers
a) The WHO model of resource allocation in cancer care from 1990 depicting “present allocation of cancer resources” and “proposed allocation of cancer resources in developed countries”.

b) WHO model of “continuum of care” in association with palliative care from 2002 [5].

c) Novel integrated lung cancer care concept with diagnostics, systemic therapy, radiotherapy, surgery, palliative care and follow-up as equitable pillars of lung cancer care.

Palliative Care

Use a palliative approach for life limiting illness

End-of-Life Care
- Weeks to months
- Palliative and medical treatments
- Ongoing supports
- Hospice Care
- Respite and caregiver relief

Last Days/Hours Care
- Pain & Symptom Mgt
- Psychosocial & Spiritual supports

Optimizing Quality of Life

Maximizing community supports

Early symptom management

Advanced care planning
We developed a booklet that consisted of **LST figures** to assist the cancer patient understanding the real situations and procedure.
Where is the patient?

- How to provide the most appropriate care for the terminal patient?
Which is the most important?

Terminal patient

Survival?

Quality of life?

Ethical reflection
Withholding/Withdrawing Futile Life-Supports Systems

Ethical Dilemma?
Patterns of Natural Systems Components (Bertalanffy, 1972)
Health axis

- Whole person
  - human right
  - be respected

Nursing philosophy

(Hu, 2004)
The continuous line: from Health to Good death

(Eds.: Hu, 2008)
The patient and family will encounter many different health problems and ethical dilemmas during the disease trajectories.
End of life care
Supportive care
Palliative care
Terminal care
Imminent death
Death

Good dying process or Dying well

Dignity death
Appropriate death
Peaceful death

Status (狀態) ?

Could we make an appointment with good death?

Pts may die from weeks/months/years.

3 types of pt (cancer, organ failure, frail elderly/dementia pts)

Everyone needs supportive care

Helping the patient/family cope better with their illness

holistic care

Some regard as overlapping or following curative treatment

Diagnosing dying - care in last hours and days of life

The moment

Before 48hrs

Process (過程) ?
Which is the patient’s choice?

(Hu, 2004)
The five blessings have descended upon one's house (五福臨門).

Respect Patient’s Wish
(Institute of Medicine, 1997)

Healthy (康寧)

Longevity (長壽)

Wealthy (富貴)

Virtue (好德)

Good death (善終)
The definition of good death

One that is free from **avoidable distress and suffering** for patients, families, and caregivers; in general **accord with patient’s and family’s wishes**; and reasonably consistent with clinical, cultural, and ethical standards.  (Institute of Medicine, 1997; Wenger & Rosenfeld, 2001)

Pain free, dignified, and one in which **active resuscitation never occurs**.  (Jones & Willis, 2003)
Appropriate Death

- Respect personal significance
- Maintain self esteem
- Minimal distress
- Relieve intractable symptom
# Good death Scale

<table>
<thead>
<tr>
<th>Indicator \ Score</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Awareness</strong></td>
<td>□ Complete ignorance</td>
<td>□ Ignorance</td>
<td>□ Partial awareness</td>
<td>□ Complete awareness</td>
</tr>
<tr>
<td><strong>2. Acceptance</strong></td>
<td>□ Complete unacceptance</td>
<td>□ Unacceptance</td>
<td>□ Acceptance</td>
<td>□ Complete acceptance</td>
</tr>
<tr>
<td><strong>3. Propriety</strong></td>
<td>□ No reference to the patient’s will</td>
<td>□ Following the family’s will alone</td>
<td>□ Following the patient’s will alone</td>
<td>□ Following the will of both the patient and their family</td>
</tr>
<tr>
<td><strong>4. Timeliness</strong></td>
<td>□ No preparation</td>
<td>□ The family alone had prepared</td>
<td>□ The patient alone had prepared</td>
<td>□ Both the patient and their family had prepared</td>
</tr>
<tr>
<td><strong>5. Comfort</strong></td>
<td>□ A lot of suffering</td>
<td>□ Suffering</td>
<td>□ A little suffering</td>
<td>□ No suffering</td>
</tr>
</tbody>
</table>

Full score: 15

related to relieve patient’s distress symptoms and total suffering
From Curative treatment to Palliative care
The Nature of Clinical Research / Trial

- "Clinical trial" is an experiment testing medical treatments on human subjects, which is well-organized study.

