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Review Article

From Do No Resuscitation to Advance Care Planning

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Abstract

As a result of the "heroic fight" by physicians, many people suffered from painful death in hospitals, inserted with variable tubes and surrounded by different medical devices. In order to improve our quality of death and quality of hospice palliative care, Taiwan passed a Hospice Palliative Care Act (Natural Death Act) in 2000 which gives people the right to choose cardiopulmonary resuscitation or do no resuscitation at the end of life. We are now working forward to the advance care planning to establish a Patient Self Determination Act. In this new Act, people can choose to refuse the terminal painful life sustaining treatments. Hope this will further improve our quality of terminal care.

Keywords: Do no resuscitation; DNR; Advance care planning; ACP; Hospice palliative care; Natural death act; NDA; Hospice palliative care act; HPCA; Patient self determination act; PSDA; Life sustaining treatments; LST; Cardiopulmonary resuscitation; CPR

Preface

"Birth, aging, sickness and death" are natural course of life. However, with the relentless advancement of medical science and technology, physicians now tend to fight for lives against all the odds. As a result of the "heroic fight" by physicians, many people suffered from painful death in hospitals, inserted with variable tubes and surrounded by different medical devices. Our life span may have increased; however, it appears reasonable to suggest that the quality of life at its end may not have improved [1] .In order to improve the quality of life at end and to ensure good death and peaceful passing, modern hospice care (St. Christopher's Hospice) was started by Dame Cicely Saunders in London in 1967 [2,3]. In 1990 the first hospice ward was opened in Taipei's Mackay Memorial Hospital by Dr. David CH Chung in Taiwan [4] .In 2000 Taiwan passed a Natural Death Act (NDA), named Hospice Palliative Care Act (HPCA) to allow patient to have the right of choosing terminal cardiopulmonary resuscitation (CPR) or do no resuscitation (DNR) [3,4]. In order to further improve the quality of terminal care, we need to step forward from terminal DNR to advance care planning (ACP) and patient self determination act (PSDA).

Revisions of the Hospice Palliative Care Act (HPCA)

In the first Act of 2000, the HPCA gave our people the right to sign an advance order or living will of DNR to ask physicians to withhold CPR at the terminal stage. A family surrogate can also sign a DNR order according to the patient's previously expressed wish, if the patient fell into unconscious state or being no more able to express

his will. However, if the person was intubated in the terminal stage without knowing or neglecting his DNR order and failed to regain consciousness and the ability to breathe spontaneously, the CPR, i.e. the ventilator could not be withdrawn.

The Law was revised for 3 times till 2013 [4]. First revision was done in 2002. It gives the physician the right and duty to withdraw the futile CPR devices, including the ventilator, if the person already signed the DNR order in advance. However, the family surrogate does not have the right to sign a DNR order for asking withdrawal of the futile CPR devices.

In 2011, second revision was done which allows the withdrawal of the CPRs if the patient's spouse, children, grandchildren and parents all signed the DNR order, then the futile ventilator can be withdrawn.

In 2013, after the third revision, a family surrogate can sign the DNR order for withdrawing the futile ventilator, which is now named life sustaining treatment (LST). If no family available, the attending physician can make the order to withdraw the LST after consultation with a hospice palliative care team [4].

This "Hospice Palliative Care Act" gives physician's legal permission: that it is legal to withhold CPR or withdraw life-sustaining-treatment (LST) for the terminal patient with consent signed by the patient in advance, by one of the family surrogate or by a medical surrogate assigned in advance. If the patient did not sign DNR consent, and no family is available, a DNR order can be prescribed by the attending physician after consultation with a hospice team to withhold CPR or withdraw LST.

Since 2006, with the person's request, the advance DNR order could be registered in the National Health Insurance (NHI) card which could be read whenever a patient asked for medical service or care in any clinic or hospital [4].

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It is Difficult to have Peaceful Dying with Dignity

Many people wish to die peacefully with dignity without suffering. The late prime minister of Singapore, LEE Kuan Yew expressed his wish of dying peacefully without tubes. In case he was severely sick without chance neither to recover nor to walk again, he wished the doctor to let him go as soon as possible [6]. Unfortunately, his wish was denied. In Taiwan, the former president of the National Tsing Hua University of Taiwan, Professor Chun Shan SHEN also made a living will of dying without medical mechanical support after his first stroke in 1999. His living will states "I believe how to manage personal life is a basic human right. If my body is injured by disease or other causes to the following conditions: 1. this injury causes prolonged suffering without the chance of normal life; 2. the situation is irreversible; 3. prolongation of life will cause my family and the society heavy burden. If the above conditions are fulfilled, I hope to receive active process to let me finish my life journey in dignity. Then, I will seek related persons to help me to end my life. In order to waive the helping persons' ethical and legal duty, I thus made this will." [7]. However, he remained in unconscious and vegetative state after his third stroke in 2007 up to the present. His living will was denied. Lots of people now die in hospitals or nursing homes inserted by many tubes and surrounded by machines or medical devices. (Fig 1) We need a Patient Self Determination Act (PSDA) to ensure our people's right of peaceful demise.