- The term "Clinical" is derived from the Greek “klinikos” meaning of or pertaining referred to a bed.

- Its original usage in the context of medical practice referred to a physician who attends bedridden patient.
Globalization of Clinical Research
Density of Actively Recruiting Clinical Sites
(per million inhabitants)

![Map showing trial density around the world with high densities in Canada, USA, Germany, and low densities in China and South Africa.]

Volume of Ongoing Clinical Trials in Asia Pacific Region

Taiwan is also the leading country in Asia

Data accessed from www.clinicaltrials.gov on May 28, 2010
# Measuring the Contribution of Clinical Research Nurses

<table>
<thead>
<tr>
<th>Contribution Area</th>
<th>Potential Outcome(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervention design and implementation planning within the clinical setting</td>
<td>Efficiency; intervention fidelity</td>
</tr>
<tr>
<td>Participant recruitment and consenting</td>
<td>Study accrual; adherence to human subjects protection standards</td>
</tr>
<tr>
<td>Participant education and support regarding self managed study procedures and evaluation</td>
<td>Participant safety; treatment fidelity; efficiency; subject retention; data quality</td>
</tr>
<tr>
<td></td>
<td>Participant safety; adherence to human subjects protection standards; data quality</td>
</tr>
<tr>
<td></td>
<td>Data quality; human subjects protection; efficiency; speed of dissemination</td>
</tr>
</tbody>
</table>

- **Data quality**
- **Participant safety**
Golden Triangle of Clinical Trials

- Ethics
  - (Declaration of Helsinki)
- Conduction
  - (Good Clinical Practice)
- Science
  - (Principle of Clinical Trials)
The Center of All Clinical Research Efforts

patients

The purpose of ethical reflection

“Culture RNs’ or CRNs’ ethical sensitivity toward clinical research situation to research participants.”
Where is the patient?

How to provide the most appropriate care for the terminal patient?
Good clinical medicine requires a marriage of scientific knowledge and human care.

~ Plato 500 BC ~
Survival?

Quality of life?

Which is the most important?

Terminal patient

Ethical reflection
Withholding/Withdrawing Futile Life-Supports Systems

Are We Killing The Patient

When we stop life supports?
Incurable patients died ➡ Medical failure?

- The current medical model, to receive life-sustaining treatments (LST) and intensive care in the end-of-life.

- The biggest problem is that our healthcare systems are designed to provide acute care when what we need is chronic care........
Patient

Benefits ↔ (experiential assessment) → Burdens

Medical staff

Positive Effects ↔ (clinical assessment) → Side Effects
Nearly 80% of research participants do not understand the context of clinical trial and palliative care.

- Families prefer the clinical trial
- Patient followed physician’s opinion
- The patient often loses his or her right to make the decision
- It’s insufficiency in nursing education regarding clinical trial or palliative care
Ethical Dilemma?

- It is not killing
  (ex: IV push KCL)

  or

- It is allowing dying
- It is letting die
Rector's model of quality of life

Heart Failure Pathophysiology → Symptoms → Functional Limitation → Quality of life → Good death

Psychological Distress

How to provide care?
The difference between Euthanasia V.S. Nature death

Quality of Life

Diagnosis

Anti-cancer Tx.

Euthanasia

Palliative care

Life survival

Death

Nature death
From Scientific research
To Palliative care

Put Nursing Humanities
into Practice
1980

Hospice Care → Palliative Medicine

Quality of death → Quality of life
There are more thirty thousands patients dying in cancer every year, but hospice beds can not meet the need in Taiwan.
Taiwan was ranked 6th in the world.

The Economist Oct 2015

Quality of Death / End-of-Life Care in Taiwan
Artificial nutrition and hydration is the first ethical dilemmas in the issues of clinical management.

Truth-telling and place of care had higher scores in the issues of communication.
Taiwanese culture

- “Food comes first for people”
- “Eating is as important as the emperor”
- “I do not become a starving soul after death and affecting one’s later generations”

A Medical Last Rite?
Intravenous Fluids and the Hospitalized Dying
excessive supply with fluid and ANH

Do ANH would briefly prolong life?

The survival period of terminal cancer patients wouldn't have differences whether using ANH or not (NTUH hospice team, 2002)

Many health providers still lack knowledge to handle this issue properly and comfortably.

the final dignity in life is often neglected
Disease trajectories and treatments of the patient at the end of life
(Hu, 2012)
Knowledge, attitudes, and behavioral intentions of nurses toward providing ANH for terminal cancer patients in Taiwan.

- Knowledge about providing ANH for terminal cancer patients was lower (accurate-answer rate, 53.67\%)

Table 5 • Behavioral Intentions of Nurses on Provision of ANH for Terminal Cancer Patients (N = 197) *

<table>
<thead>
<tr>
<th>Labeling</th>
<th>Item (Scoring Range for Each Item Is 1–4 Points)</th>
<th>Never, No. (%)</th>
<th>Unlikely, No. (%)</th>
<th>Likely, No. (%)</th>
<th>Very Likely, No. (%)</th>
<th>Mean (SD)</th>
<th>Ranking</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>In terminal stomach cancer patients who cannot be fed orally because of intestinal obstruction, and who have a projected survival time of less than 1 month, will I provide intravenous fluids?</td>
<td>1 (0.5)</td>
<td>3 (1.5)</td>
<td>102 (51.8)</td>
<td>91 (46.2)</td>
<td>1.56 (0.56)</td>
<td>2</td>
</tr>
<tr>
<td>2</td>
<td>In terminal gastric patients who cannot be fed orally, what is the likelihood that I will provide artificial nutrition?</td>
<td>1 (0.5)</td>
<td>4 (2.0)</td>
<td>120 (60.9)</td>
<td>73 (37.1)</td>
<td>1.65 (0.52)</td>
<td>1</td>
</tr>
</tbody>
</table>

Average total behavioral score = 3.21 (0.95)

- **98% of nurses** were likely or very likely to provide intravenous fluids and artificial nutrition
- **Nurses’ behavioral intentions still favored providing ANH**
- **“attending physicians” (45.3%) is important influencing persons on nurses’ support for ANH**

Abbreviation: ANH, artificial nutrition and hydration

*Total behavioral intention scoring range = 2–8. A higher total behavioral intention score indicates a positive behavioral intention of leaning toward not providing ANH for terminal cancer patients.
<table>
<thead>
<tr>
<th>Variable</th>
<th>Pretest</th>
<th>Post-test</th>
<th>t value or z value</th>
<th>95% CI</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Control, mean (SD)</td>
<td>5.68 (2.62)</td>
<td>5.21 (2.58)</td>
<td>(z=-1.517)</td>
<td>–</td>
<td>0.129</td>
</tr>
</tbody>
</table>
| Experimental, mean (SD)  | 6.80 (3.11)   | 10.96 (2.95)  | \(z=-5.255\)     | –        | 0.000   ***
| Attitude                 |               |               |                   |          |         |
| Control, mean (SD)       | 10.49 (1.61)  | 10.66 (1.42)  | \(t=-0.774\)     | 0.61~0.27| 0.443   |
| Experimental, mean (SD)  | 10.65 (2.03)  | 12.79 (2.57)  | \(t=-5.191\)     | \(-2.96\)~\(-1.3\) | 0.000   ***
| Behavioral intentions    |               |               |                   |          |         |
| Control, mean (SD)       | 1.58 (0.44)   | 1.61 (0.47)   | \(z=-0.050\)     | –        | 0.960   ***
| Experimental, mean (SD)  | 1.67 (0.42)   | 1.97 (0.36)   | \(z=-3.274\)     | –        | 0.001   |

The nurses’ attitudes about providing ANH for terminal cancer patients viewed ANH as having **more burdens than benefits**.
Effects of educational intervention on nurses' knowledge, attitudes, and behavioral intentions toward supplying artificial nutrition and hydration to terminal cancer patients.