Life Sustaining Treatments

Besides the CPR of endotracheal intubation and mechanical ventilation, there are many life sustaining treatments (LST) or life sustaining measures used to maintain life at the final stage of progressive incurable diseases or irreversible comatous or vegetative states. These treatments can only prolong the suffering but cannot regain a useful and dignified life for the patient. These include artificial tube feeding through nasal gastric tube, percutaneous endogastric tube, intravenous nutritional fluid supplies or artificial nutrition; repeated blood transfusions or blood substitutes, chemotherapies, dialysis, antibiotics in severe terminal infection, and even mechanical life sustaining measures such as extracorporeal membrane oxygenation (ECMO). When the patient remains in prolonged unconscious or vegetative state, and these measures can no longer bring back a useful and dignified life, can only prolong the suffering and waste the precious medical facilities or expenses, we have the right to ask doctors to withhold or withdraw this futile medicine. Just as the late Prime Minister LEE and the professor SHEN had asked for but was unfortunately denied as mentioned in the previous paragraph [6,7]. We need a Patient Self Determination Act (PSDA) to protect the right of peaceful dying or good death.



Fig 1: A dying patient in the Intensive Care Unit surrounded by tubes, lines and machines. (Photo provided by Dr. Sheng-Jean HUANG)

Biomedical Ethics

Modern biomedical ethics as summarized by Beauchamp and Childress [8] stressed the importance of respect for autonomy,

nonmaleficence, beneficence, justice and professional-patient relationships. At the final stage of life, physicians should respect the patient's autonomic wish of withholding or withdrawal of certain maleficent medical measures. Unfortunately, physicians cannot accept the defeat of losing a patient, while relatives are unwilling to let their family member go or believe they are disloyal or unloving if they do not let the physician attempt to do life sustaining measures [1]. Physicians also are afraid of medico-legal dispute law sue if they do not "fight" to the last minutes [9]. At the final stage of life, filial duty and love should find its expression of being with the family member at the end of his life, and in encouraging acceptance of disease, quiet life in last days and peaceful passing. Where it is unavoidable, the death of a patient is not a medical failure. Not being able to facilitate a peaceful and dignified demise is, however [1]. We need a law to protect the physicians to withhold or withdraw futile medical measures and to encourage patient's family members to respect the patient's living will or advance directive.

Advance Care Planning

"Advance care planning (ACP) is the process of thinking about, talking about and planning for future health care and end of life care. Advance care planning gives everyone a chance to say what's important to them. It helps people understand what the future might hold and to say what treatment they would and would not want. It helps people, their families and their healthcare teams plan for future and end of life care. This makes it much easier for families and healthcare providers to know what the person would want - particularly if they can no longer speak for themselves" [10]. This concept was supported by the California Natural Death Act (NDA) in 1976 [11]. The Act gives the people in California to have the right of making advance directive on acceptance or refusal of terminal life sustaining treatment. Taiwan's Hospice Palliative Care Act covers only on the major CPR process, i.e. cardiac massage or electro cardiac shock, endotracheal intubation, ventilator and ECMO. It does not include the other life sustaining treatments, such as artificial nutritional supplies, chemotherapy, antibiotics, surgery at terminal stage. We need a law specific for these issues to respect the right of the patients.

Patient's Self Determination Act

The World Medical Association (WMA) Declaration of Lisbon on the Rights of the Patient states that "If the patient is unconscious and if a legally entitled representative is not available but a medical intervention is urgently needed, consent of the patient may be presumed unless it is obvious and beyond any doubt on the basis of the patient's previous firm expression or conviction that he/she would refuse consent to the intervention in that situation" [12].

Ms Yu-xing YANG, a legislator (senator) led the team to make the third revision of the Hospice Palliative Care Act (HPCA) in 2013 [4]. Her husband, Professor Hsiao-chih SUN of the Department of Philosophy, National Taiwan University joined her in promotion of the quality of terminal care of Taiwan. After the successful revision of the HPCA, they started to write up a Patient's Self Determination Bill (PSDB). Many lawyers and hospice palliative care team members participated in making the draft of this Bill. It is now processing in the Legislative Yuan (Senate). Hope we will

succeed to pass this law in the near future to have Taiwan's Patient's Self Determination Act (PSDA).

In Article 3 of this Bill, the Life Sustaining Treatment (LST) is defined as the following measures: Any medical and nursing measures which can prolong the life such as cardiopulmonary resuscitation (CPR), artificial ventilation, mechanical life sustaining system (such as ECMO), blood substitutes, special treatment for specific diseases, for example, chemotherapy, dialysis, antibiotics for fatal infections, artificial nutrition and artificial liquid feeding, etc.

In Article 13, the patient can ask for withholding or withdrawal of whole or part of the life sustaining treatments if he/she is 1. A terminal patient, 2. In irreversible comatous state, 3. In persistent vegetative state, 4. In severe dementic state, 5. Patient is in intolerable pain, incurable disease without adequate solution under the current medical standard. The above items must be confirmed by 2 specialists and Item 5 must be confirmed by consultation with hospice team.

In Article 14, when patient asks for withholding or withdrawal of Life Sustaining Treatments in the advance directive, the hospital or medical facility must provide adequate palliative care or medical care (Fig 2).

In 2015, Taiwan's quality of death index and end-of-life care was ranked as the first in Asia and 6th in the world by the Lien Foundation of Singapore [13]. Hope this coming PSDA will further elevate our quality of hospice palliative care.

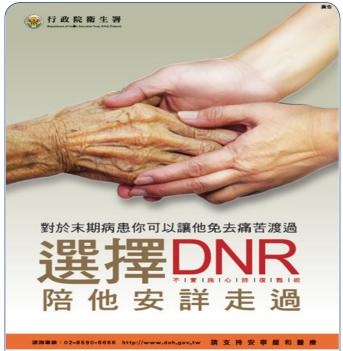


Fig 2: Patient died peacefully in the hands of loving relatives. (Photo provided by the Ministry of Health and Welfare)

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