Table 4 Comparison of mean score changes in 2 groups

<table>
<thead>
<tr>
<th>Variable</th>
<th>Control (n=44)</th>
<th>Experimental (n=44)</th>
<th>t value &amp; z value</th>
<th>95% CI</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean score change (SD)</td>
<td>−0.48 (2.72)</td>
<td>4.18 (3.24)</td>
<td>t=−7.306</td>
<td>−5.92~−3.39</td>
<td>0.000</td>
</tr>
<tr>
<td>Attitudes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean score change (SD)</td>
<td>0.18 (1.44)</td>
<td>1.86 (2.25)</td>
<td>t=−4.165</td>
<td>−2.48~−0.87</td>
<td>0.000</td>
</tr>
<tr>
<td>Behavioral intentions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean score change (SD)</td>
<td>0.03 (0.56)</td>
<td>0.30 (0.52)</td>
<td>z=−1.943</td>
<td>−</td>
<td>0.052</td>
</tr>
</tbody>
</table>

- After educational intervention, the mean score of knowledge and attitude had significantly increased.
- However, the mean scores of changes of behavioral intentions between two groups were not significant.

98.8% of nurses would provide intravenous fluids and artificial nutrition. However, families requiring ANH followed physician’s orders, leading to ethical considerations.

- Sufficient knowledge
- Ethical reflection

- The patient often loses his or her right to make the decision
- Insufficiency in nursing education regarding end of life care
"If you do not recognize through to life, how can you recognize through to death?"

(The Analects of Confucius)

A taboo concept to telling the truth
The family oriented decision-making in Taiwan

69.5% cancer patients at terminal stage
the preeminent role of family in end-of-life decision making

82.1% terminal ill patients whose consent sheet was signed only by family
( Huang, Hu, Chiu & Chen, 2008)

Physicians (43.9%) and nurses (49.4%) had the ethical dilemmas in truth telling and discussing the advance directives
A myth in Taiwan

*respect the families’ wishes* rather than *patients’ wishes*

→ *conflict* with the goals of palliative care
For the past 20 years, legal and medical ethical exploration of medical decision making in Taiwan has revolved around the idea of patient autonomy.

- **Hospice-Palliative Care Act** (Taiwan, 2000)
- **Patient Autonomy Act** (Taiwan, 2015)

**Core values**
- Respects patients’ **autonomy**
- Refuse **unnecessary medical management**

**Related ethical issues**
- **Truth Telling**
- Executing **Advance directives**
## Family-related barriers to truthfulness of terminal cancer in Taiwan

<table>
<thead>
<tr>
<th>Puzzling factors</th>
<th>Canonical Loading</th>
<th>Canonical Weight</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Families don’t know how to tell patients the truth</td>
<td>0.85</td>
<td>0.63</td>
</tr>
<tr>
<td>2. Unnecessary to tell aged patients the truth</td>
<td>0.71</td>
<td>0.34</td>
</tr>
<tr>
<td>3. Patients can be happier without awareness of truth</td>
<td>0.70</td>
<td>0.37</td>
</tr>
</tbody>
</table>

Solutions (adequacy = 40.69\%) | Canonical Loading | Canonical Weight
--- | --- | ---
1. To communicate with and encourage families to accept patients’ prognoses | 0.59 | 0.83 | 0.59
2. To discuss the sickness gently with patients and determine what patients know | 0.33 | 0.76

“What do you think about your sickness?”

“Would you like to have more information about your illness?”

Nationwide guidelines for truth telling in Taiwan

**ACTs**

- Assess and preparation
- Communication with family
- Truth telling process
- Support and follow up

[Website](http://health99.doh.gov.tw/educZone/edu_detail.aspx?Catid=21568&Type=SEARCH)
The knowledge and barriers of the advanced cancer patient receiving hospice palliative care

A National Survey in Taiwan

- A questionnaire survey
- Two-stage systematic with unequal proportion random sampling
- Institutes: 18 medical centers or local hospitals

<table>
<thead>
<tr>
<th>Subjects Number</th>
<th>Physician</th>
<th>Nurse</th>
<th>Cancer Patient</th>
<th>Family</th>
<th>Public</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>249</td>
<td>496</td>
<td>156</td>
<td>176</td>
<td>536</td>
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<tr>
<td></td>
<td>745</td>
<td></td>
<td></td>
<td></td>
<td>868</td>
</tr>
<tr>
<td><strong>Total number</strong></td>
<td><strong>1613</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

It’s the positive attitude of truth telling and they agree to execute ADs.

There are only 2 important predictors, the total explain variance ($R^2$) is 22.5%.

- Prefer QOL at terminal stage
- Agree with ADs
- Agree to relative to execute ADs
- Have ADs or not
- Agree to himself to execute ADs
- Relative with terminal illness
- Relative who had been received H/P care
- Relative with incurable disease
- Ethics in DNR

Attitude (truth telling-positive)
For patient should not be told the truth

- Negative attitude of truth telling among family

There are 3 important predictors the total explain variance ($R^2$) is 32.3%

- For patient should not be told the truth
- Negative attitude of truth telling among family
- Better knowledge about hospice care and advance directives of cancer patient and family

$R^2=32.3\%$
Behavior Intention in Executing ADs: Patient

- Marital status
- Want to be disclosed the terminal illness
- Sex
- Occupation
- Education
- Relative with terminal illness
- Relative who had been received H/P care
- Relative with incurable disease
- Ethics in DNR

Knowledge (H/P care and HPCA)

Understanding (H-P)
Understanding (CPR)
Understanding (HPCA)
Understanding (DNR)
Understand ADs

Agree with ADs
Possibility to execute ADs
Agree to relative to execute ADs
Death Place (home)

Prefer QOL at terminal stage

Death Place (home)

Ethics in DNR

Prefer QOL at terminal stage

Agree with ADs
Possibility to execute ADs
Agree to relative to execute ADs

Health provider Intention in Executing ADs

R²=60.3%

Barrier (truth telling and H/P care)

Acceptance level hospice/palliative care

Consultation of laying the terminal illness

Intention in Truth telling

Intention in Hospice-Palliative care

Agreement to execute ADs

Agreement to execute ADs

Attitude (truth telling)

Attitude Hospice/Palliative (Positive)
Behavior Intention in Executing Ads: Family

- Marital status
- Want to be disclosed the terminal illness
- Relative with terminal illness
- Relative who had been received H/P care
- Relative with incurable disease
- Ethics in DNR
- Sex (F)
- Occupation
- Education

**Knowledge** (H/P care and HPCA)

- Understanding (H-P)
- Understanding (CPR)
- Understanding (HPCA)
- Understanding (DNR)
- Understanding (ADs)

**Acceptance level hospice/palliative care**

- Agree with ADs
- Agree relative to execute ADs
- Have ADs or not

**Intention in Executing ADs**

- Agree to myself to execute ADs
- Agree to relative to execute ADs

**Barrier (truth telling and H/P care)**

- Attitude (truth telling)

**Attitude Hospice/Palliative (Positive)**

**Intention in Hospice-Palliative care**

- Intention in Truth telling

**Decision Balance ADs (Cons)**

- Health provider

R² = 36.3%
Important Factors Related to Behavior intention to provide (execute) ADs

- The more knowledge and the
- Heath providers, the publics and cancer patients with positive aspects of intention behavior of discussion or execution advance directives are more earlier to discuss or execute advance directives
attitudes toward executing advance directives (ADs)

Western countries (culture)
- based on individualism,
- ADs are acceptable, regarded as basic rights

Eastern countries (Confucian culture)
- family-centered model
- family member might become the designated medical agent.

62.1% patients: family members signed consent without the patients’ involvement in the discussions. *(Huang, Hu, Chiu & Chen, 2008)*

The issue of executing ADs is becoming more important in Taiwan.
The relationship among Ads, ACP and DNR

autonomy

Living will

DNR

Durable power of Attorney for health care

ADs

ACP
To provide information about the HPCA and related materials about **ADs proactively**, (including answering questions about obtaining legal documents and the actual process of execution of Ads).

- **Advance Care Planning**

- **Life and Death education**
Palliative care needs for Chronic disease

- Under **Chinese filial piety and familism culture**, **self-determination** for the Chinese elderly at the end of life.

- Such as **signing DNR (do-not-resuscitate) consent**, it is difficult for both elderly residents and their family members.

How about the Asia culture?
The difference between the Western / Eastern principle of autonomy

- “For Western people, the issues of life and death are too important to be left with others, even if they are members of one’s family”

- “For Eastern people, these issues above are too important to be left only with oneself, even if one is competent”

(Fan, 1997)
Respect choice
Patient Autonomy Act in Taiwan

2017/01/06
Sharing Your Wishes

Advance Care Planning
ACP is a constant communicated process

1. Presenting and illustrating topic
2. Facilitating a structured discussion
3. Completing document with advanced directives
4. Reviewing and updating the ADs
5. Applying the ADs in clinical circumstances
The process of ACP

1. **presenting and illustrating topic**
   (呈現、說明並引發病人討論ADs相關的醫療主題)

2. **facilitating a structured discussion**
   (促進結構性討論病人的價值觀與期望醫療方式)

3. **completing document with advanced directives**
   (完成ADs書面文件簽署)

4. **reviewing and updating the ADs**
   (再審視、修改或更新ADs內容)

5. **applying the ADs in clinical circumstances**
   (實際落實ADs於臨床照護決策情境)
ACP discussion

**How?**
- opportunistic informal conversation
- Formalised systematic

**What?**
- What matters to you?
- What do you wish to happen?
- What do you do not want to happen?

**Who?**
- Named spokesperson (informal)
- Lasting power of Attorney (formal)

**Where?**
- Preferred place of care
- Carer’s preferred place of care

**Others?**
- Special instructions-organ/tissue donation
Break bad news & Sign the DNR

Medical ethics + Communication skills
Communication is the key

- Silence
  (靜默)
- Listening
  (傾聽)
- Empathy
  (同理)
- It is the obligation of the physician to inform the patient/family about the burdens and benefits of palliative care.

**Nurse** is an advocate and coordinator between physician - patient – family.
Purpose:
This study aimed to explore elderly nursing home residents’ attitudes when they need to sign their own Do-not-resuscitate Consent in Taiwan.
Methods: in-depth interview

- **Sampling** (in the eastern Taiwan)
  - Consecutive sampling was used to select participants.

- **Inclusion criteria**
  - Aged $\geq 65$ years and spoke Mandarin or Taiwanese
  - Living in the nursing home $\geq 1$ month
  - Families who are their caregivers or someone who can make decision for them
  - The SPMSQ of the elderly $\geq 8$
Subjects

11 residents were recruited

The mean age of residents: 80.6 years

The average number of chronic diseases:

3 / each person

The most common chronic disease among the residents were CVA (60%), HTN (50%), DM (20%), CAD (16%), and arthritis (13%)
Most of elderly nursing home residents in this study refused to make decision by themselves. Content analysis of the interviews revealed four themes for declining to sign their own DNR.

Theme I: Depending on children’s decision
- “doctors…they are professionals…they know what decision is the best for me…if they said my condition is too bad to live longer…I will die soon…just let me pass away”
- “I have told to my children that they need to trust doctors’ ability and follow their orders without questions…”
- “I am a good person and I always treat people very kind…the God knows what is the best arrangement for me and he will bless me everything…”
- “…and I will also accept any arrangement from him happily…, if he think I need to have the CPR at the end of my life before going to see him… it is my destiny to have this challenge from him…”
- “it is not necessary for me to make decision about the end of life care for myself …when the timing is coming…everyone knows how and what to do is best for you…”
- “the only thing you need to do is accept it…why do I think too much to cause my families or myself trouble? it is an unnecessary thing for me…”

Theme II: Trusting the doctor’s ability

Theme III: Accepting the arrangement from God

Theme IV: Regarding making decision by themselves as an unnecessary thing
The cultural issues, such as filial piety and family-center decision making, did affect the elderly autonomy and the elderly residents tended to make decision by someone except themselves in Taiwanese nursing homes.

Nurses can increase the family-center autonomy by actively implementing the advance care planning for elderly residents, their families as well as the health providers to make decision together.
Current long term care services in Taiwan

- Community care
  - Community general practitioners
  - Health center

- Nursing facilities
  - Nursing home
  - Long term care institution
  - Hospital based institution

- Home-based care
  - Home care
  - Home social care
  - Delivery services
  - Home rehabilitation
  - Elder activity center, etc.

- Other special

The resources from civil society.
Hospice home care

- The public has a well of fear, anger and distrust about the care they will receive and how they and their families will die.
Provide Appropriate end of life care

RN/APN ↔ Teaching material ↔ SN

Research results as Evidence

Evidenced base practice

Family distress

Total suffering

Pain

Spiritual

Physical Symptoms

Cultural

Psychological

Social

Health

survival & Quality of life

Good death
The overview results of the decade (2003~2018) series survey and action research were conducted.
<table>
<thead>
<tr>
<th>Basic</th>
<th>Advanced</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Level A</strong></td>
<td><strong>Level B</strong></td>
</tr>
<tr>
<td>Undergraduate SN</td>
<td>Postgraduate RN (new) General setting</td>
</tr>
<tr>
<td></td>
<td>Postgraduate RN Palliative ward</td>
</tr>
<tr>
<td></td>
<td>Postgraduate Specialist Palliative care</td>
</tr>
</tbody>
</table>

5. Health system
4. Society
3. Team
2. Family
1. Patient

**Figure 3. Dimensions of the Palliative Care learning process**
- European Association for Palliative Care (EAPC, 2004)
**Figure 3. Dimensions of the Palliative Care learning process**  
- Taiwan Palliative Nursing Association (TPNA, 2008)
Action research reflection

1st practicum manual

1st suggestion

Change (一)

2nd practicum manual

2nd suggestion

3rd practicum Change (二)

3rd suggestion

4th practicum manual

4th suggestion

Change (三)

Continue...
Patient-oriented Multimedia-directed Interactive Clinical skill teaching method
The teaching material fits in scenario simulation.

- More than 40 native multimedia teaching films that were case-based were completed, and placed on the e-learning platform.

The last sixty days - manual for teacher

Pearls of Palliative Care for Nursing Practice - manual
E - learning

- Cancer movies
- Non cancer movies
  ① Critical disease
  ② COPD
  ③ ESRD

}{
- 14- Base course (Teamwork)
- 18- Advance course (Nursing)
- 18-Advance course (Medicine)

Case-based at end of life care
The Teacher’s Guide was applied for flipped classroom teaching since 2010

http://tis.mc.ntu.edu.tw/xms/
Grade A+
All goals achieved beyond expectation (4.3)
TC - OSCE

(Team Compassionate Based – OSCE )
Making sense of Magic Leap and the future of reality...
Thinking and feeling are complementary.

Thinking destroys the beauty of feeling.

Without thinking - feeling has no meaning.

Whole-person learning
The core competencies of nursing professional

- APN (C level)
- RN (B level)
- SN (A level)

- Caring & Respect

- Medical Humanities
How to cultivate the student in palliative care field

Novice

To cultivate sensitivity

( practice → reflection → growth)

Expert
Table 3  Attitudes of student nurses on ANH for terminal cancer patients (con’t)  n=89

<table>
<thead>
<tr>
<th>Item</th>
<th>Mean</th>
<th>(SD)</th>
<th>Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>Burdens of providing ANH</td>
<td>2.44</td>
<td>(0.72)</td>
<td>2</td>
</tr>
<tr>
<td>In terminally ill patients, increased respiratory tract mucous</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>production may result from intravenous infusions with subsequent</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>need of suction</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fluid overload is likely to result in pleural effusion or pulmonary</td>
<td>2.02</td>
<td>(0.48)</td>
<td>7</td>
</tr>
<tr>
<td>edema</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Attitude toward supplying terminal cancer patients with ANH had a mean score of 2.75 (SD=0.72, range 1–5), which shows the negative attitude of student nurses toward being inclined to supply ANH to terminal cancer patients.
Don’t loss The opportunity of survival

Respect patient’s choice

Advance care planning

Ethical reflection

Do grasp The opportunity of good death

Clinical trial

Life threaten disease treatment

Hospice/Palliative care

Total suffering

Family distress

Health

Survival & quality of life

Good death
Strategies and Process

Improving nursing competencies in palliative Nursing education

- Thinking globalization
- Strategy nationalization
- Action localization
Building the Collaborative Research Platform and Professional Training Workshop for Cancer Treatment, Hospice/Palliative Care and Bioethics in Southeast Asian Countries

The main goal is to establish an academic and cultural translational platform connecting academic institutions in Asia and around the world.

HOST National Taiwan University
The professional training workshop (2012 ~ 2016)
Practice-based research
Shifting the paradigm of palliative care research in Asia

- The ultimate goal of Practice-based research network is to generate knowledge and evidence to be as teaching materials, to upgrade clinical quality of care

- Train practice-based research collaborators, to establish a communicative website with data bank capacities, and to forge a consensus on international collaborative framework

1. Can countries of Asia learn from each other about best practices relevant to the Asian region?

2. What are the cultural traditions relevant to palliative care practice that have changed / are changing?
Developing a palliative course in ASIAN countries

Hu Wen-Yu

National Taiwan University
School of Nursing and Hospital, Professor & Director

April 19, 2018
Global Education And Research Center for Life Care Science

(GEAR-LCS)

全球生命關懷教育與研究中心
Figure. The structure of the Global Education and Research Center for Life Care Science (GEAR-LCS)
Global Education and Research Center For Life Care Science aim to keep communicating with multidisciplinary and international Humanity in Medicine and Bioethics research teams in Southeast Asia, whilst promoting Holistic Medicine Education and End-of-life Care practice.
International Cross Cultural - Collaborative Research

The research issues:

- What is the **good death** (COPD, ESRD, Cancer patients)?
- To understand the perception and acceptance of **withdrawal** hemodialysis for hemodialysis patients.
- To understand the perception and acceptance of **hospice care** for hemodialysis patients.
- To understand the **spirituality** for hemodialysis patients.
- To understand the perception and expectance of **ADs** for hemodialysis patients.
- To understand the expectance of **Five Wishes** for hemodialysis patients........
Southeast Asian Clinical Research Consortium (SEACRC)

PI: Prof. Wen-Yu Hu

Co PI:
- Taiwan: National Taiwan University
- Japan: Tsukuba and Chiba University
- Indonesia: Universitas Gadjah Mada
- Thailand: Mahidol University and Chiang Mai University

Research concepts
- The need of Nursing education on palliative care
- Palliative care issues (Good death, quality of life... )
To help medical professionals further put humanistic and social care into practice, increase ethical reflection in end of life care and nursing competency.
It is the obligation of the physician to inform the patient/family about the burdens and benefits of truth-telling.

Team conference

Nurse (CRN) is an advocate and coordinator (physician - patient – family)

Family conference
Total suffering

Family distress

health

survival & quality of life

good death

Clinical trial

Life threaten disease treatment

Hospice/Palliative care

Don’t loss
The opportunity of survival

Respect patient’s choice

Advance care planning

Ethical reflection

Do grasp
The opportunity of good death
Facing the suffering of death and despair

Hope
Let life be beautiful like summer flowers.

Indian poet
Rabindranath Tagore
“Stray Birds”
Death like autumn leaves.

Indian poet Rabindranath Tagore
"Stray Birds"
Thanks your attention.
Any Questions?

National Taiwan University Hospital